

Doctoral (PhD) Dissertation

# POSTTRAUMATIC GROWTH OF CHILDHOOD AND ADULT SURVIVORS OF CANCER

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**Posttraumatic growth of childhood and adult survivors of cancer**

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**Doctoral (PhD) dissertation**

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- b) a doktori értekezés és a tézisek nyomtatott változatai és az elektronikus adathordozón benyújtott tartalmak (szöveg és ábrák) mindenben megegyeznek.

3. A doktori értekezés szerzőjeként hozzájárulok a doktori értekezés és a tézisek szövegének plágiumkereső adatbázisba helyezéséhez és plágiumellenőrző vizsgálatok lefuttatásához.

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**A doktori értekezés szerzőjének aláírása**

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## **List of Abbreviations**

**ALL= Acute lymphoid leukaemia**

**AML= Acute myeloid leukaemia**

**ANOVA= Analysis of variance**

**ASC= Altered state of consciousness**

**BL= Burkitt lymphoma**

**BRCA1, BRCA2= Breast cancer gene 1, 2**

**CI= Confidence interval**

**CIPN= Chemo-induced peripheral neuropathy**

**CML= Chronic myeloid leukaemia**

**CNS= Central nervous system**

**DSM= Diagnostic and Statistical Manual of Mental Disorders**

**H= Hypnosis group**

**HL= Hodgkin's lymphoma**

**M= Music group**

**M= mean**

**n= number of cases**

**NHL= Non-Hodgkin's lymphoma**

**NIO= National Institute of Oncology**

**PTG= Posttraumatic growth**

**PTSD= Posttraumatic Stress Disorder**

**PTSS= Posttraumatic Stress Symptoms**

**PSDS FR= Frequency of Posttraumatic Stress Symptoms**

**PSDS ES= Emotional Severity of Posttraumatic Stress Symptoms**

**SA= Special attention group**

**SD= Standard deviation**

**T1-T6= Measuring points**

**WHO= World Health Organization**

# 1 INTRODUCTION

One of the biggest health problems in the developing world is that with increasing age, the incidence of chronic diseases increases (Tompa, 2011). Cancer has become the second leading cause of death globally (WHO, 2018) and also in Hungary (Juhos, 2006). The increasing cancer burden will mostly affect the low and middle income countries due to increasing life expectancy and the increase in prevalence of cancer risk factors (Torre, Islami, Siegel, Ward, & Jemal, 2017). Although mortality statistics are improving, the diagnosis and treatment affect the patients emotionally, physically, socially and contribute to greater risk of psychological vulnerability (Rowland & Massie, 2010). Cancer diagnosis is still associated with death, even if the statistics are getting better and most of the breast and childhood cancer patients survive (later discussed). Several studies have been exploring the negative psychological consequences of the cancer diagnosis and treatment– for example: posttraumatic stress, anxiety, depression, body image problems, declining quality of life (Cordova et al. 2007; Fors, Bertheussen, & Thune, 2011; Helms, Ohea, & Corso, 2008). Although cancer may have many negative psychological consequences, it can also be considered as an existential challenge that can result in personal growth (Brix et al, 2013), which has been most often referred to as posttraumatic growth (Tedeschi & Calhoun, 1996). A significant proportion of patients who survived cancer (above 80%), including young adults who had recovered from childhood cancer, reported that their life changed in a positive direction as a result of the disease (Sears, Stanton, & Danoff-Burg, 2003). Although international researchers have been studying the phenomenon widely in the cancer population in the last 25 years, in Hungary it is still under-represented, especially in patients with pediatric cancer. Thus, our plan was to explore the factors contributing to posttraumatic growth in two special groups of cancer patients in Hungary.

Since the beginning of my university studies, I have been interested in the psychological treatment of cancer patients, in which my prevailing supervisor - Éva Bányai - plays a major role. Thus, I have been involved in her clinical, psychotherapeutic trial with breast cancer patients since the beginning (2011), as a member of the research team and I was also working in the field with the patients. Although the focus of my interest was two-sided: besides psycho-oncology, in my clinical field job I have always worked with children as a psychologist, and their wellbeing is the most valuable to me. My work experience in the Department of Pediatric Oncohematology has fundamentally determined the development of my personality and professional attitude. It was an

emotionally challenging but very motivational path and I became aware, that in Hungary there is no education for psychologists regarding pediatric oncology, although it is very important. So, as an inspiration from my field work, during my doctoral training, I created my own course on the subject (*Applications of psychological methods in pediatric oncology*), which aimed to teach practical (and not just theoretical) knowledge from a psychological sub-area with limited research (pediatric oncology). To sum up, I have always been an integrative thinker, interested in complex mechanisms underlying different phenomenon and I also would like to contribute to the integration of research and practice in psycho-oncology. Thus, my doctoral dissertation is aimed to analyze posttraumatic growth from three perspectives: firstly, the experience of women who underwent breast cancer as adults, secondly, young adults who were treated with cancer in their childhood and lastly, parents of childhood cancer patients.

In the first study, we examined a group of breast cancer patients in a randomized, controlled, longitudinal, prospective trial – PSYCHOLOGICAL RESOURCES AND HEALING, with principal investigator Éva Bányai - containing psychological interventions. The research project started in 2011 and aimed to analyze the effect of adjuvant hypnosis on survival, quality of life, immune functions and coping. The study involved medium and high risk breast cancer patients, who were treated with standard chemotherapy protocol. Patients were randomized into two intervention groups (hypnosis=H or music=M), and for ethical considerations, a third, special attention group (SA) (willing to take part in the study but did not prefer to listen to hypnosis or music) received psychological interventions during all chemotherapy sessions and also during blood count controls. Patients received a standard hypnotherapeutic advocacy line for chemotherapy or a musical composition of the same length and dynamics. Patients in the SA group had nothing to listen to, but received extra social support above standard medical care, and were asked about their emotional and physical well-being. During treatment and follow-up beyond asking the participants about their emotional and physical well-being, psychological questionnaires were registered 6 times (psychological immune competence, quality of life) and questionnaires regarding posttraumatic stress symptoms, posttraumatic growth, and serious life events were assessed at the end of the trial. Psychological interviews were conducted at the end of the treatment period and end of the study. My part of the research project was to explore the factors contributing to posttraumatic growth. I conducted a quantitative analysis of the data and also a qualitative analysis of the psychological interviews regarding posttraumatic growth. I have been part

of the research team since 2011 and been working directly with patients, data and also administrative tasks.

In the second study I examined young adult survivors of childhood cancer and their parents retrospectively. The aim of the study was to explore factors contributing to posttraumatic growth in the sample of young adult survivors and their parents. It is important to recognize that parents of children diagnosed with cancer - especially mothers – are sharing the experience of the cancer trajectory with the child and have a great influence on how the child cope with it, therefore parental examination is also of paramount importance. There has been no comprehensive study of this patient population in a Hungarian sample yet - the study attempts to fill this gap and provide a descriptive picture of how PTG appears in these groups and how underlying factors are associated with it. This direction of research is very important for the planning of psychological interventions, especially in the field of post-disease rehabilitation - both in terms of the person undergoing the disease and the functioning of the family. Also, I wanted to create my own study, regarding my interest in pediatric oncology, from planning to conducting and analyzing.

The presentation of the above mentioned trials is preceded with a detailed theoretical introduction of the medical, social and psychological characteristics and consequences of the examined cancer types, followed by an integrative overview of literature on the concept of cancer as a trauma. In addition, the latest literature related to posttraumatic growth and explanatory variables in the examined cancer groups is presented. In this dissertation I am framing cancer as a specific traumatic event and process and in the meantime as a potential to grow personally and experience posttraumatic growth.

## 2 THEORETICAL BACKGROUND

### 2.1 BREAST CANCER

#### 2.1.1 Prevalence, risk factors and medical aspects of breast cancer

Breast cancer is the **most prevalent form of cancer in women** around the world (Ferlay, Parkin, & Steliarova-Foucher, 2010), in 2012 an estimated 1,7 million new cases occurred with 521.900 deaths (Ferlay et al, 2012). In 2018, this number increased to an estimated 2,09 million cases with 627.000 deaths (WHO, 2018). Breast cancer is responsible for a quarter of all cancers diagnosed in women (Ferlay et al, 2015), but the incidence rates vary greatly in different regions of the world with the highest rates in Western Europe and the United States and the lowest rates in Africa and Asia (Torre, Siegel, Ward, & Jemal, 2015). Breast cancer is also the most frequent typology of all tumors in Hungary (Juhos, 2006). Breast cancer mortality rates decreased in Hungary in spite of increasing incidence rates over the period from 1993 to 2012 (DeSantis et al, 2015).

Breast cancer risk factors include non-lifestyle-related and lifestyle-related risk factors (American Cancer Society, 2009). Among **non-lifestyle-related risk factors** age and gender are the most important predictors of developing cancer. Breast cancer is 100 times more common in women and increases with age. Also, genetic risk factors (5-10% of breast cancer cases resulting most commonly because of the mutations of the BRCA1 and BRCA2 genes), family history (doubles the risk), personal history (after breast cancer the risk of secondary cancer is higher), race (white women have greater risk, than African American women), previous breast radiation, long menstrual history and DES (Diethylstilbestrol) treatment for their mothers during pregnancy could increase the risk for breast cancer occurrence. **Lifestyle-related risk factors** include postmenopausal hormone therapy, incidence of being overweight, physical inactivity and alcohol use. Also, nulliparity, child bearing at an older age, oral contraception use or the absence of breastfeeding during pregnancy correlate with slightly higher risks for developing breast cancer (Paskett & McLaughlin, 2010). A recent study also showed an association between smoking and breast cancer (Ordóñez-Mena et al, 2016).

In conclusion, breast cancer risk can be reduced by a healthy lifestyle (physical activity, maintaining a healthy weight and avoiding alcohol consumption) and with the help of early detection (regular mammography screenings) breast cancer can be treated early and more effectively (Pace & Keating, 2014).

In the case of breast cancer, most patients receive combined treatment: local (surgical intervention and radiation) and systemic therapy (chemotherapy). In case of **surgical intervention**, the tumor and surrounding tissues are removed, and breast-sparing surgery or radical intervention (mastectomy) is performed on clinical grounds. For higher risk breast cancer (axillary lymph node-positive tumor, higher histological grade, undifferentiated tumor, extensive tumor, estrogen receptor negative, younger age), **systemic (chemotherapy) treatment** is essential. The chemotherapy treatment is used as an adjuvant treatment or prior to surgery as primary systemic treatment. In addition to chemotherapy, **hormonal therapy** is also used (Juhos, 2006). The St. Gallen international expert consensus on the primary therapy of early breast cancer (Goldhirsch et al, 2011) adopted a new approach within the systemic therapy recommendations based on the biological subtypes classification in the breast cancer spectrum. The subtypes of breast cancer have varying risk factors, different natural histories and responses to the treatment options. The guideline is also used in Hungary to determine which systemic therapy to follow in different breast cancer cases.

### **2.1.2 Psychosocial aspects of breast cancer, psychological adjustment to breast cancer**

The focus of psycho-oncology research is most often breast cancer (Chambers, Hyde, Au, Ip, Shum, & Dunn, 2013). Breast cancer is widely studied because of its high prevalence, the involvement of women of all ages, the complex care required for patients and the focus impacts on an important body part for women and their partners (Rowland & Massie, 2010).

Although breast cancer mortality rates continue to decline and the 5-year survival rate has shown to be increasing (relative 5-year overall survival rates in the U.S. is 90%, DeSantis et al, 2014), and most women with breast cancer can be cured or live for long periods with the disease, **the treatment process is very intensive and challenging**. Treatment causes short and long-term side effects (Rowland & Massie, 2010), which could affect the psychosocial adaptation of the patients. **Short term side effects of adjuvant chemotherapy** (0-6 months during and after chemotherapy) could include cytopenias, fatigue, alopecia (hair loss), pain, chemo-induced peripheral neuropathy (CIPN) and neurocognitive dysfunctions. **Late effects** could include cardiomyopathy, CIPN, neurocognitive dysfunction, secondary cancers, psychosocial impact, early menopause and infertility (Tao, Visvanathan, & Wolff, 2015). The **appearance related**

**side effects** also play an important role in the women's changed self-confidence and body image. The loss or the deformity of the breast, tissue damage, decreased sense of motion, lymphedema, alopecia, weight gain and muscle weakness all affect women's valuation of their bodies (Brunet, Sabiston, & Burke, 2013). Body image perceptions can have also an impact on overall quality of life (Rosenberg et al, 2013).

The psychosocial effects of breast cancer and women's **psychological responses** to the illness and the side effects have great degrees of individual variability. The psychological response of breast cancer patients is determined by their sociocultural environment, patient and environment specific psychological factors, and medical issues associated with the healing process (Juhos, 2006; Mehta & Roth, 2015; Rowland & Massie, 2010).

The treatment and public attitudes toward breast cancer have changed: patients have a bigger role in **decision making** and have more therapeutic options to choose from. From the initial discovery of a lump or symptom the patient has to face three major decision points. First, whether and when she seeks further evaluation, which depends on sociocultural factors (age, education level, beliefs about cancer, personality, coping style and the relationship with her primary care doctor). Second, the diagnosed have to choose from breast cancer treatment plans regarding local and systemic therapy which could be associated with many justified fears. Most women also have to choose between mastectomy (with or without reconstruction) or breast conservation (with or without radiation). Third, patients must decide whether to seek follow-up care and who should perform it and how often. Physician recommendations play a significant role in the decision making process and multidisciplinary consultation could be helpful in reducing stress (Rowland & Massie, 2010). Although the changes in decision making have given bigger control to the breast cancer patients, the perceived psychological stress could increase for some due to the decision making processes.

The psychological responses related to breast cancer have been historically identified in three groups: **psychological discomfort** (distress, anxiety, depression, anger), **behavioral changes** caused by the physical and psychological discomfort (lower activity level, sexual, marital problems and family issues) and **fears related to the illness, recurrence, death and body image** (Juhos, 2006). The most common psychological issues in breast cancer patients are fear of recurrence, body image disruption, sexual dysfunction, treatment related anxieties, intrusive thoughts about the illness and the treatment, marital communication problems, feeling of vulnerability and existential



concerns (Ganz, 2008). The psychological response to the illness is affected by the patients age, personality, coping style, attitudes toward breast cancer and the psychological and social support received (Rowland & Massie, 2010).

**Medical factors** that contribute to the psychological responses of breast cancer patients are the stage of cancer at diagnosis, the treatment, prognosis and availability of physical and psychological rehabilitation (Rowland & Massie, 2010).

It is clear that the diagnosis and treatment are particularly distressful (Helms et al, 2008) resulting in anxiety, depression and in some cases even **post-traumatic stress disorder** (PTSD) (Cordova et al. 2007; Fors et al, 2011). The prevalence of PTSD is low (2-6%) in breast cancer patients (Mechnert & Koch, 2007), but **posttraumatic stress symptoms (PTSS)** which do not meet the full criteria of PTSD are frequent in this patient sample (O'Connor, Christensen, Jensen, Møller, & Zachariae, 2016). Psychological distress may be present at any time during the course of treatment and even after treatment, although there are certain points with increased frequency of distress: diagnosis, recurrence, in advanced cancer stages and even after treatment (Kangas, Henry, & Bryant, 2005). 30% of the breast cancer patients experience **anxiety and depression** over the course of treatment, especially after surgery (Kydd, Reid, & Adams, 2010).

In most cases, the illness affects **self-image** (Piot-Ziegler, Sassi, Raffouk, & Delaloye, 2010), **self-confidence** (Berterö, 2002), **body image** (Helms et al, 2008) and **relationships** (Mellon, Northouse, & Weiss, 2006).

Certain patient characteristics can be considered as **risk factors for psychological distress**. Risk factors include younger age, because the early occurrence is relatively uncommon (75% of breast cancer occurs above 50 years) and is often related to pregnancy and for younger women who have not already had children increases the likelihood of infertility. Preexisting mental illness, comorbid conditions and the lack of social support (instrumental and emotional support) also play an important role in psychological distress (Ganz, 2008).

In conclusion, fortunately, even with the above listed negative psychological consequences and stressors, most women adjust well to breast cancer diagnosis and treatment and manage their distress well, using social support system and psychological resources that are available (nurses, social workers, psychologists, health care team and support groups) (Ganz, 2008).

### 2.1.3 Psychological interventions during and after medical treatment

Increased survival rates have brought greater importance on supporting high quality of life and optimal psychological functioning and adaptation to the cancer trajectory among breast cancer patients (Matthews, Grunfeld, & Turner, 2017). The experience of breast cancer requires psychological adaptation (McFarland & Holland, 2016), in which **doctor-patient communication** is essential (Riskó, 2010). Understanding the three main factor (medical, patient-related and sociocultural) – discussed above - related to adjustment helps physicians and health-care professionals to evaluate each patient better and customize their psychosocial care specifically (McFarland & Holland, 2016).

One quarter of cancer patients require **psychological support** from their family, another quarter require **professional psychotherapeutic care** (Riskó, 2010). Collaborative work among the physicians and professionals of psychosocial care and the integration of psychosocial care into the oncology setting is essential and is becoming increasingly important. The differentiation between normal and pathological responses to the experience of cancer and treating anxiety and depression is crucial (Wein, Sulkes, & Stemmer, 2010). The majority of psychological problems are reactive to the psychological stressor of having cancer (McFarland & Holland, 2016), so psychological treatment can improve psychosocial outcomes (Piquart & Duberstein, 2010). According to a recent systematic review and meta-analysis, the use of interventions for psychological adaptation and to improve coping process has increased over the past decade, including group therapy, individual counselling, psychotherapy and psychoeducational interventions (Matthews et al, 2017).

Psycho-oncology is a relatively new field and since its early stages of research in the 1970s has been through continuous development in clinical care and also in research. Psycho-oncology became a sub-speciality within oncology, and the psychological domain of cancer has been integrated in the complex care field in the United States. Psycho-oncology units are present in each cancer center and community hospitals and are composed of multidisciplinary treatment offering psychological services. (Holland & Weiss, 2010). According to Holland and Weiss (2010) psycho-oncology covers the psychological, social, behavioral and ethical aspects of cancer and can be divided into two large psychological dimensions:

1. The effects of cancer screening, receiving the diagnosis, oncology treatment and regular monitoring of the mental and social functioning of the patient, relatives and health professionals.
2. The role of psychological and behavioral factors in the risk, management and control of cancer and survival.

In Hungary clinical psychologists and psychiatrists have been working in the field of oncology since the 1960s. The Psycho-oncology Ambulance in the National Oncology Institute has been in operation since 1988. The Hungarian National Cancer Control Program and the Clinical Psychology Professional Protocol (1998) consider the clinical psychologist, psychiatrist, social worker and mental health professionals to be members of the oncological healing team (Riskó, 2006). According to Riskó (2015) psycho-oncology covers the overall care of patients coping with cancer, of their caregivers, and the healing medical team. It focuses on the role of psychological and behavioural factors in the emergence and survival of the diseases. For example, in the Hungarian National Oncology Institute, the Psycho-oncology Unit offers individual counselling and psychotherapy, psychological preparation and rehabilitation groups in addition to relaxation and Simonton training.

Historically, psychological challenges and negative consequences associated with breast cancer have been treated through problem-focused therapies. The most frequently examined psychological interventions are mindfulness based stress reduction (Kabat-Zinn, 1990), mindfulness based cognitive therapy (Segal, Williams, & Teasdale, 2002) and cognitive behavioral stress management (Stanton, 2015). Alternatively, positive psychology has broadened our understanding about the personality resources of an individual and the potential for improvement after facing critical life events such as breast cancer (Casellas-Grau, Font, & Vives, 2014). These therapies are aimed to facilitate positive thoughts and behaviors supporting well-being and personal strengths (Wong, 2011). From the positive psychology therapies (Seligman et al, 2006) only mindfulness (Matchim, Armer, & Stewart, 2011; Hoffman, Ersser, & Hopkinson, 2012) and hope therapy (Rustøen, Cooper, & Miaskowski, 2011) have been used among breast cancer patients.

Numerous studies investigate the psychological methods that can be used to reduce the physical and psychological symptoms of cancer patients (for example: Boyle, Stanton, Ganz, Crespi, & Bower, 2017). Receiving a diagnosis, patients face mortality - their sense of inviolability is suddenly gone - testing faith in their world, and leaving

entire reference system vulnerable. All this, coupled with a lack of information on the disease, can result in a negatively **altered state of consciousness (ASC)**, characterized by relinquishment of control and strengthened emotionality (Bányai, 2011). This state of consciousness could be associated with positive emotions and could help to exceed the self-centeredness, which could result in transcendent experiences and even PTG (Kulcsár, 2009). It is fundamental that due to extreme distress, caused by the diagnosis and the treatment, many patients seek **social support** to talk about the stressful event. Besides its comforting effect, self-discovery in a safe social environment can also affect the process of restoring the patient's shaken world and deliberate rumination processes (Ramos, Leal, & Tedeschi, 2016). Social support also helps facilitating the coping processes and finding meaning in the experience (Brix et al, 2013). After the confronting effect (with the illness and the side effects) of the treatment phase, patients may have mobilized their inner resources and started to reshape their self-concept (Silva, Crespo, & Cannavaro, 2012). While experiencing ASC, evoked by the diagnosis of cancer, patients become more susceptible to suggestions, suggestive techniques like hypnosis or music can be especially effective in mediating social support (Bányai, 2015). With appropriately controlled suggestions, the negative trans state caused by the diagnosis and treatment can be translated into adaptive altered state of consciousness. This provides a way to reduce anxiety and pain, deeper self-examination, discover hidden resources, and examine new perspectives (Bányai, 2011).

Many studies have shown that **hypnosis**, in addition to having a positive effect on various immune variables, also affects psychological well-being. Hypnosis has long been applied in the medical setting for controlling pain and distress and could be effective in supporting patients' sense of control during the cancer trajectory. Hypnosis involves relaxation and imagery which takes the focus of attention away from pain (Spiegel & Moore, 1997). It also has a beneficial effect on reducing anxiety, depression, side effects and pain (Bányai, 2015; Walker, 2004; Rajasekaran, Edmondson, & Higginson, 2005). For a detailed summary on the beneficial effects of hypnosis in cancer care see Wortzel and Spiegel's (2017) review. **Well-chosen music** can also be beneficial to physical and psychological conditions (for example: Bradt, Dileo, Magill, & Teague, 2016). Hypnosis and music have been used during oncology care, applied to similar areas of the psychological and physical difficulties resulting from cancer (pain and distress management, supporting quality of life, managing side effects) (Cramer et al, 2015, Stanczyk, 2011, Vargay et al, 2018).

In conclusion, **social support** (from the family, informational social support and social support from the health care staff) **is essential in the psychological adjustment of breast cancer patients and also suggestive techniques could help** the patients in various ways from pain management to reducing anxiety and in facilitating coping.

## 2.2 CHILDHOOD CANCER

### 2.2.1 Prevalence, types and characteristics and risk factors of pediatric cancer

Childhood cancer diseases are rare, but their psychosocial significance is very high. The yearly incidence of childhood cancer in Europe is 12-15/100.000 (Garami, 2006). In Hungary the National Childhood Cancer Registry (existing since 1971) documents the prevalence of childhood cancer in Hungary, operated by the Hungarian Pediatric Oncology Network. The Registry is internet-based since 2010 and contains data of all pediatric cancer patients, who have insurance. According to their data, the relative incidence of malignant diseases in Hungary did not differ from the Eastern European data in 2012 (Garami, Schuler, & Jakab, 2014). The cumulative incidence standardized by age was 160,4/million/year in 2012 in Hungary (Garami, et al, 2014), the **second leading cause of death in children after accidents (Garami, 2006).**

The survival of pediatric cancer has been improving significantly over the past decades (from 20% to 80%) due to the improvement of combined treatments. In the U.S. pediatric cancer is the leading cause of death from disease in children, although it affects only 1% of children and the survival rate has reached 80% (Stuber & Strom, 2012). Most of the childhood cancers can be cured, the number of long-term survivors reaching adulthood is growing (Garami, et al, 2014). The incidence rate is increasing by 1.5-2% per year, so pediatric oncology and its research have become a very important area. In addition to the increased incidence rate, the importance of childhood oncology is further enhanced by the fact that the lifespan of cured children is much longer (65 years of active life) than adults with cancer (Schuler, 2012).

In children aged 0-14 years, the most common form of cancer in Hungary (National Childhood Cancer Registry 2012, Garami et al, 2014) and also in western cultures (Stuber& Strom, 2012) and most world regions (Steliarova-Foucher et al, 2017) are **leukemias, central nervous system (CNS) tumors, lymphomas and neuroblastomas followed by a much smaller incidence of solid tumors:** Wilms tumor, retinoblastoma, soft tissue and bone tumors. In adolescents aged 15–19 years, lymphomas are the most common in all regions combined, followed by a smaller incidence of epithelial tumors and melanoma (Steliarova-Foucher et al, 2017), but the geographical variations in incidence are high.

Leukemias are malignant diseases of the hematopoietic and lymphatic systems. The number of normal red blood cells, leukocytes and platelets is reduced and leads to infections, the central nervous system is also involved and can also cause organ

manifestations (Garami, 2006). Its main subtypes are acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML). CNS tumors affect the central nervous system causing neurological symptoms and tumor specific lesions. Their cause is not yet known, but is more common in certain genetically determined diseases (Garami, 2006). Neuroblastomas are occurring usually in the early years (mean age: 2 years) formatting from sympathetic ganglion cells during the maturation process of the sympathetic nervous system.

The characteristics of pediatric cancer are different from those detected in adults. Usually they formulate in the most rapidly developing tissues and organs resulting from unfortunate developmental discrepancies with no external cause and in most cases, it is not preventable (Israeli & Rechavi, 2004). The risk of childhood leukemia and other cancers can increase due to exposure to ionizing radiation, the risk for non-Hodgkin lymphoma can increase due to organ rejection preventing drugs for solid organ transplant recipients and the risk also increases with certain genetic syndromes (e.g., Down syndrome, Li-Fraumeni syndrome, and Beckwith Wiedemann syndrome) (American Cancer Society, 2019).

### **2.2.2 Medical and physical aspects and consequences of pediatric cancer**

The primary purpose of pediatric oncology is to **promote complete healing**. The success of pediatric oncology is one of the greatest medical achievements in the last 50 years. The progress of the treatment protocols occurred in almost all types of pediatric cancers. The success is due to the sensitivity of these diseases to chemotherapy and the countless collaborative empirical trials in Europe and in the U.S. (Israeli & Rechavi, 2004).

Childhood cancer is treated with **surgery/radiation, chemotherapy and immunotherapy and maintenance treatment** depending on the type of cancer, age and aggressiveness and intensity of the disease. Chemotherapy treatment is used as an adjuvant treatment or prior to surgery as primary systemic treatment (neoadjuvant treatment). For example, chemotherapy is curative for lymphomas, but applied adjuvant for solid tumors enhancing the surgical treatment (Garami, Nagy, & Kiss, 2013). In Hungary, the medical treatment of childhood cancer takes place in one of the hospitals of Hungarian Pediatric Oncology Network (since 1971) with the help of international standard protocols and treatment guidelines (Garami, 2010).

In addition to the significant increase in the chances of survival in childhood cancer in the last decades (80% survival of 5 years) (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014), it is important to note that even after healing, there is a **greater chance of recurrence** of the primary tumor, or the formation of a secondary tumor, or even other chronic illness may also occur as a result of the cancer disease. In addition, the disease and treatments can also cause **permanent functional impairments** (musculoskeletal problems, metabolic problems, diabetes, visual impairment, etc.) (Armstrong et al., 2009), all of which add to the family's stress (Ward et al, 2014). A minority of the childhood cancer survivors are at risk for **infertility** in adulthood as a result of the treatment, which is a traumatic reminder of the disease (Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004).

The **short and long term side effects of the treatment** depend on the type of treatment and the dose-intensity. Children tolerate chemotherapy better than adults, although growing children are more vulnerable to the long-term effects of the treatment, such as the effects on growth, the endocrine system, fertility, cardiotoxicity, appearance of a secondary tumor and neuropsychological functioning (Garami, 2006; Izraeli & Rechavi, 2004; Oeffinger et al, 2006). Even with the newer, less toxic treatments and the reduced use of aggressive treatments (such as cranial radiation) the risk of serious side effects and health conditions increases following chemo-, and radiation therapy (Miller et al, 2016). Although the radiation doses are lower in children, they are still causing **long-term neuropsychological problems**, mainly in attention capacity and nonverbal cognitive processing skills (Izraeli & Rechavi, 2004). In the long run chemotherapy can also cause cognitive or social-emotional delay in development (Scanlon, 2018). Neurocognitive late effects of the treatment include decreased intelligence quotient, impairments in attention and concentration, processing speed, visual perceptual skills, memory and executive functioning (Nathan et al, 2007).

In conclusion, the survivors of childhood cancer need **long-term medical surveillance** and **advanced health-promoting behavior**, because of their vulnerable health status. Health-promoting behaviors are dietary eating habits, regular physical activity, tobacco and alcohol avoidance, sunscreen use and safe sexual practices (Schwartz et al, 2010).



### 2.2.3 Psychosocial aspects of pediatric cancer in the family perspective

Childhood cancer is a **persistent source of stress** for both children and their families during and after treatments (Zsigmond, Rigó, & Bányai, 2017). The pediatric cancer diagnosis and treatment include a series of stressors, involving frequent medical visits, invasive procedures, difficult side effects, and financial expenses. A large proportion of the families could cope and make a successful adjustment (Kurtz & Abrams, 2010; Van Schoors, 2015), but for those with poorer sociodemographic variables it's more difficult (Bemis et al, 2015). In this chapter I will list the potential psychological reactions to childhood cancer diagnosis and treatment regarding the child and the parents.

The **stressors** appear even **before the diagnosis**. Beginning with the suspicious symptoms, the fatigue of the child, the medical examinations and the parental anxiety provoked by unnamed symptoms of the child (Oppenheim, 2004) may all be distressing. **Before treatment** the child and family also faces severe psychosocial stressors, like the difficulty of explaining the diagnosis to the child, coping with the reaction of other family members, getting into the hospital setting and in the meantime disturbing the everyday life environment, the child's fear from the interventions, pain and medications and drastic reduction of peer relations (Zsámbor, 2006).

Psychological problems **during treatment** involves fear and limitations caused by the medical interventions, intellectual, affective and behavioral regression (the illness lowers the gained level of independence), symbiotic relationships with parents, seeing other children being sick, limitations in activity and relationships, mood swings and changes in behavior, difficulties in social adaptation, lack of social routine and schedule, separation anxiety, fears, body scheme insecurity and fear of death. The **treatment related stressors** are procedural distress, pain, nausea and vomiting and anticipatory anxiety (Patenaude & Kupst, 2005).

Children's reaction to the illness is impacted according to age, specific characteristics of their cancer (type, stage of cancer, treatment specifics, medical condition), and their family's attitude to life, reference systems and ways of thinking (Oppenheim, 2004). For infants and toddlers, safety and comfort is essential, explanations of the treatment and the illness have a smaller importance. Thus, parents providing safety and a dependable base and a language rich environment allow them to continue to develop during the time of the treatment. For preschoolers who are characterized by magical thinking, anxiety is a common issue in the hospital setting, because it is difficult for them to comprehend why adults in the setting are seemingly harming them by prodding them

with needles and making them ingest medicines that make them feel sick and why their parents support this. Thus, parents providing calmness, safety and familiar toys and blankets may help. School-aged children thinking more logically, but still they have difficulty to understand multiple factors in causations, and are less dependent on their parents and more likely in the need for peer relations. Regarding adolescents, cancer brings them back to a regression state, making them dependent again (Stuber & Strom, 2012). Thus, adolescents are at greater risk of decreased quality of life and stress symptoms than younger children while under treatment, because normative developmental tasks are inhibited – the protective factor is the quality of family functioning (Barakat, Marmer, & Schwartz, 2010). There is a special, understudied group of childhood cancer patients, the adolescent and young adult (AYA) patients, who are developmentally distinct from younger children and older adults and therefore treated in children's hospitals or adult facilities with a lack of appropriate psychological treatment (Zebrack, Block, & Hayes-Lattin, 2013). For AYA's the most common challenges are treatments and associated physical difficulties, body changes, problems of academic achievements and social isolation (Barakat, Galtieri, Szalda, & Schwartz, 2015).

Parental distress is also an important factor in regard to the child's psychological response (Zsámor, 2006). The wellbeing of the children during cancer treatment is linked to the psychosocial health of parents and can have an impact on the child's adjustment to the illness (Kazak et al, 2011). Recent findings suggest that, the symptoms of anxiety, depression, and PTSS experienced by the child may be related to maternal negative communication, which could impair mothers' ability to communicate positively with their children (Murphy et al, 2018).

Parents of childhood cancer patients also report traumatic responses to their child's illness (Patino-Fernandez et al, 2008). Parents are often at greater risk for psychological effects than their children with cancer (Pai et al, 2007). From the parent's perspective, one of the most difficult tasks are talking with their child about the diagnosis, treatment, and prognosis, providing emotional support and in the meantime providing care for other children in the family and simultaneously managing their own distress (Dunn et al., 2012).

In conclusion, childhood cancer remains a traumatic and overwhelming experience, which affects the children's body image, family functioning, sense of personal identity and also their sociocultural environment (Oppenheim, 2004).

Developmental implications and family functioning are essential to understand what the child is experiencing.

#### **2.2.4 Long-term psychosocial consequences of pediatric cancer on young adult survivors and their parents**

Childhood cancer survivors underwent treatment during crucial developmental periods, therefore their long-term psychological, physical and cognitive late effects differ regarding their **developmental level** at the time of diagnosis and treatment. Similarly, depending on their developmental stage, their cognitive ability to process (coping skills, emotion regulation) the trauma of cancer may not have been fully developed at the time of treatment. Thus when entering adulthood and gaining the cognitive ability to process the trauma, their risk of psychological difficulties increase. Generally, the psychosocial outcomes of childhood cancer survivors are positive, but there are some areas of concern, especially in young adulthood. The **young adult developmental period** is stressful, because it includes plans of employment, spouse selection and parenthood, which could have been affected by the late effects of cancer (Schwartz, Werba, & Kazak, 2010).

There are many negative psychological consequences for survivors of childhood cancer regarding **psychological vulnerability and social and romantic development**. Social and romantic development may be impacted for young adult survivors of childhood cancer. A review regarding young adult survivors of childhood cancer reported, that they have fewer social relationships, difficulties in contemporary relationships, school problems, concerns about future relationships, fewer intimate relationships in adulthood, and less likelihood of marriage (Bruce, 2006). A recent qualitative study found that for young adult survivors of cancer romantic relationships and marriage, fertility and the health of future children, work and social life, family, and physical health were the most important areas of worry (Yi, Kim, & Sang, 2016).

Regarding psychological vulnerability, a recent review suggested that studies generally state that childhood cancer survivors are at elevated risk for **anxiety, posttraumatic stress symptoms and cancer-related worry**. The **anxiety** experienced by the childhood cancer survivors is an understudied area of research (McDonnell et al, 2017) and presents mixed results. As opposed to the study above, a previous review found that childhood cancer survivors did not differ on measures of anxiety, depression, or self-esteem compared with population norms or matched controls (Eiser, Hill, & Vance, 2000). But, some previous studies showed more depressive symptoms and negative

moods in young adult survivors of cancer, then in their siblings (for example: Zeltzer et al, 1997).

Stress-related symptoms of trauma may appear in avoidance behavior, in the form of intrusive thoughts and hyperarousal (Kangas, Henry, & Bryant, 2002). In a systematic review (Bruce, 2006) exploring the **PTSD** diagnosis and symptoms in childhood cancer survivors and their parents, 24 studies were considered. Several studies used PTSD symptom scales and found that lifetime prevalence of cancer-related PTSD symptoms ranged from 20,5%-35% in childhood cancer survivors and from 27%-54% in their parents. It has also been found that mothers experienced higher rates of PTSD symptoms than fathers and children. Cancer-related **posttraumatic stress symptoms (PTSS)** in the form of intrusive thoughts, avoidant behavior and hyperarousal symptoms, ranged from 0%-12,5% in childhood cancer survivors and 9,8%-44% of parents. Another study has found, that moderate-to-severe symptoms are present in 5%–20% of childhood cancer survivors and among them **young adult survivors experiencing more posttraumatic stress symptoms than younger survivors** (Hobbie et al., 2000). In 88% of survivors diagnosed with cancer in childhood, somatic (like pain and fatigue) and traumatic symptoms were still significant after 5 years (Erickson & Steiner, 2000).

Childhood cancer can be an **ongoing trauma for young adult survivors**, because of future concerns of cancer, late effects of the illness and the treatment, reminders of the cancer experience, and decreased social, cognitive and reproductive functions. Young adult survivors are re-experiencing the trauma when newly identified late effects occur. PTSS include rumination, intrusive thoughts, nightmares about cancer-related themes, avoidance of the healthcare system and thinking about cancer, hyperarousal when thinking about it and hypervigilance of body symptoms (Schwartz et al, 2010).

Regarding psychological vulnerability of survivors of childhood cancer, **time since treatment** is also an important factor. In a controlled longitudinal study of adolescent survivors of cancer (Jörngården, Mattsson, & von Essen, 2007), patients were found to have more severe values in anxiety, quality of life and depression than the healthy control group when they received the diagnosis. But, 1.5 years after the diagnosis, not only did the difference disappear, but their results were much better for mental health, than the healthy control group. It is therefore obvious that the planning of interventions has significant impacts. The authors believe that children treated with cancer often develop a repressive coping style that may be adaptive in the short term but, in the long run, may hinder emotional processing and lead to symptom formation.

It is important to recognize that parents of children diagnosed with cancer - especially mothers - may have the same or more serious posttraumatic stress symptoms or disorders as the patients (Yalug, Tufan, Doksat, & Yaluğ, 2011), so **parental examination** is also of paramount importance. In a systematic review exploring long term psychological late effects of parents it was found, that after the successful treatment phase elevated distress level could remain for the parents including cancer-related thoughts, fear of recurrence, marital strain and loneliness. 21-44% of parents experienced PTSS (Ljungman et al, 2014). In another systematic review on 56 eligible studies regarding risk factors for distress in parents of pediatric cancer survivors was found, that disease severity, treatment intensity, being a mother, negative affectivity and poor personal resources and family stressors or weaknesses before the diagnosis increased the risk of distress (Sultan et al, 2016).

**In conclusion, childhood cancer could be framed as an ongoing trauma for the child and their parents.** Generally, the psychosocial outcomes of childhood cancer survivors and their parents are positive, but there are some areas of concern, especially in young adulthood. Regarding the level of PTSS experienced by the child and the family the results are mixed, but the importance of screening for the late symptoms is really high regarding prevention and interventions.

In spite of developments in psycho-oncology, the pediatric cancer area has been given less attention in Hungary. In the U.S., the area has gained greater importance in the last 30 years and also there are strong efforts for the integration of psychology in pediatric oncology research and practice (Kazak & Noll, 2015). Despite the fact that the training for clinical psychologists and health care professionals in the field of oncology is improving, the portions of training focusing on pediatric psycho-oncology are absent.

## **2.3 THE JANUS FACES OF THE CANCER EXPERIENCE**

In this chapter I will characterize the **two-sidedness of the cancer trajectory**. In the ancient Rome, Janus was the god of transitions, duality, doorways and passages. He had a double nature symbolized usually as having two faces, since he looked to the future and to the past. Similarly, to the Janus phenomenon, I discuss the cancer experience from two sides parallel and stating that the two side could affect each other. In this dissertation I am framing cancer as a specific traumatic event and process and in the meantime as a potential to grow personally and experience posttraumatic growth. The ongoing traumatic nature of cancer has been described above regarding the different, investigated types of cancer, but in the present chapter a more specified picture will be presented in light of the trauma literature (“Cancer as a traumatic experience”).

Facing a traumatic event or a series of events does not necessarily lead to pathological conditions such as the much-researched posttraumatic stress disorder (PTSD), but the struggle with a difficult life situation (like cancer) can even lead to personality development (Jansen, Hoffmeister, Chang-Claude, Brenner, & Arndt, 2011; Nenova, DuHamel, Zemon, Rini, & Redd, 2013; Schmidt, Blank, Bellizzi, & Park, 2012). Living with chronic diseases and the subject of psychological adaptation to diagnosis and treatment has been in the focus of research for a few decades. In recent years, the spread of positive psychology has led to a growing emphasis on the fact that besides the symptoms of stress, positive psychological changes can occur in the individual as well which can result in positive psychological change in personality and psychological growth (posttraumatic growth, hereinafter referred to as PTG). Through cognitive reintegration processes relationships, belief systems, attitudes towards life and the future, priorities and personal power could be reassessed (Tedeschi & Calhoun, 1996, 2004). In the second part of the chapter “Cancer as a potential for posttraumatic growth” will be discussed.

### 2.3.1 Cancer as a traumatic experience

All the physical, social and psychological difficulties resulting from the cancer diagnosis and treatments listed above in the cases of breast and childhood cancers can be experienced as traumatic. In this chapter I discuss the special characteristics of cancer in the context of trauma literature.

According to the classical view two basic trauma types could be distinguished. First, traumas caused by natural disasters (earthquakes, floods, etc.) or accidents. Second, traumas caused by others, which could be physical, sexual and emotional abuse and in a larger perspective wars, assassinations, political and religious events. Chronic somatic disease is clearly different from both and was not considered traumatic by previous diagnostic systems (Rigó & Zsigmond, 2015). DSM-III-R (American Psychiatric Association, 1987) stated that chronic somatic disease is not considered as a stressor that could cause posttraumatic stress disorder (PTSD). However, DSM-IV (American Psychiatric Association, 1994) and DSM-IV-TR (American Psychiatric Association, 2000) already **allow serious events such as a life-threatening illness** (in our case the cancer disease) which may endanger life and physical integrity in a subjective or real manner **to specifically cause PTSD**. A traumatic stressor has two parts (criterion A1 and A2). The first part consists the actual or witnessed experience of an event involving actual or threatened death or serious injury, or a threat to the physical integrity of the individual or others. Also, **learning that one's child has a life threatening illness is a qualifying event for trauma** (APA, 1994) so it's potentially traumatic and has been considered as one **of the most severe stressors experienced by a parent** (Kazak, 1998). The second part involves a response characterized by intense fear, helplessness, and horror. Since, parents (mainly mothers) are witnessing painful and distressful procedures or treatments on their child, they struggle with their own anxiety which experience may lead to posttraumatic stress (Best, Streisand, Catania, & Kazak, 2001). DSM-IV-TR explicitly states, that being diagnosed with a life threatening illness is a traumatic stressor. This change in attitude in psychotraumatology has inspired valuable literature documenting the stress symptoms caused by cancer. However, the current - DSM-V (American Psychiatric Association, 2013) - diagnostic system does not explicitly state whether a cancer disease can cause PTSD or not, but it is an important change to have a specific category of trauma and stress-related disorders - indicating that the effects of the trauma varies individually (Rigó & Zsigmond, 2015). A new line of research indicates, that with

the reformulation of criterion A (direct exposure to a near death experience/injury/sexual violence) the experience of cancer should be reformulated as an adaptive disorder, not a traumatic stressor (Kangas, 2013). The present dissertation discusses the experience of cancer from two sides: as a traumatic stressor and also an opportunity to grow.

Accordingly, recent scientific research focuses not only on single, acute traumas, but also on **chronic, somatic diseases as traumatic processes** and it has gained great scientific interest (for example: Einsle, Kraft, & Köllner, 2012; Tedstone & Tarrier, 2003). From the different somatic diseases, the traumatic nature of cancer has received great attention (for example: Cordova et al., 2007; French-Rosas, Moye, & Naik, 2011; Sumalla, Ochoa, & Blanco, 2009). It is clear, however, that the applicability of PTSD diagnosis is problematic in cancer diseases, since the nature of the stressor, the nature of the psychiatric symptoms, and the role of the serious illness in the process is undefined (Kangas, Henry, & Bryant, 2002). However, **cancer diagnosis and treatment cause a series of physical, emotional, practical, and social stressors** (listed in the previous chapters), which are demanding on the individual and their support network and **which are potentially traumatic** (Cordova, Riba, & Spiegel, 2017).

Several studies suggest, that an important proportion of patients, experience cancer diagnosis and treatment traumatic. A recent study (Andrykowski, Steffens, Bush, & Tucker 2015) found that using DSM-IV criteria 70 patients of 189, using DSM-V criteria 108 patients of 189 experienced cancer as a traumatic stressor and showed greater distress and growth. Similarly, another study found that breast cancer was a traumatic stressor for more than half of the patient sample (Mehnert & Koch, 2006). In a recent study (Mulligan, Wachen, Naik, Gosian, & Moye, 2014), approximately 50% of combat veterans treated with cancer experienced their illness traumatic according to the DSM-IV criteria. Several studies suggest that increased levels of parent PTSS persist for years even after the completion of the child's treatment, but decreasing over time (Kazak et al, 2004; Kazak et al, 2005).

**Cancer as a stressor**, that can precipitate PTSD diagnosis **is distinct from other stressors in many aspects** (French-Rosas et al, 2011). Cancer is not a discrete event with a clear threat, but a **multi-faceted, extending stressor** (Cordova et al, 2017). Compared to classical traumas, the stressor is more complex, it's not a one-time event and it contains a group of traumatic events regarding the chronic nature of the disease: diagnosis, severity and prognosis of the disease, type of treatment, side effects, body image problems, loss of functionality and role changes in social life (Sumalla, et al, 2009). The traumatic



stressor may not only be a reminder of the diagnosis and treatment, but also a possibility of recurrence, progressive deterioration and subsequent death (Gurevich, Devins, & Rodin, 2002). This seriousness of the threat to life depends on the personality of the patient, the type and severity of the disease, the time of detection, family characteristics and the type of treatment received. Invasive interventions (surgery, bone marrow transplantation) have a greater risk than chemotherapy and radiotherapy (Smith, Redd, Peyser, & Vogl, 1999). Also, most importantly, the threat might never be eliminated even after treatment completion, because cancer recurrence is an ongoing fear which involves constant monitoring, which is rational and also prescribed. Most survivors should actively monitor the **ongoing threat** with healthier lifestyle, medications and doctor visits, which are functioning like reminders of the original trauma (Edmondson, 2014; Schwartz et al, 2010).

Compared to classical traumas, a specific difference is that **the disease and its source** are not found in the environment (such as survivors of wars or abusers), but **have an internal nature** - that is what can play a key role in the change of self-image (Edmondson, 2014; Sumalla et al, 2009). Cancer diagnosis and treatment occur within the context of health care, and there is no individual responsible for the abuse (Mulligan et al, 2014). It is harder to blame the other, others or nature; and since it does not involve masses (such as natural disasters) in one place, it is more difficult to share the experience, to use the protective role of the social network. Hence, cancer as a trauma may favor self-accusation and isolation (Rigó & Zsigmond, 2015). Also the intrinsic nature of the threat implies some kind of **inevitability** (Gurevich et al, 2002) and **inescapability** (Mulligan et al, 2014). Also, bodily signs could function as persistent reminders of the cancer experience (French-Rosas et al, 2011). The appraisal of the threat caused by cancer varies individually and is based on the characteristics of cancer (type, stage, experience of the treatment) and regarding the sociocultural experiences of the individual (Mulligan et al, 2014).

The **coping process** with cancer is not a recovery after a past event, but requires **continuous future (re-)integration**, because patients are most likely to suffer from the consequences of the disease (Sumalla et al., 2009). It is also difficult to determine when someone will overcome the trauma (both physically and psychologically), because the disease may reoccur (Smith et al., 1999).

Despite of all these fundamental differences, there are, of course characteristics where cancer and other traumatic life events are the same. The diagnosis and treatment

of cancer is often **sudden**, it has a **life threatening** nature and **seems uncontrollable**, like other traumatic experiences (French-Rosas, et al, 2011). When the diagnosis is made, the **patients face death** (Sontag, 1983) - their sense of inviolability is suddenly gone - so their faith in their world may be shaken, and their entire reference system (typically in the areas of health, inviolability, immortality) may fail (Rigó & Zsigmond, 2015). All this, coupled with a lack of information about the disease, the **experience of vulnerability, helplessness and loss of control** (both in the area of symptoms and treatment) can result in a similar state as in classic traumas. They may enter into a negative state of consciousness, which may be accompanied by narrowing and dissociation (Spiegel & Cardeña, 1991). The feeling of vulnerability can be very strong, coupled with loss of control and inertia. All of these can be observed in classical traumas. The unpleasant physical side effects (nausea, dizziness, vomiting, hair loss, change in body image, pain, social isolation) could strengthen the effects of the negative feelings experienced (fear, anxiety, hopelessness, and loss of control), all of which may trigger an **aversive reaction**, similar to what has been documented about PTSD (Keane, Fisher, Krinsley, & Niles, 1994). The **anticipatory nature of the stressors** (for example: treatment room, operating staff, hospital scents, etc.) can bring back stress repeatedly, through the exposure to aversive reminders, which is also typical of PTSD. Also, the **inescapable nature of cancer** is similar to the experience of the victims of sudden, acute traumas.

In conclusion, the above listed factors contribute to the experience of cancer as traumatic. Despite the fact that cancer is in many aspects different from classic traumas, fundamental similarities and evidences of the ongoing traumatic nature of cancer was discussed. The present dissertation discusses breast cancer and childhood cancer not only for the women and the children, but also for the parents as traumatic.

## **2.3.2 Cancer as a potential for posttraumatic growth**

### **2.3.2.1 The concept and dimensions of posttraumatic growth**

Traumatic life events (such as cancer) encourage us to confront our own mortality and act as a test for adaptation to the changed order of life. The possibilities are two-sided. The struggle with a crisis could result in a more disharmonic state or also in a **positive, developmental change** (Hajduska, 2010). In a fitting descriptive parallel, the

word ‘crisis’ in the Chinese language also consists of two symbols: danger and opportunity (Yalom, 2003). In this chapter **opportunity** is discussed.

The **positive, transformative force of suffering** has long been recognized in ancient philosophy, religion and literature. Great philosophers of the 20<sup>th</sup> century also addressed the possibility of growth and personal change from the experience of the struggle with a traumatic event or loss (Tedeschi & Calhoun, 1995). For example, Heidegger pointed out, that (1962, quoted by Yalom, 2003) the awareness of mortality can encourage the perceiver to transform into a higher order of existence. The existential psychologist Irvin G. Yalom (2003) used the term “**personal growth**” for the same experience reported by his cancer patients in his clinical practice, to describe the personal change in the time of crisis. His patients reported changes in priorities, strengthened relationships, release of feelings and the importance of “here and now”. The change may be occurring due to the fact that patients were confronted with their own mortality, as a result of which the absolute values became relative and the collapse of the basic schemes were essentially threatening. Maslow, also thought, that if there is no pain, there is no development (2003). The logotherapist, Victor Frankl (1977/2007) through his work as a psychiatrist and his own experience in a concentration camp came to discover the importance of **finding meaning in traumatic life events** as a source of inner strength.

Despite the fact that many religious and philosophical examples can be found describing the positive, transformative force of suffering and that the phenomenon was also addressed in psychological literature, psycho-traumatology largely focused on the negative psychological consequences of serious stressful events up until the 1990s. However, with the **emergence of positive psychology**, it has been recognized that the impact of critical life situations may not only be negative, but may also result in positive psychological changes and examining their interaction has a great importance (Kállay, 2007). However, in more recent decades, the literature discussing the facilitating effect of the experience of a trauma on personality development process has grown enormously.

Referring to Linley and Joseph (2004) and Tedeschi and Calhoun (2004), a **number of terms have emerged to describe this phenomenon**, in which trauma does not only result in negative but also positive and neutral psychological consequences. These include *perceived benefits* (Calhoun & Tedeschi, 1991), *positive psychological changes* (Yalom & Liebermann, 1991), *benefit finding* (Affleck & Tennen, 1996), *stress-related growth* (Park et al, 1996), *flourishing* (Ryff & Singer, 1998), *positive by-products* (McMillen, Howard, Nower, & Chung, 2001), *discovery of meaning* (Bower et al, 1998),

*positive emotions* (Folkman & Moskowitz, 2000), *transformational coping* (Aldwin, 1994), *positive illusions* (Taylor & Brown, 1998) and *thriving* (O’Leary & Ickovics, 1995). The present dissertation focuses on the most widely studied phenomenon, posttraumatic growth. In contrast to the above listed terms, posttraumatic growth refers to life changes which appear to be transformative and go beyond illusions, also posttraumatic growth is an ongoing process, rather than a coping mechanism and it requires a significant threat (as opposed to flourishing) (Tedeschi & Calhoun, 1996). The struggle with a traumatic life situation can thus lead to a higher level of development, through which more advanced coping strategies, higher self-confidence, new self-expression techniques and higher levels of loss management can be achieved (Hajduska, 2010).

**The term posttraumatic growth (PTG) was used first by Tedeschi and Calhoun (1995, 1996) and refers to a positive psychological change after struggling with highly challenging life events.** During the process of PTG, the personality development of individuals **exceeds pre-traumatic levels**: the ability to adapt is improved and the **personality integration goes beyond the trauma level**. So the person is not only the survivor of the trauma, but the **changes override the pre-trauma condition**. Therefore, posttraumatic growth should be distinguished from the concept of resilience and fitness, as they are associated with a successful coping with a serious life situation and thus result in a return to pre-traumatic development levels (O’Leary & Ickovics, 1995).

In the original functional descriptive model, **PTG is a multidimensional phenomenon**. Traditionally five basic dimensions of posttraumatic growth have been distinguished (Tedeschi & Calhoun, 2004), however, recent research on somatic diseases has identified an additional sixth area:

1. **An increased appreciation of life and change in everyday priorities**: this change involves the recognition of the small pleasures of life (such as the beauty of the flowers), the sense of being lucky (the increase in appreciation of what one already has), and the significant transformation of how one experiences everyday life.
2. **Closer, more meaningful relationships with greater intimacy**: people invest more time and energy in their relationships and engage in deeper communication, which, however, also involves a re-evaluation of their relationships (with the loss

or disappearance of other relationships), and greater empathy for the suffering of others.

3. **Increased sense of personal power, coupled with an increased sense of vulnerability:** growth is experienced as a combination of knowing that bad things can happen (thus life becomes more realistic) and the discovery, that one possesses the inner power to cope with it.
4. **Discovering new life opportunities or the possibility to take a new path in life:** this change involves the re-evaluation of previous goals (similar to the re-evaluation of relationships), and only keeping the ones which are worthwhile to invest in.
5. **Turning to spirituality and existential issues:** this change includes immersion in spiritual, religious, and philosophical themes during and after the struggle with the trauma. This change largely depends on the extent to which trauma disrupted the former belief system of the individual. It is important that growth can take place in a particular religious system, but individuals who are not religious can also experience growth through a greater engagement with existential questions.
6. **Favorable change in health behavior, improved health assessment,** which have been identified by qualitative research on somatic diseases (Stanton, Bower, & Low, 2006): serious illness can lead to changes in lifestyle and health attitudes (Tanyi, 2015). This change has been identified in cancer and cardiovascular disease so far, so it can be assumed that it is a specific feature of the trauma caused by somatic diseases. It has not yet received a standard measuring instrument for its assessment and has appeared most notably as a result of qualitative research (Hassani, Afrasiabifar, Khoshknab, & Yaqhmaei, 2009).

### 2.3.2.2 The process and descriptive theories of posttraumatic growth

Tedeschi and Calhoun (2004) discuss in their **functional, descriptive model of PTG** (See Figure 1.) the severe crisis with the help of the seismic event metaphor. They assume, among others (for example: Janoff-Bullman, 1992), that people create a system of beliefs and assumptions about the world that guides their behavior, helps them to understand the causes of events, and can provide a general sense of meaning. Regarding the basic hypothesis, these beliefs and schemas are naive and positive, and the possibility of bad things to happen are not part of them. (Janoff-Bullman, 1992).

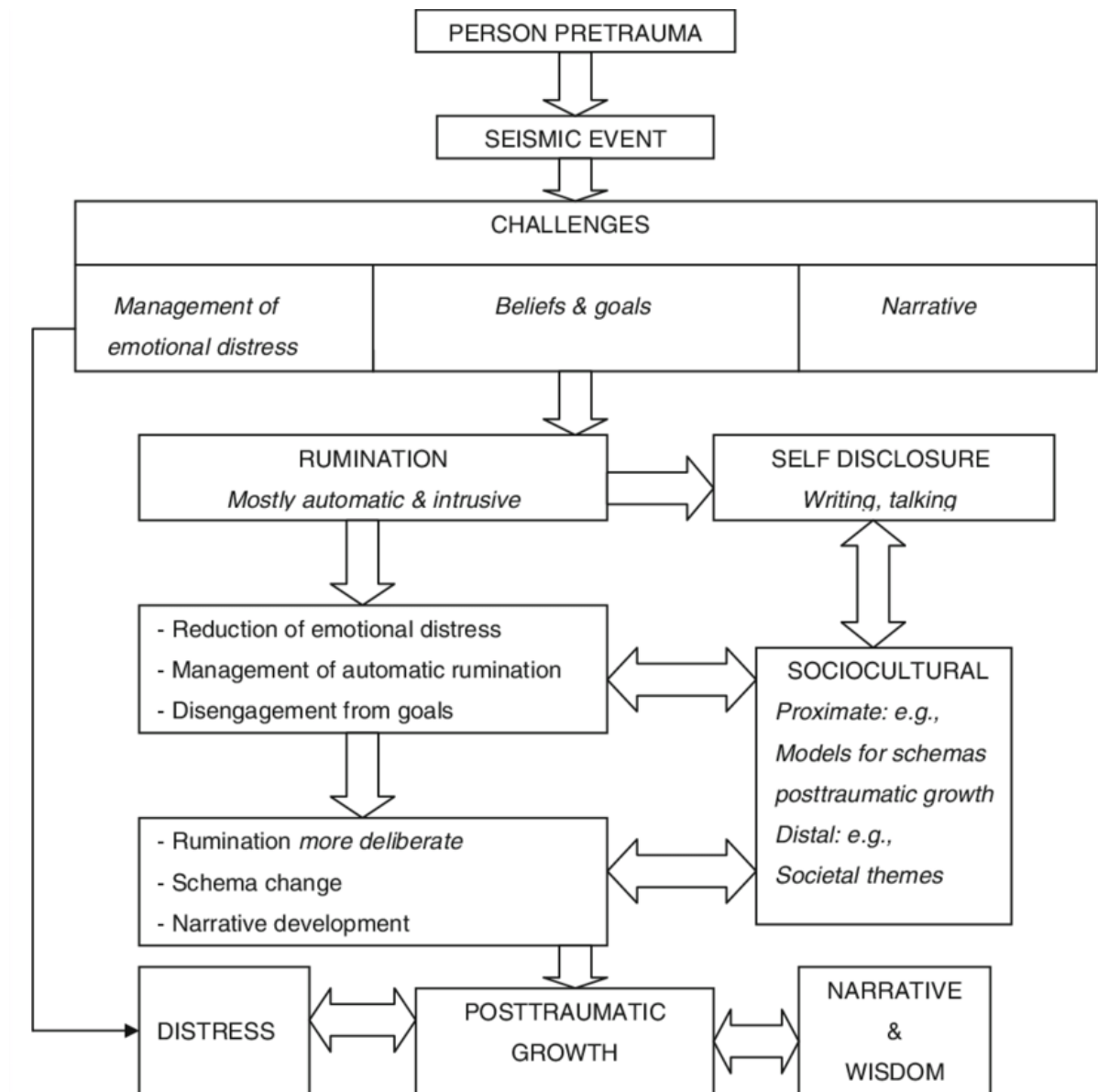
Based on the functional model of Calhoun and Tedeschi (2004, 2006), posttraumatic growth occurs due to the **distress caused by the trauma**, the **collapse of the previous schema and belief system** (for example: "the world is safe, nothing bad can happen to me ") and the **cognitive processing of the trauma**. According to Tedeschi and Calhoun (2004) the severe, traumatic event threatens the person's cognitive **belief and schema system to collapse** (like during an earthquake), because it questions their validity. The schemas which have been working before are not working during a severe life event which has not been experienced before and does not fit in the naive world view framing previous events. Such experience of threat to the assumptive world generates a serious amount of **psychological distress**. Struggling with the trauma however also includes the potential for personal growth, as a post-earthquake reconstruction. To build a new reality, the schema system need to be more resilient to serious life events. Adaptation to the new situation can be achieved through **cognitive processing** and restructuring, which leads to the transformation of the basic assumptions. The schema system should be more resilient and resistant to severe life events in the future.

Their functional model also describes how the traumatic psychological distress triggers **automatic and deliberate rumination processes** of the serious event and the reactions associated with it. In the early stages of the response to trauma, cognitive processing is manifested in the form of automatic and intrusive rumination. This negative rumination process perceived during initial struggles is replaced by a constructive form of rumination that involves repetitive, purposeful processing aimed to cope with the trauma. Rumination occurs only when the individual is able to revise old patterns and build new ones (Tedeschi & Calhoun, 2006). Rumination is therefore fundamentally important in the process leading from the broken world view to the development of PTG (Lindstrom, Cann, Calhoun, & Tedeschi, 2013). Several studies suggested that PTG is more likely to occur when the cognitive activity regarding the elements of the trauma is significant (Linley & Joseph, 2004; Manne et al, 2004).

It is important to note that recent research shows, that not only emotional regulation and rumination processes related to negative effects, but also **responses to positive emotions** may be important in the development of PTG or depressive symptoms (Feldman, Joormann, & Johnson, 2008; Bijttebier, Raes, Vasej, & Feldman, 2012) .

Tedeschi and Calhoun (2006) suggest in an expanded framework, that in understanding the process of PTG, the distal (larger society, country) and proximal (small community, social network) **cultural context of the individual** should also be

considered. The degree and characteristics of PTG is influenced by the primary reference group (family, close friends, professional peers and so on). They think, that if the individual is allowed to engage in self-disclosure about the trauma, if the ruminations are congruent with the thoughts of significant others and if growth themes are part of the proximal cultures narratives, growth would more likely to occur. Also, after the successful cognitive reintegration process, the person builds up a **new narrative** about life experienced before and after the trauma (Tedeschi & Calhoun, 2006).



**Figure 1.** A comprehensive model of PTG by Tedeschi and Calhoun (2006). Copyright Lawrence Erlbaum Associates Publishers (2006).

The functional PTG model has been supported by various empirical studies in a number of areas - such as grief (Calhoun, Tedeschi, Cann, & Hanks, 2010), HIV infection

(Milam, 2006), rape, sexual abuse, violence (Elderton, Berry, & Chan, 2017; Lev-Wiesel, Amir, & Besser, 2004), war (Powell, Rosner, Butollo, Tedeschi, & Calhoun, 2003), somatic diseases (Hefferon, Greal, & Mutrie, 2009; Leung et al, 2012), natural disasters (García, Cova, Rincón, Vázquez, & Páez, 2016), refugees (Sleijpen, Haagen, Mooren & Kleber, 2016), bereavement (Taku, Tedeschi, & Cann, 2015) and many other areas. However, in this dissertation the review of the enormous literature will be narrowed to PTG in breast and childhood cancers.

Despite the fact that Tedeschi and Calhoun's functional model is the most accepted and studied in the various trauma groups, there is still an open discussion about the process of posttraumatic growth. The fundamental question is whether we can speak of a **one-dimensional or multidimensional construct** (Tanyi, 2015). According to a line of theorists (for example: Nolen-Hoeksema & Davis, 2004) posttraumatic growth should be discussed in a one-dimensional model, and considered as a global phenomenon of adaptation to trauma. The process of its formation can thus be considered as unified.

However, other theorists argue for multidimensionality. According to **Janoff-Bulman's** (2004) theory, certain **areas of PTG are formed through different processes**, which are conceived in three explanatory models (strength through suffering, existential re-evaluation, psychological preparedness) which are in relation with each other. First, in the model of **strength through suffering** the coping task with the traumatic life event concludes in the sense of increased personal power and self-confidence which opens the door for new possibilities in life. Thus the two dimensions of the original model of PTG – increased sense of personal power and discovering new life opportunities – are formulating in this process. Second, in the model of **existential re-evaluation**, facing death the survivors of the trauma are re-evaluating the values of life and finding meaning in it. This path of growth contains the 3 other dimensions of the original PTG model (appreciation of life, more meaningful relationships and spiritual/existential change). Third, in the model of **psychological preparedness**, the growth derived from the existential re-evaluation and schema system change, the new perspective contains the uncontrollable nature of the universe. Thus it is a preventive psychological state, which prepare the trauma survivor for subsequent tragedies. However, these theories are somewhat contradicted by the fact that the different subscales of PTG are in strong correlation (Park & Lechner, 2006).



The functional model (Tedeschi & Calhoun, 2004) could be considered as a midway approach, which also implies a multidimensional construct, but assumes common paths of development in the different dimensions.

When discussing the process of PTG, the question also arises as to whether **PTG can really be separated from coping or if it is to be classified as an additional form of coping**. The literature on posttraumatic growth follows two perspectives in conceptualizing the phenomenon. Some authors consider the phenomenon as a coping strategy, while others say that posttraumatic growth is the result of struggling with a traumatic event (Zoellner & Maercker, 2006). According to Tedeschi and Calhoun (2004), PTG develops during the struggle with trauma, but Park and Folkman (1997) believe that the processing of a critical life situation can be seen as a kind of coping strategy in which the situational meaning is integrated into the global meaning (existing experiences and beliefs). Another view is that posttraumatic growth acts as a positive illusion. The experience of posttraumatic growth is a possible self-strengthening interpretation that helps to cope with the danger (Taylor & Armor, 1996). The two-component model of posttraumatic growth (Zoellner & Maercker, 2006) attempts to integrate these two perspectives. The Janus-face model of PTG includes the constructive, functional component described by Tedeschi and Calhoun (2004) and an illusory and dysfunctional component described by Taylor and Brown (1994). The constructive side leads to an adaptive outcome and healthy adjustment in the long run. In contrast, the illusory component is initially stronger, which helps in the processing of emotional stress after the first shock caused by trauma, but is dysfunctional in the long run because is associated with cognitive avoidance strategies, possibly causing denial. The successful coping with the trauma assumes that the constructive side grows over time and the illusory component of PTG is decreasing over time (Zoellner & Maercker, 2006). Another synthetic view is concluding that 1) coping and PTG are forming in interaction with each other and 2) coping could affect equally the reconstruction of the pre-traumatic condition (in this case, it does not lead to PTG) or the personality development (Kulcsár, 2005).

Another important, Hungarian model originates PTG from the need to belong. Regarding this line of thought, the first impulses of PTG are the social emotions, which are facilitating the experience of more meaningful relationships (one dimension of PTG). Thus, the need to belong, the social support is an essential, human function (Kulcsár, 2005; Kulcsár, Rózsa, & Reinhardt, 2006).

In conclusion, the theoretical PTG literature is enormous and fails to come to a consensus about the process and nature of PTG. It seems, that the phenomenon is very complex and needs further evaluation. In the present dissertation the most accepted and studied model of PTG (Tedeschi and Calhoun's functional model) will be examined.

### **2.3.2.3 The assessment of posttraumatic growth: qualitative and quantitative methods**

**Quantitative scales** are often cited as a requirement within larger-scale studies, however just few of these inventories are valid measures of PTG. The three psychometrically validated measures – Stress-Related Growth Scale; Posttraumatic Growth Inventory (PTGI) and Benefit Finding Scale (Park & Lechner, 2006) - will be presented in this dissertation, focusing on the PTGI, the validation framework used in the present dissertation.

The **Stress-Related Growth Scale** (SRGS, Park et al, 1996) is a 50 item self-report measure regarding changes in personal resources, social relations, philosophy of life and coping after a traumatic event on a 0-3 scale. Its internal consistency is high.

The **Benefit Finding Scale** (BFS, Tomich & Helgeson, 2004) is a 17 item self-report questionnaire assessing growth on a 5-point scale, developed among women with breast cancer. Its internal consistency is high.

The original and most often used form of the **Posttraumatic Growth Inventory (PTGI)** (Tedeschi & Calhoun, 1996, 2004) is a 21 item self-report measure assessing the five separate domains of PTG according to Tedeschi and Calhoun on a 0-5 scale, indicating the degree to which the individuals experienced changes in their life after crisis (in this case, the cancer diagnosis). The internal consistency of the normative sample was high (Cronbach-alfa: 0,9). The Hungarian validation of PTGI also provided high reliability (Cronbach's alpha=0,94) (Kovács, Balogh, & Preisz, 2012).

There are several versions of the inventory: a shortened version, **PTGI-SF** (Cann et al, 2010); a version examining children, **PTGI-C** (Cryder et al, 2006) and a new revision from the original working group, **PTGI-X** (Tedeschi, Cann, Taku, Senol-Durak, & Calhoun, 2017). The Spirituality Scale in the original version of PTGI contains very few items and its reliability is below other scales. Additionally, the authors of PTGI-X came to acknowledge that spirituality could be culturally affected, so Tedeschi and colleagues (2017) suggested a revision and expansion of PTGI. The new spirituality metrics reflect the diversity of perspectives on spiritual and existential thinking

represented in different cultures and also solve the problem of insufficient number of items in the Spirituality Scale.

Despite the fact that the PTGI is widely trusted, there are a number of limiting factors associated with its use: it is used irrespective of the type of trauma, it is a subjective self-report measure and only measures positive changes, therefore it is also useful to use an additional questionnaire for the detection of stress symptoms, and behavioral and physiological indicators of PTG.

An important shortcoming of the research so far is that in most cases only quantitative methods were used to explore PTG. In a recent review of positive psychological changes following breast cancer (Casellas-Grau, Vives, Font, & Ochoa, 2016) was found, that only one of the 38 articles on PTG used a qualitative method. Qualitative research can also play a major role in an area that has already been researched by quantitative methods, because the subjective perception of the disease can be better described by the survivors, thus providing a more accurate picture of their **individual experience** with the disease (Emslie, 2005). Also, a deeper understanding of the dimensions of PTG would be of great help in designing goal-oriented interventions in clinical work (Stefanic, Caputi, Lane, & Iverson, 2015). Another advantage of qualitative methods is that participants are not primed with specific items, so the growth reported could be particularly relevant (McMillen, 2004).

**Qualitative methods** regarding PTG involve open question formats (indirect and explicit questions about PTG after a serious life event), written essays, focus groups and interviews (Park & Lechner, 2006). Open question formats contain questions about positive life changes following a trauma. Regarding interview formats, in an earlier study (Taylor, Lichtman, & Wood, 1984) breast cancer patients were asked 1-60 months following surgery in an interview about how their illness influenced their future plans, daily activities, self-views, world-view and their relationship with others. The questions were whether open-ended, deliberately initiated or questions with varying response options. The interview data was coded and quantitative measures were also used.

In a systematic review of the qualitative literature on PTG experienced in somatic diseases cancer was the leading illness studied and mostly semi-structured interviews were used, the qualitative analysis methods contained content analysis, phenomenology thematic analysis, open-ended coding, grounded theory and comparative data analysis (Hefferon, Greal, & Mutrie, 2009).

In a special form of content analysis open-ended questions can be used and the responses are analyzed using predefined codes based on an existing theory. Thus, the coding task is of recognizing patterns with enough indicators based on existing definitions of the phenomenon in the interviews and record their presence (Potter & Levin-Donnerstein, 1999). A recent systematic review states that studies using content analysis should include illustrative examples from the content, coding rules and the subjectivity of the procedure (Vourvachis & Woodward, 2015). For illuminating high subjectivity is to use multiple, independent coders (Steenkamp & Northcott, 2007).

#### **2.3.2.4 Posttraumatic growth among cancer patients**

As we have seen, PTG can have positive adaptive consequences, making it an important construct in clinical and health psychology (Rigó & Zsigmond, 2015). Chronic illness can also be considered as a journey if one feels that the disease has some purpose (Frank, 1995). In the classic work of Campbell (2010) the illness appears as an analogy of a hero's journey and helps us understand the possibilities of the emergence of posttraumatic growth. The hero's journey can be divided into three stages. The first stage is the departure, which starts with a call, which is the symptom of cancer itself, and is often denied at first. In the next phase the existence of the symptom can not be denied, a diagnosis is formulating - this is the stage of the first threshold - followed by hospitalization, surgery, and when the severity of the illness also becomes clear. The second is the initiation phase, which is framed as "a long road with obstacles" - the disease causes suffering in a physical, emotional and social sense. During the journey, the patient undergoes a transformation, possessing a new experience which is carried forever. In the final stage - the return - the protagonist of the story returns healed, but must share the experience of the integrative effect of suffering with others.

The appearance of PTG has already been demonstrated in many groups of cancer patients: in breast cancer (Brix et al. 2013), colorectal cancer (Jansen et al., 2011; Rinaldis, Pakenham, & Lynch, 2010), cervical cancer (Smith, Dalen, Bernard, & Baumgartner, 2008), prostate cancer (Thornton & Perez, 2006), oral cancer (Ho et al, 2011), melanoma (Dirksen, 1995), hepatoma (Dunigan, Carr, & Steel, 2007), childhood cancer (Gianiazzi et al, 2016; Picoraro et al, 2014) and Non-Hodgkin lymphoma (Crespi, Smith, Petersen, Zimmerman, & Ganz, 2010). In general, 80% of cancer patients experience PTG (Sumalla et al., 2009) - at least in one area of growth. This type of

personality change is similar in people who have undergone cancer in adolescence (Barakat, Alderfer, & Kazak, 2006).

The results suggest so far, that people with cancer can experience change in all areas of PTG, but it seems that **specific areas of PTG are more pronounced in this group**. Several studies have highlighted the fact that the most important areas of PTG among cancer patients are increased appreciation of life, more meaningful relationships and the increased sense of personal power (Cordova et al., 2007; Mols, Vingerhoets, Coebergh, & van de Pollen, 2009; Widows, Jacobsen, Booth-Jones, & Fields, 2005). This result has also been demonstrated by controlled studies. For example, women breast cancer survivors have reported higher scores of PTG compared to their healthy controls and the above mentioned three areas were the most important dimensions of development. The authors assumed, that PTG could depend on the severity of the disease (for example: tumor size, number of positive lymph nodes, hormone treatment, etc.) (Brix et al., 2013).

Earlier research focused on the prevalence of PTG regarding cancer patients, but recent studies exploring the factors predicting and influencing the PTG process and discussing individual differences in the PTG experience. Posttraumatic growth has been explored in terms of the type or characteristics of cancer, but most of the studies focused on breast cancer or used mixed patient groups (Rajandram, Jenewein, McGrath, & Zwahlen, 2011). A priority area is the process of PTG (Zoellner & Maercker, 2006), because according to Tedeschi and Calhoun's (2004) theory, cognitive processes related to the trauma are time consuming, and the management of emotional distress also requires a lot of effort. The results regarding the predictors of PTG (for example: distress, depression, personality traits, self-discovery, coping, social support, environment, spirituality, optimism, etc.) in cancer samples have been mixed (Ramos & Leal, 2013). Thus, cross-sectional and longitudinal studies of multiple tumor groups are required, of which little concentrated study has been performed so far.

Research in different patient groups and knowledge gained through qualitative techniques have shown that posttraumatic growth could occur due to the interaction of many factors (Garnefski, Kraaij, Schroevers, & Somsen, 2008; Leung et al., 2012). In terms of cancer, **individual** (gender, age, marital status, education, health-related quality of life, degree of threat perception, coping skills, another serious life events experienced), **social** (quality of relationships, social support system, environmental factors) and **cancer specific characteristics** (type of tumor, stage, time since diagnosis, subjective severity of the disease and types of treatments, cancer-related posttraumatic stress) could affect

the ability of the person to develop (Kulcsár, 2005; Sawyer, Ayers, & Field, 2010; Tanyi, 2015; Zsigmond, Rigó, Bányai, 2017).

### **2.3.3 Factors contributing to PTG among breast cancer patients**

Although breast cancer may have many negative psychological consequences, it can also be considered as an existential challenge that can result in personal growth (Brix et al, 2013; Wang, Liu, Wang, Chen, & Li, 2014). 59% to 83% of women experiencing breast cancer find the potential for personal development during and after illness (Sears, Stanton, & Danoff-Burg, 2003). In Hungary, 74 percent of surveyed female breast cancer patients reported, that their life had changed in a positive direction after surviving of the disease (Riskó, 2006). A number of studies have reported PTG in women diagnosed with breast cancer in the period of five years after diagnosis (Danhauer et al., 2013, Coroiu, Körner, Burke, Meterissian, & Sabiston 2016, Belizzi & Blank, 2006).

The results of previous studies suggest that women treated with breast cancer can experience change in all areas of PTG. Patients have been reported to experience greater appreciation of life (Belizzi & Blank, 2006; Bower et al., 2005, Mols et al, 2009) and consequently, favorable change in health behavior and improved health assessment (Hefferon, Greal, & Mutrie, 2010; Coward, Kahn, 2005) following breast cancer. An increased sense of personal strengths (Morris, Shakespeare-Finch, 2011; Liu, Wang, Wang, Su, 2014) and spiritual/existential changes (Lelorain, Bonnaud-Antignac, & Florin, 2010) also appeared in the studies. The need for more meaningful relationships and the re-evaluation of relationships arising from the need for social support is also a key area of growth cited (Svetina & Nastran, 2012; Weiss, 2004; Manne, 2004).

However, the most significant domains of change experienced by breast cancer patients have been manifested in greater appreciation of life, in the need for more meaningful relationships and in increased sense of personal strength (Cordova et al., 2007; Mols, et al, 2009; Svetina & Nastran, 2012; Weiss, 2004; Manne, 2004). This results also appeared in a controlled study (Brix et al, 2013): breast cancer survivors showed a higher score compared to their healthy controls in the above mentioned dimensions of PTG. However, this may depend on the severity of the disease, such as tumor size, number of positive lymph nodes and hormone treatment. However, there was no detectable difference between the two groups regarding the total score of PTG. (Brix et al, 2013).

PTG in breast cancer patients is influenced by many individual, social and disease-related factors. In this chapter these factors will be discussed in an integrative manner. All the studies reviewed used the PTGI for examining PTG.

### **2.3.3.1 Individual and social factors in relation to PTG**

PTG in breast cancer is influenced by many individual and social factors, such as age (Boyle et al, 2017), educational level (Uruchojo et al, 2005), marital status (Mystakidou, Tsilika, Parpa, Kyriakopoulos, Malamos, & Damigos, 2008), quality of life (Lerolain et al, 2010), social support (Lelorain, Tessier, Florin, & Bonnaud-Antignac, 2012) coping (Cordova et al, 2007) and occurrence of additional serious life threatening events. In terms of individual and social factors, the results have been inconsistent, which may be due to the fact that studies have used different methodologies and study groups. Nevertheless, research has proven consistently that **core predictors of PTG are the level of social support and the various coping strategies** (Bussell & Naus, 2010) - mostly positive coping - that are also interacting with each other (Cordova, Cunningham, Carlson, & Andrykowski, 2001).

#### **2.3.3.1.1 Social support**

**Social support** provides assistance through frequent conversations about the experiences related to the illness, while offering a sense of comfort and togetherness, while functions through emotional and informational support (Cordova et al., 2001). It is fundamental, that due to extreme distress caused by the diagnosis and the treatment, many patients seek social support to talk about the stressful event. Besides its comforting effect, self-discovery in a safe social environment can also affect the process of restoring the patient's shaken world view and deliberate rumination processes (Ramos, Leal, & Tedeschi, 2016).

According to the theory and also previous research literature, social support at the time of diagnosis and during treatment is one of the key factors for mobilizing inner resources and even PTG in the long run (Tedeschi & Calhoun, 2006; Scignaro, Barni, & Magrin, 2011). However, regarding self-disclosure and rumination processes examined in relation to PTG and PTSD, attention is also drawn to the study of socio-cultural factors (Lindstrom et al., 2013). This is supported by a comprehensive meta-analysis of women diagnosed with breast cancer (Casellas-Grau et al, 2016), which identified socio-cultural differences in coping and PTG. As Tedeschi and Calhoun (2006) state in their original

theory, the degree and characteristics of PTG is influenced by the primary reference group. If the individual is allowed to engage in self-disclosure about the trauma, and if ruminations are congruent with the thoughts of significant others while growth themes are part of the proximal cultures narratives, growth is more likely to occur. Social support also helps to facilitate coping processes and in finding meaning through the experience (Brix et al, 2013). Thus, the positive social emotions created by the traumatic situation can facilitate the onset of the posttraumatic growth process (Kulcsár, 2005).

Previous empirical studies of breast cancer patients also reported significant positive relationships between self-disclosure of the disease and posttraumatic growth and also the increases in social support are associated with greater PTG (Danhauer et al, 2013; Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002). In a controlled study, females diagnosed with breast cancer and healthy control subjects did not differ in their degree of depression and well-being, but diagnosed breast cancer patients showed higher levels of PTG associated with perceived life threat, prior discussion of the disease, and time since diagnosis (Cordova et al., 2001).

Another branch of research emphasizes the importance of the PTG of the partner - in some of the studies, the partner's PTG was a fundamental predictor of posttraumatic growth in women with breast cancer (Manne et al., 2004; Weiss, 2004).

#### **2.3.3.1.2 Coping**

Tedeschi and Calhoun (2004) states that early coping success is prognostic for later PTG. Therefore, **personal coping skills and strategies are considered as key components of PTG.**

A vast amount of literature is available regarding coping styles and strategies, even when examining just the cancer-related literature. According to Lazarus (1966, 1993), any cognitive or behavioral effort that an individual seeks to handle events that outweigh their personal resources may be considered coping. Traditionally, two coping categories are distinguished: problem-focused (direct action to solve the problem and to decrease stress) and emotion-focused (regulates emotional responses to stress) coping.

After a paradigm shift in stress research, instead of examining pathological consequences, the studies have focused on revealing the **personality resources that protect against stress.** Regarding a Hungarian theoretical concept on integrating personality resources that maintain the psychological health of an individual, coping strategies have been conceptualized as an integrated system in the personality, which is



defined as the **Psychological Immune System (Oláh, 2005)**. The demonstration of the concept is more detailed here, because it is measured in the present dissertation. "The concept of the psychological immune system is intended to denote personality resources that enable individuals to endure prolonging stressful effects, to successfully cope with the threats in a way that the integrity of the personality, operational efficiency and development potential are not compromised, but rather enrich the active occupation with stress." (Oláh, 2005, p. 85). The psychological immune system consists of three subsystems built up by the different protective factors that perform the same functions. The **Approach-Belief Subsystem** integrates the personality resources that enable us to get to know, control and monitor positive consequences of the physical and social environment (for example: optimism, sense of coherence, sense of self-growth, sense of control, aso.). The personality resources that build up the **Mobilizing-Creating-Executing Subsystem** allow the meeting of personal needs and the ability to be able to change social and physical environment to achieve these goals (for example: problem-solving ability, self-efficacy, social creativity, aso.). The **Self-Regulating Subsystem** includes personality factors (for example: impulse control, emotional control) that ensure the control of attention and consciousness, the adherence to achieving goals and the control of emotional states resulting from threats (Oláh, 2005). The Psychological Immune Competence Inventory (PICI) (Oláh, 2005), which contains the three subsystems and 16 dimensions described above, is used to measure coping capacity (see later). There have been no studies to date which analyze the relationship between psychological immune competence and PTG in a breast cancer sample. The Hungarian validation study of PTGI stated, that certain coping qualities (measured with PICI) contribute to experiencing growth (Kovács et al, 2012).

In a previous review of PTG in clinical psychology (Zoellner & Maercker, 2006) **acceptance coping, positive reappraisal coping, sense making and rumination** were emphasized as potentially functional coping types regarding PTG. This finding is supported by another meta-analysis (Helgeson, Reynolds, & Tomich, 2006) which also showed that positive reappraisal and acceptance coping are in relation to PTG. According to a previous study, (Sears et al., 2003) the type of coping style is closely related to the cognitive processing style of the individual, which may later lead to PTG. In their research on breast cancer patients, it was found that positive reappraisal coping strategy was related to higher rates of PTG 12 months after diagnosis. A longitudinal study involving breast cancer patients reported that emotionally focused coping strategies were positively

related to psychological distress during the chemotherapy treatment. At the two-year follow-up religion, acceptance coping and positive reframing explained 46% of PTG variance (Bussel & Naus, 2010). In a recent study active-adaptive coping style was in a positive relation to PTG regarding 653 cases of breast cancer (Danhauer et al, 2013). In a cross-sectional study positive reframing and active-adaptive coping were in positive relation to PTG regarding cancer survivors (Schmidt, Blank, Belizzi, & Park, 2011). A recent longitudinal study of 189 breast cancer patients reported that positive coping strategies were positively related to PTG six months after the completion of treatment, and even more strongly linked together after two years (Hamama-Raz, Pat-Horenczyk, Roziner, Perry, & Stemmer, 2019).

In conclusion based on the existing literature, positive coping strategies are positively linked to PTG and could be prognostic for later PTG. Regarding psychological immune competence similar assumptions could be made.

#### **2.3.3.1.3 Age, marital status, education, employment**

Age, marital status, education and employment are also important predictors of PTG (Bellizzi & Blank, 2006; Manne et al., 2004; Danhauer et al., 2013), but the results are inconsistent.

Regarding the relationship between **age and PTG**, several studies and reviews found (Belizzi et al, 2012; Casellas-Grau et al, 2016; Koutrouli et al, 2012; Manne et al, 2004; Mystakidou et al, 2010) that younger women with breast cancer experience higher levels of PTG. Younger age can influence the perceived threat of the cancer diagnosis with higher rates of psychological distress and younger patients could be more engaged in the re-evaluation of their schema system than older patients (aged above 50-60 years) who have already experienced serious life events (Boyle et al, 2017; Mystakidou et al, 2010). Regarding **marital status**, the results are mixed. Several studies and reviews reported positive relationship between marital status and PTG – married/in a relationship breast cancer patients experienced higher rates of PTG (Belizzi & Blank, 2006; Casellas-Grau et al, 2016; Mystakidou et al, 2010). This result highlights the importance of spousal social support. However, several studies found no significant positive relationship (Dunn et al, 2011; Danhauer et al, 2015). Regarding **education**, the results are controversial. Some of the studies found positive relationship between higher education and PTG (Cordova et al, 2007; Danhauer et al, 2013), some of them found no connection at all (for example: Mystakidou et al, 2008) and some of them found a negative relationship (Morill

et al, 2008). Regarding **employment status**, the results of empirical studies are also mixed. Some of them found no correlation with PTG (Danhauer et al, 2013) and some of them found a positive relationship (Belizzi & Blank, 2006). It may be due to the fact that the different studies examined multiple disease groups and differed in the methodology (both in measuring instruments and in the applied constructs and statistical methods).

### **2.3.3.2 Cancer-related factors in relation to PTG**

PTG in breast cancer is influenced by many cancer-related factors, such as time since diagnosis (Sears et al, 2003), perceived severity of the disease (Cordova et al, 2007), treatment types (Lerolain, 2012, Yanez et al, 2009) and cancer related posttraumatic stress (Koutrouli, Anagnostopoulos, & Potamianos, 2012).

**Time since diagnosis** seems to be an important moderating factor regarding PTG in breast cancer patients (Cormio et al, 2016), but the findings are mixed and just a few longitudinal studies are available. Cross-sectional studies have found mostly no correlating relationship between time since diagnosis and PTG (Cordova et al, 2007; Lerolain et al, 2010). But several longitudinal studies found positive associations between a longer time duration since diagnosis and higher PTG (Cordova et al, 2001; Sears et al, 2003; Manne et al, 2004). In another longitudinal study PTG had a quadratic relationship with time since diagnosis, increasing initially after diagnosis and leveling off over time (1-21 months after diagnosis) (Danhauer et al, 2013). The original statement of Tedeschi and Calhoun (2004) stating that longer time is needed after diagnosis for PTG is therefore no longer applicable.

Theorists also state that **PTG and posttraumatic stress** have a common basis: the subjective **perception of threat and vulnerability** (Ochoa, Sánchez, Sumalla, & Casellas-Grau, 2019). According to a meta-analysis of factors related to PTG in breast cancer, the perceived threat and uncertainty related to diagnosis, the treatment itself and the prognosis are consistently in positive correlation with PTG (Sumalla et al., 2009). This result also supports the theory of Tedeschi and Calhoun (2004), according to which the stressor that precedes the process of PTG should be severely traumatic. Thus, the **subjective perception of the disease** could play a prominent role in predicting growth (Manne et al., 2004). Given that cancer is a multidimensional trauma, many factors can affect the level of perceived threat in the different stages of the cancer trajectory (Gurevich et al., 2002). Several studies (for example: Rajandram et al., 2011) have pointed out that the possibility of recurrence and the severity of the disease - as they affect

the extent of the threat - may have different effects on PTG in the different cancer types. Most of the studies involve older aged patients and also differ in which stage of the treatment PTG is examined. It is also difficult to compare different studies on cancer, because of varying time determinations of traumatic events (for example: diagnosis, before / after treatment, recurrence) (Gurevich et al., 2002). Additionally, the **experience of chemotherapy** can be also important regarding to PTG, because it is very strenuous both physically and emotionally, thus, it has an activating effect on the individual's social network. This may have positive consequences in the long run regarding the onset of posttraumatic growth (Casellas-Grau et al., 2016). It should also be emphasized that symptoms of the trauma may not be stress symptoms, but may also be symptoms of the disease, such as sleep problems, memory problems, irritability, concentration problems, drug side effects, and so more detailed differentiation is essential (Gurevich et al., 2002).

As discussed in previous chapters, the experience of threat to the assumptive world generates a serious amount of **psychological distress**. Struggling with the trauma however also includes the potential for PTG (Tedeschi & Calhoun, 2004, 2006). Thus, breast cancer as a traumatic stressor could be a catalyst for PTG (Groarke et al, 2017). Regarding traumatic stress, the emotional information becomes dominant, which could favor the experience of togetherness and religiousness, but also could result in emotional paralysis, which is observed in PTSD (Kulcsár, 2009). The cognitive processing of trauma indicates constant, but manageable stress levels (Tedeschi & Calhoun, 1996, 2004, 2006). However, empirical evidence on the role of distress is mixed. Several studies reported a positive relationship between PTG and PTSD or PTSS (Tomich & Helgeson, 2004), even the increased distress and the experience of PTSD symptoms could predict PTG (Merecz, Waskowska, & Wezyk, 2012). A recent meta-analysis (Shakespeare-Finch & Beck, 2014) confirmed that with increases in traumatic distress symptoms, growth is also increasing, but they also pointed out that while a linear relationship between the two variables has been previously described, the relationship can be better explained by the quadratic relationship. Although, in a recent systematic review PTSD and PTG in breast cancer samples were not related (Koutrouli et al, 2012). Another direction of research has revealed a curvilinear relationship between stress and posttraumatic growth (for example: Kleim & Ehlers, 2009). An additional study indicated a negative association between distress and PTG (Urcuyo, Boyers, Carver, & Antoni, 2005). It may be due to the fact that the different studies examined multiple disease groups

and differed in the methodology (both in measuring instruments, examining variables and in the applied constructs and statistical methods).

PTG may also be associated with various indicators of **quality of life** (Sawyer et al., 2010; Zoellner & Maercker, 2006), but the question is whether it can improve quality of life (Tomich & Helgeson, 2012). A number of studies suggest that PTG is related to better quality of life and more optimal functioning in women with breast cancer (Brix et al., 2013, Danhauer et al., 2013) therefore it may have an adaptive function. A comprehensive meta-analysis (Sawyer et al., 2010) found that there is a slight positive relationship between PTG and positive mental health, psychological well-being and subjective physical wellbeing, and a negative relationship between PTG and negative mental health. The authors have suggested that, as PTG increases as a result of the disease, it may later have a greater impact on positive well-being. PTG has also been associated with spiritual well-being (Bishop et al., 2007). However, the results regarding the relationship between PTG and quality of life are not consistent. This may be due to the characteristics of different disease groups, methodology and personality factors (Coyne & Tennen, 2010; Zoellner & Maercker, 2006). Another aspect is that growth is facilitated by the serious threat and vulnerability, resulting in little chance of a linear relationship between well-being and PTG indicators (Sumalla et al., 2009). Others question whether PTG is encouraging better well-being (Sawyer, Ayers, & Field, 2010) or if reciprocal relationships can be cited, as in a state of stable well-being, people may be more inclined to see more positive changes that are reflected in their own well-being notions.

#### **2.3.3.3 Integration of the predictive factors of PTG**

It can be seen that the predictive factors and the process of development of PTG in breast cancer would be worth examining in an integrated model. Several factors influencing PTG have common basis and similar underlying factors.

A study conducted with breast cancer patients hypothesized, that many patients can seek social support because of extreme distress caused by the diagnosis in order to talk about stressful events. Self-discovery in a safe, social environment can also affect the process of restoring a shaken world and deliberate rumination (Ramos, Leal, & Tedeschi, 2016) - which have been key factors in the development of PTG in breast cancer patients (Danhauer et al., 2013).

Another possible model for the development of PTG was established based on a systematic review focusing on cancer patients (Rajandram et al., 2011). In an adaptive

reaction to severe trauma (diagnosis of cancer and treatment processes), certain personality traits (for example: optimism), social support (both family and treatment staff) and strong spousal support are the most likely to assist with positive active and problem-focused coping processes and in finding meaning in the experience. According to their model, these and disease-related rumination processes can help to develop PTG.

However, attempts to integrate the above mentioned factors are missing the stress-related factors outlined in previous chapters. It is striking that the current literature on PTG is dominated by studies which emphasize the positive relationship between growth and quality of life and optimal functioning (for example: Brix et al., 2013; Sawyer et al., 2010). However, there is very little research on harder, biological indicators (for example: prognosis, survival time, disease specific biological and immune parameters, etc.) and their relationship with PTG. An exception is the study by Diaz, Aldridge-Gerry and Spiegel (2014), where authors found a link between PTG and a healthier daily cortisol pattern that could indicate lower stress levels. In another study, patients with higher PTG were found to stabilize faster after chemotherapy based on their white blood cell count (Dunigan et al., 2007).

The more critical line of theorists are also considering the fact that, before the beneficial relationship between PTG and physical well-being (which is difficult to detect) is proven to be evident, it would be important to design studies that examine immune functions, and the progression of cancer and mortality in the context of PTG (Gorin, 2010). All this would require the registration of psychological and physical resources so that changes and causal factors can be followed (Coyne & Tennen, 2010).

In an integrated, **biopsychosocial-evolutionist** perspective Christopher (2004) believes that the basic mechanisms associated with PTSD also include the potential for growth (see more detailed in: Rigó & Zsigmond, 2015). Hypervigilance can help the person avoid future traumatic situations; and cognitive "replay" can lead to alternative responses. Emotional dissociation can be useful to be able to look at events from afar to avoid similar mistakes, and to create new interpretations. A person facing and adapting to chronic somatic disease is biologically (and in the long run) not healthy. Thus, the person is most likely more vulnerable to all types of traumatic events, whether related to the disease or independent of it. The adaptation is more difficult because of the disturbance of symptoms and also the alteration of neuroendocrine systems and immune functions, which makes the person more vulnerable. Many aspects of chronic illness (symptoms, treatments, medications, interventions, sleep problems) are significant

stressors for the body - even if the person does not experience them as psychologically stressful and a burden on the functioning of stress systems. It is of particular importance how the person interprets their illness, and how they frame it. Successful “cognitive reconstructioning” is both a function of the patient’s coping skills and, on the other hand, influenced by the knowledge, schemas and stereotypes offered by the social and cultural environment. Thus, in mitigating the traumatic experiences of physical illness, social environment (media, medical staff, family, fellows) can play a prominent role in the 'cognitive' sphere. The **stress-relieving task of the social environment** is outstanding in other areas as well: sharing the experiences of the trauma (diagnosis, fears, experiences of more serious interventions, etc.) and the understanding and acceptance by others, emotionally supporting the patients.

#### **2.3.4 Factors contributing to PTG among adult survivors of childhood cancer**

Despite the fact that the survival rate of childhood cancer has increased significantly, few studies address the possible positive psychological changes and PTG, instead largely focusing on the negative psychological factors experienced during the traumatic process.

However, there are examples of recent PTG studies in survivors of childhood cancer (for example: Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Barakat et al, 2006; Gianinazzi et al., 2016; Kamibeppu et al., 2010; McDonell, Pope, Schuler, & Ford, 2018; Yi, Zebrack, Kim, & Cousino, 2015; Zebrack et al., 2015).

84-88% of young adults who have experienced cancer in their childhood experience PTG to some level, at least in one area of growth (Barakat et al., 2006, Yi et al., 2015). The results of previous studies suggest that childhood cancer survivors can experience change in all areas of PTG. However, the most significant domains of change experienced have been manifested in greater appreciation of life and in the need for more meaningful relationships (Yi et al., 2015, Gianiazzi et al., 2016).

No consensus has been reached on the factors that influence the development of PTG. In the case of young adults who have experienced childhood cancer disease, **gender** (Arpawong et al., 2013; Gianiazzi et al., 2016; Yi et al., 2015) and the **age at diagnosis** (Barakat et al., 2006; Devine, Reed- Knight, Loiselle, Fenton, & Blount, 2010; Yi et al., 2015) are among the exploratory variables of PTG. The results of the previously mentioned studies suggest that women and patients who are older at the time of diagnosis can experience higher levels of PTG.

**Various cancer-specific variables** (Arpawong et al., 2013; Devine et al., 2010; Turner-Sack, Menna, & Setchell, 2012), the **perceived severity** (Devine et al., 2010) and the **objective severity of the treatment** (Barakat et al., 2006), **well-being** (Kamibepu et al., 2010; Zebrack & Chesler, 2002) and **posttraumatic stress symptoms** (PTSS) (Arpawong et al., 2013; Barakat et al., 2006; Gunst et al., 2016) may also be related to PTG. However, the results regarding these variables show a mixed picture, for each predictor there could be found examples of positive relationships, but also the lack of connection with PTG. It may be due to the fact that the research examined multiple disease groups and differed in the methodology (both in measuring instruments and in the applied constructs and statistical methods).

Nonetheless, it seems consistent to see a higher rate of **general social support associated with higher levels of PTG** (Ekim & Ocakci, 2015; Gunst et al., 2016; Yi et al., 2015). In addition, **positive coping strategies** are also positively associated with PTG (Turner Sack et al., 2012, Bussel & Naus, 2010). A recent study also showed a positive relationship between PTG and **rumination** (Kilmer & Gil-Rivas, 2010). The significance of rumination processes may be to help to better understand the trauma and to better accept the (positive) meaning that facilitates the change of cognitive patterns of the survivors during the integration of trauma (Kilmer, 2006; Tedeschi, Calhoun, Cann, 2007). Recent research indicates that not only emotional regulation, and rumination processes related to negative effects, but also **responses to positive emotions** may be important for the development of depressive symptoms (Feldman et al, 2008; Bijttebier, et al, 2012) and maybe even for PTG.

A recent study on survivors of childhood cancer between the ages of 18 and 39 (Yi et al, 2015) found that PTG was related to **gender** (higher in women), to **ethnicity** (lower in white patients), to **age at time of diagnosis** (for older survivors at diagnosis PTG was higher) to the **type of cancer** (for solid, soft tissue tumors PTG was lower) and the amount of **social support** and **certain personality factors** (PTG was higher for optimistic survivors). In this sample, 88% of survivors of childhood cancer reported PTG in at least one area of growth. These results are also supported by a recent study of young adults who survived childhood cancer (Gianinazzi et al., 2016), in which the majority of participants experienced PTG. Higher PTG was associated with older age at diagnosis, longer time since treatment, and gender (more pronounced presence in women). The positive association of longer time since diagnosis and greater PTG was supported by another recent study on young adult survivors of childhood cancer (Klosky et al, 2014).



On the other hand, other studies found that greater time since diagnosis was associated with lower levels of PTG (Barakat et al, 2006; Yi & Kim, 2014).

In summary, the examination of young adult survivors of childhood cancer is still underrepresented regarding PTG, and study results to date provide an inconsistent picture and the modeling of the explanatory variables of PTG is also expected. However, it can be stated that the development of PTG is influenced by many individual (demographic factors: gender, age, perception of the threat, coping capacity, rumination processes), social (social support) and disease-related factors (time since diagnosis, treatment types, age at diagnosis) (Zsigmond, et al, 2017). All of these variables can affect PTG and also the development and persistence of posttraumatic stress symptoms in a complex relationship. No comprehensive study has been conducted on a Hungarian sample in this patient population so far.

### **2.3.5 Factors contributing to PTG among parents of adult survivors of childhood cancer**

Previous research regarding parents of children living with cancer has been focusing on pathology, such as PTSS (Kazak et al, 2012). However, a recent study found, that current and lifetime PTSD for parents of children with cancer were low and there has been no difference from comparison parents, but PTG was higher for parents of children with cancer (Phipps et al, 2015). In the case of parents of children with cancer, the examination of the predicting variables of PTG is underrepresented (Picoraro et al., 2014), so future exploration of this group is essential. The few published studies link the PTG of parents to **anxiety during treatment** (Best, Streisand, Catania, & Kazak, 2001), the **functioning of the family** and to **distress experienced** and the **severity of the child's diagnosis** (Hungerbuehler, Vollrath, & Landolt, 2011).

80-90% of parents of children with childhood cancer experience PTG to some level, at least in one area of growth (Barakat et al., 2006). In another study, 62% of parents reported moderate growth, with the strongest explanatory variables being the perceived severity of the diagnosis and the degree of distress (Hungerbuehler et al, 2011).

From the point of view of parents, it is important to mention the phenomenon of the so-called **vicarious (substitute) PTG**. For those who have undergone cancer and their partner, it has been found that the supporting partner can indirectly experience trauma and, in parallel, PTG, but at a slightly lower level than the person suffering from trauma (Manne et al., 2004; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010). However,

in my experience the illness of the partner is also a primary trauma for the supporting partner. The primary facilitators of cognitive and emotional processing of trauma are parents of close relatives, for children with cancer. However, in my opinion, the child's cancer disease is also a primary trauma for parents, which is made even more intense by the indirect experience of the child's trauma.

No comprehensive study has been conducted on a Hungarian sample in this patient population so far regarding the factors contributing to PTG.

## 2.4 SUMMARY

To summarize, cancer diseases cannot be classified as “typical” traumas; however, studies have shown that traumatic phenomena, such as posttraumatic stress symptoms and posttraumatic growth, are common in cancer patients. The different phases of cancer and adaptation to it can be conceptualized as a trauma (or even a series of traumas) to those affected. The disease itself can, by its associated biological changes, fundamentally determine a more vulnerable state of action. The proportion and severity of the traumatic symptoms associated with the trauma and the starting of the growth process depends on the nature of the disease, the coping capacity of the person, and the social relationships of the person (Rigó & Zsigmond, 2015). Besides the traumatic nature and process of cancer, it can be conceptualized in the meantime as a potential to grow personally and experience posttraumatic growth (Jansen, Hoffmeister, Chang-Claude, Brenner, & Arndt, 2011; Nenova, DuHamel, Zemon, Rini, & Redd, 2013; Schmidt, Blank, Bellizzi, & Park, 2012). Processes which facilitate PTG, as well as the trauma and the associated symptoms, are obviously unique, but the role of the social environment should be emphasized (Rigó & Zsigmond, 2015). It is fundamental that due to extreme distress, caused by the diagnosis and the treatment, many patient’s need to belong is strengthening and they seek social support to talk about the stressful event (Kulcsár, 2005). The main mechanisms of coping with the trauma - sharing experiences, cognitive restructuring, developing new ways of coping, restoring trust and self-esteem - require social interactions that fundamentally help. It is also social responsibility to create opportunities for those suffering from physical illnesses to cope with the diseases and to integrate the trauma in to their schema system (Rigó & Zsigmond, 2015). In terms of cancer, **individual** (gender, age, marital status, education, quality of life, degree of threat perception, coping skills, another serious life events experienced), **social** (quality of relationships, social support system, environmental factors) and **cancer specific characteristics** (type of tumor, stage, time since diagnosis, subjective severity of the disease and types of treatments, cancer-related posttraumatic stress) could affect the ability of the person to develop (Kulcsár, 2005; Sawyer, Ayers, & Field, 2010; Tanyi, 2015; Zsigmond, Rigó, & Bányai, 2017). The present dissertation focuses on the examination of these factors affecting PTG in 3 groups (breast cancer patients, young adult survivors of childhood cancer and parents of childhood cancer survivors).

### 3 EMPIRICAL STUDIES

#### 3.1 RANDOMIZED LONGITUDINAL CLINICAL TRIAL CONTAINING PSYCHOLOGICAL INTERVENTIONS: Posttraumatic growth among breast cancer patients

##### 3.1.1 Research questions

The purpose of this first, clinical, longitudinal trial was to explore the factors that influence posttraumatic growth 3 years after diagnosis in intermediate and high-risk breast cancer patients who underwent the same chemotherapy protocol and different psychosocial interventions. A number of studies have reported PTG in women diagnosed with breast cancer in the period of five years after diagnosis (Belizzi & Blank, 2006; Coroiu et al, 2016; Danhauer et al, 2013, Tanyi, 2015), but few studies explored the phenomenon in relation to psychological interventions (for example: Pat-Horenczyk et al, 2015). However, one Hungarian study group conducted an integrated lifestyle and psychosocial intervention program tying in with a conventional tumor therapy, examining PTG and social support regarding intervention and control group (Kovács, Rigó, Sebestyén, Kökönyei, & Szabó, 2015).

An important shortcoming of the research so far is that in most studies only quantitative methods were used to explore PTG, proven by a recent review (Casellas-Grau et al, 2016). Qualitative research can also play a major role in an area that has already been researched by quantitative methods, because the subjective perception of the disease can be better described by the survivors, thus providing a more accurate summary of their **individual experience** with the disease (Emslie, 2005). Also, a deeper understanding of the dimensions of PTG would be of great help in designing goal-oriented interventions in clinical work (Stefanic, Caputi, Lane, & Iverson, 2015). Another advantage of qualitative methods is that participants are not primed with specific items, so the growth reported could be particularly relevant (McMillen, 2004). The parallel usage of quantitative and qualitative methods would provide a complex understanding of PTG in breast cancer. There has been no combined study of PTG of this group in a Hungarian sample yet - this study attempts to fill this gap and provide a descriptive picture of how PTG appears in this group and how underlying factors are associated with it. In this study we examined the following questions:

- Do breast cancer patients experience posttraumatic growth 3 years after diagnosis? If so, what is the frequency of PTG in this group?

- What are the most significant dimensions of change experienced regarding posttraumatic growth in breast cancer survivors?
- Is it expected that the presence of PTG will be stronger in the intervention and especially in the hypnosis group than in the control group receiving special attention only (SA group)?
- How do the PTG scores relate to PTG scores studied abroad in the group of breast cancer patients?
- Does age, educational level, employment status or marital status have an affect on PTG in the group of breast cancer patients?
- Is there a positive relationship between posttraumatic stress symptoms and PTG?
- Is there a relationship between quality of life and PTG?
- In what way do different individual, social and disease-related factors influence PTG in this sample?
- How do the results of the qualitative analysis enrich the understanding of PTG in breast cancer patients?

### **3.1.2 Research hypotheses**

Some of the possible explanatory variables of PTG have been controlled in our study: disease-related factors such as the characteristics of breast cancer (see below), the treatment protocol (see below); gender (only women participated in the study); time since diagnosis (was the same for all of the participants). Therefore, these factors would not appear in the hypotheses.

- 1. Hypothesis:** The present dissertation supposes, that most of the women underwent breast cancer were able to experience posttraumatic growth at least at a minimal level at least in one dimension of growth. This hypothesis is supported by previously described studies (for example: (Brix et al, 2013; Riskó, 2006; Sears et al, 2003; Wang, Liu, Wang, Chen, & Li, 2014).
- 2. Hypothesis:** In line with previous research abroad we suggest that breast cancer patients can experience change in all areas of PTG. However, we suppose that the most significant domains of change experienced will be Appreciation of life,

Relationships and Personal Strength (Cordova et al., 2007; Manne, 2004; Mols et al, 2009; Svetina & Nastran, 2012; Weiss, 2004).

3. **Hypothesis:** We suggest, that from demographic characteristics (age, marital status, educational level) age will affect PTG. In line with previous research we suggest, that younger age can influence the perceived threat of the cancer diagnosis with higher rates of psychological distress and younger patients could be more engaged in the re-evaluation of their schema system than older patients who have already experienced serious life events (Boyle et al, 2017; Mystakidou et al, 2010). Regarding marital status (Belizzi & Blank, 2006; Casellas-Grau et al, 2016; Danhauer et al, 2015; Mystakidou et al, 2010) and educational level (Danhauer et al, 2013; Mystakidou et al, 2010) the results are mixed, so our study would be exploratory regarding these factors.
4. **Hypothesis:** We hypothesize, that positive coping will be one of the key factors influencing PTG, as supported by several studies (Bussel & Naus, 2010; Cordova et al, 2007) and also a longitudinal study (Hamama-Raz et al, 2019).
5. **Hypothesis:** We hypothesize, that posttraumatic stress symptoms (PTSS) would be in a positive relationship with PTG (Shakespeare-Finch & Beck, 2014), but the nature of the relationship is questioned (linear, quadratic, curvilinear), therefore our study is exploratory.
6. **Hypothesis:** We hypothesize, that PTG is related to better quality of life and more optimal functioning in women with breast cancer (Brix et al, 2013; Sawyer, et al, 2010), therefore it may have an adaptive function.
7. **Hypothesis:** We suggest that because of the traumatic nature of cancer, the patients become more susceptible to suggestions and suggestive techniques like hypnosis which maybe especially effective in mediating social support (Bányai, 2015), which has a crucial effect on PTG (Danhauer et al, 2013; Tedeschi, Calhoun, 2006; Scrignaro, Barni, Magrin, 2011). In our study music was designed to have similar suggestive affect as hypnosis, so we suppose, that PTG would be

higher in the intervention groups (hypnosis or music), than in the control (SA) group.

Regarding the qualitative analysis our study is exploratory, so further hypotheses could not have been made.

### **3.1.3 Methods**

#### **3.1.3.1 Study framework**

The presented data is part of a prospective, randomized, single-blind, controlled study entitled “PSYCHOLOGICAL RESOURCES AND HEALING” (Research ethical approval:15530-0/2010-1018EKU (670/PI/10.) and 39447-/2013/EKU (465/2013.), supported by the Hungarian Scientific Research Fund – OTKA K109187, principal investigator Prof. Éva Bányai), which aimed to analyze the beneficial effect of adjuvant hypnosis administered during chemotherapy on medium and high-risk breast cancer patients in terms of disease-free survival, cell-mediated immunity, nausea and vomiting, quality of life, psychological immune competence as a coping resource, and posttraumatic growth.

The multistage psycho-oncological research project started with a qualitative pilot investigation exploring psychosocial characteristics of high-risk Hungarian breast cancer patients, and a matched healthy control to establish a basis for further research (Mersdorf, Vargay, Horváth, & Bányai, 2013, 2014a,b). In the next phase the preparing of the protocol for the study and for the text of hypnotic suggestions and a selection of classical music took place. The randomized controlled, clinical trial, PSYCHOLOGICAL RESOURCES AND HEALING began in 2011, and a follow-up period is currently in progress.

The prospective, randomized, single-blind, controlled study involved medium and high risk breast cancer patients, who were diagnosed with histologically confirmed HER2-negative, axillary lymph node-positive or high-risk, lymph node-negative tumors, without distant metastases and were treated with standard chemotherapy protocol based on the St. Gallen Consensus Guideline on adjuvant chemotherapy (Goldhirsch et al, 2011). The risk of breast cancer depends on the size of the tumour, histological type, the tumour grade, the stage of the cancer and hormone sensitivity. All patients underwent surgical resection before the chemotherapy.

The patients were recruited for our study in three different Oncology Institutes in Hungary, with the collaboration of our multidisciplinary team, in the following locations: The National Institute of Oncology (NIO) (Budapest), The Oncology Ward of the Markusovszky Lajos Hospital (Szombathely) and the Institute of Oncology of Debrecen University (Debrecen). The study was coordinated by the ELTE (Eötvös Loránd University) Institute of Psychology, Department of Affective Psychology and demanded tremendous organization, energy and dedication from the research team. The oncologists



described the nature of the study on their first visits with patients. The participation in the trial was voluntary, officiated by a signed, informed consent document. Randomisation in the intervention groups at NIO and the measurement of hypnotic susceptibility took place during the first meeting with the research team.

Patients were randomized into two intervention groups before the chemotherapy started (hypnosis=H or music=M). For ethical reasons, the idea for a randomized control group receiving only standard medical care as opposed to the intervention groups was rejected, because we did not want the patients – randomized to this group – feel socially rejected. Thus, all patients who agreed to take part in the study comparing the affects of psychological interventions received either hypnosis or music. For ethical considerations, as a control, a third, special attention group (SA) was formed. The special attention group consisted of patients who either refused to receive intervention, or were recruited in distinct oncology centres (Szombathely, Debrecen) where the patients originally applied to participate in a research studying the relationship between psychological and physical states. We asked them after signing the informed consent as if there were a study in which they can receive hypnosis or music, would they be participating. Special attention was provided for all patients (not just for the SA group) in a form as being accompanied throughout the chemotherapy treatment by a member of the research team, who asked about their physical and emotional well-being on each occasion. The participants received psychological interventions in the chemotherapy treatment rooms while receiving the chemotherapy treatment and also during blood count controls, so the intervention did not require any extra effort or time from the patients. While receiving cytostatic infusion or waiting for blood test results, patients in the H group were listening to a recorded standard hypnotic induction, positive suggestions for strengthening immune functions and hidden psychological resources. In the M group patients listened to a musical composition of the same length and dynamics. All patients were receiving extra social support above standard medical care (as being accompanied by throughout the chemotherapy treatment and providing informational social support). In addition, there were also supportive relationships forming between patients and joint events were organized by them. A hypnotherapist was present during all sessions along with several participants from our research team.

The patients enrolled in the study underwent the same chemotherapy protocol. Regarding the standard chemotherapy protocol patients has been received a taxane-antacycline chemotherapy protocol: 4 cycles of Adriamicin and Cyclophosphamide (AC)

and 12 cycles of Paclitaxel (PAC) in 24 weeks. 1 cycle of AC took 3 weeks: in the first week patients received chemotherapy, during the second week they had to come to the hospital for blood work control and in the third week they were resting at home. Regarding PAC cycles, patients received chemotherapy every week. Regarding the experience of our patients during the treatment, we saw from close that it was highly stressful and traumatic in many ways. After they discovered their diagnosis, they underwent complete surgical resection of their breast and had to decide whether they would want implants at a later stage. After the first traumatic experiences of the diagnosis and surgery, they had to start the chemotherapy protocol (described above) immediately, which took half a year to complete. During this period, they faced many side effects (hair loss, weight gain, nausea, vomiting, weakness, atony, and so on), psychosocial challenges and problems, tiring hospital stays, negative suggestions (as some of their fellow patients were not be able to complete the therapy or had allergic reactions and so on) and other countless difficulties. Their whole world view collapsed, their everyday life became limited by the disease and the treatment, their relationships transformed, and everyday roles became compromised. Because of the ongoing traumatic nature of the breast cancer trajectory, they needed all possible support which was available. The interventions took place 3 days per week in Budapest, thus the research team including me, was present in the hospital most of the time for years. The study became part of the everyday routine of the chemotherapy ward, without any further room or staff requirements, thus this kind of intervention could be easily integrated into the standard medical care. During treatment and follow-up beyond asking the participants about their emotional and physical well-being, psychological questionnaires were registered 6 times and also at the end of the treatment and at the end of the trial psychological interviews were performed by our psychotherapists (Bányai, 2013, 2015; Bányai et al, 2017) (see below in *Figure 3.*). An overview of the study sample is summarized in *Figure 2.*

Figure 2. Overview of the breast cancer study sample (Bányai et al, 2017)

Overview of study framework						
National Institute of Oncology			Department of Oncoradiology in Szombathely, Institute of Oncology of Debrecen University			
Recruiting for studying psychological effects: hypnosis/music			“Control of control”: recruiting for studying <i>relationship between psychological and physical states</i>			
Agreed		Rejected: Control/Special attention		Agreed		Rejected
Random assignment		Recruiting for studying <i>relationship between state of mind and healing</i>		Questionnaire: Would you accept music/hypnosis?		
				Agreed	Rejected	
Gets attention + HYPNOSIS	Gets attention + MUSIC	Gets attention	No data	Gets attention	Gets attention	No data
Assessment of QOL, PICI, PSDS, PTGI, Life Events List	Assessment of QOL, PICI, PSDS, PTGI, Life Events List	Assessment of QOL, PICI, PSDS, PTGI, Life Events List		Assessment QOL, PICI, PSDS, PTGI, Life Events List	Assessment of QOL, PICI, PSDS, PTGI, Life Events List	

### 3.1.3.2 Participants

The study involved non-metastatic medium-high risk HER2-negative breast cancer patients receiving standard chemotherapy protocol (see above). The inclusion criteria for the characteristics of breast cancer were really strict and precise and determined medium or high risk breast cancer, characterized by the following:

- Triple-negativity or hormone-receptor positivity
- With at least one of the following:
  1. pN2, pN3 lymph-node status (i.e., more than 4 positive axillary lymph nodes)
  2. pN1 and pT $\geq$ 2 and high cell-division rate (MAI $>$ 20 or Ki67 $>$ 30%) and/or histological grade II-III tumour

3. Under the age of 40 and with at least two characteristics of criteria No. 2
4. Probability of a 10-year progression without treatment as determined by AdjuvantOnline<sup>®</sup> program is higher than 30%

Originally the estimated minimum size of the groups was calculated to be 50 patients in each groups. However, because of the time-consuming nature of our study and the change in the chemotherapy standard protocol we could not reach the estimated minimum group sizes. From our originally planned 250 patients, 71 women completed the 3-year-long study until now. This dissertation analyzes their outcomes. From the 71 women, 30 patients received hypnosis, 26 received music therapy and 15 received no extra therapy, only special attention during the treatment.

### 3.1.3.3 Measures

#### 3.1.3.3.1 Demographic and clinical variables

Demographic and clinical variables contained the participant's age at diagnosis, educational level and marital status.

#### 3.1.3.3.2 Posttraumatic Growth Inventory (PTGI)

PTG was measured by the original and most often used form of the Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996, 2004). The internal consistency of the normative sample was high (Cronbach- $\alpha$ : 0,9). The Hungarian version (translated by the Department of Personality and Health Psychology of ELTE) of PTGI also provided high reliability (Cronbach- $\alpha$  =0,94) (Kovács et al, 2012). The validation studies showed, that PTGI could be separated from the conceptually relevant measures (Psychological Immune Competence Inventory, Social Support Dimension Scale, Beck Depression Inventory: Short version, Spielberger Trait Anxiety Inventory, 10 Items Personality Inventory and Aspiration Index: short version) (Kovács et al, 2012). The 21 item self-report measure assessed the five separate domains of PTG according to Tedeschi and Calhoun (1996) on a 0-5 Likert scale, indicating the degree to which the individuals experienced changes in their life after crisis (in this case, the cancer diagnosis). The scale contains the following degrees to which the change occurred as a result of the cancer experience:

- 0 = I did not experience this change as a result of my crisis.
- 1 = I experienced this change to a very small degree as a result of my crisis.
- 2 = I experienced this change to a small degree as a result of my crisis.
- 3 = I experienced this change to a moderate degree as a result of my crisis.
- 4 = I experienced this change to a great degree as a result of my crisis.
- 5 = I experienced this change to a very great degree as a result of my crisis.

Responses above 1 point are representative of a very small degree of change, above 3 points to a moderate degree of change, and above 4 points a great degree of change. The items in the questionnaire form 5 factors: *Relationships*, *New Possibilities*, *Personal Strengths*, *Spiritual Change and Appreciation of Life*. The higher the score on the scales, the higher the degree of posttraumatic growth. The questionnaire also had strong internal consistency in the present study, with Cronbach- $\alpha$  being 0.952. The

reliability of the sub-scales was also good, with Cronbach- $\alpha$  0.809 for Appreciation of Life, 0.908 for Relationships, 0.834 for Personal Strengths and 0.909 for New Possibilities, except for the factor Spiritual Change (Cronbach- $\alpha$  = 0.612), that fell behind the expected criterion (Cronbach- $\alpha$  above 0.7). As discussed earlier, the Spiritual Change subscale of the PTGI consist just 2 items, which is always a problem, but in the present study we can accept the 0.612 score and interpret the result regarding this scale with caution.

#### **3.1.3.3.3 WHO Quality of Life-100 (QOL)**

Quality of life was measured by WHOQOL-100, a cross-culturally developed, multilingual tool with excellent overall and internal consistency. It measures the satisfaction of a person with physical, psychological, social and spiritual domains of everyday functioning, in the context of culture and belief systems (WHO QOL Group, 1998). The 100 questions covering 24 facets, hierarchically organized within six domains: Physical Health, Level of Independence, Psychological, Social Relations, Environment, Spirituality/Religion/Personal Beliefs. The 25<sup>th</sup> facet, Overall QoL and General Health, is not part of the domains covering general items. In the current study, Cronbach  $\alpha$  was acceptable, for Psychological Domain 0.746, for Social Domain 0.801, for Environmental Domain 0.577, for Level of Independence 0.760, for Spiritual Domain 0.925, except Physical Health, which was 0,577, which fell behind the expected criterion, therefore we would interpret the results regarding this domain with caution.

#### **3.1.3.3.4 Psychological Immune Competence Inventory (PICI)**

Coping capacity was measured by the Psychological Immune Competence Inventory (PICI) (Oláh, 2005) which is an 80-item inventory, containing 16 scales and 3 subordinate systems. PICI maps the personality resources that enable the individual to withstand and overcome persistent and intense stressful effects and containing positive coping strategies. The 16 scales are: Positive Thinking, Sense of Control, Sense of Coherence, Creative Self-Concept, Sense of Self-Growth, Change and Challenge Orientation, Social Monitoring Capacity, Problem-Solving Capacity, Self-Efficacy, Social Mobilizing Capacity, Social Creation Capacity, Synchronicity, Goal Orientation, Impulse Control, Emotional Control, and Irritability Control. The 16 scales build up three subordinate systems: Approach-belief subsystem, Monitoring-creating-executing subsystem, Self-regulating subsystem. The items of PICI should be answered on a 4 point Likert scale,

ranging from “*Does not describe me at all*” (1) to “*Describes me completely*” (4) (Oláh, 2005). Oláh (2005) examined the reliability of the PICI on a big sample (1612 people), the Cronbach  $\alpha$  scores were acceptable and also the convergent validity of the questionnaire was acceptable examining the big-5 dimensions. General immune competence can be described by the cumulative PICI score by adding up the scores of all the scales (Perczel Forintos, Kiss, & Ajtay, 2007). In the current analysis PICI cumulative score (total score) was used. In the current study the internal consistency coefficient, Cronbach-alpha was 0,899.

#### **3.1.3.3.5 Posttraumatic Stress Diagnostic Scale (PSDS)**

The self-report measure was developed by Foa (1996) and validated by Foa, Cashman, Jaycox, & Perry (1997) using the DSM-IV criteria for posttraumatic stress disorder (PTSD). The test consists of 4 parts (A, B, C, D). In the shortened, Hungarian version (Perczel-Forintos, Ajtay, Barna, Kiss, & Komlósi, 2012; Perczel-Forintos, 2002), the patient was required to indicate the frequency (A) and the emotional severity (B) of the possible symptoms (PTSS) of PTSD on a 0-3 scale. In the third part (C) the patient was required to determine the extent to which trauma has affected the areas of life such as work, social life or family life on a 0 to 10 scale. In the D part patients had to report about their present feelings regarding the trauma through two questions. The C and D part of the questionnaire were not used in this dissertation. The total score indicates the frequency (PSDS FR) and the emotional severity (PSDS ES) of the symptoms of PTSD. The 3 symptom groups of PTSD (intrusive thoughts, hyperarousal and avoidance) is also measurable with the scale. The severity of the symptoms is as follows: 1-10 points mild; 11-20 points medium; 21-35 points of medium weight; 36-51 points are serious. In the current study the internal consistency coefficient, Cronbach-alpha was great, between 0.922 for frequency (A) and 0,935 for emotional severity (B) of PTSS.

#### **3.1.3.3.6 Life Event List by Holmes and Rahe**

Major life events and their emotional affectivity were measured by the 27 Life Event List from the Hungarian adaptation (Rózsa et al, 2005) of The Brief Stress and Coping Inventory (Rahe & Tolles, 2002). The list of 27 items covers a wide range of positive and negative life events: accessing health, work, home and family functioning, changes in personal life and social relationships, and economic changes. Patients must report whether they have experienced the particular life event and how they were emotionally

influenced (severity) by it on a scale of 1 to 10 (0 = not serious - 10 = the most serious trauma). In the current study the internal consistency coefficient, Cronbach-alpha was between 0,720-0,931.

#### **3.1.3.3.7 Qualitative analysis**

The content analysis method used in this study was theoretical based and guided. This special form of content analysis uses open-ended questions and the responses are analyzed using predefined codes based on an existing theory. Thus, the coding task requires recognizing patterns with enough indicators based on existing definitions of the phenomenon in the interviews and recording presence (Potter & Levin-Donnerstein, 1999). For illuminating high subjectivity is necessary to use multiple, independent coders (Steenkamp & Northcott, 2007). Also a recent systematic review states that studies using content analysis should include illustrative examples from the content, coding rules and the subjectivity of the procedure (Vourvachis & Woodward, 2015). We conducted our content analysis accordingly to the outlined specifications.

At the end of the chemotherapy treatment and at the closing of the research (3 years after the diagnosis), in addition to a number of psychological tests (see above), we also included structured, psychological interviews conducted by professional psychotherapists. The present dissertation demonstrates the content analysis of the psychological interview at the end of the chemotherapy treatment (0,5 years after diagnosis). We discuss here only portions of the interview relevant to this work. At the end of the chemotherapy treatment during the psychological interview, participants were asked to complete 13+3 open ended questions regarding health issues, psychological state, the period of chemotherapy treatment, the effect of hypnosis/music and 3 additional questions for those quitting the trial. These open ended questions were developed by the research team and originally were not intended to be a basis for PTG focused content analysis. The questions were not developed to prime experiences regarding PTG, thus we hypothesized that PTG would appear genuinely. The open-ended questions regarding psychological state were the following:

- *Recently, my state of mind was ..*
- *My current state of mind is ..*
- *Did you feel a change in your attitude to the world during the treatment and study period? If so, what is the change?*



- *Has any decision been made about the future during the treatment and the study period? If so, what decision did you make?*

Psychological interviews were recorded on mp3 devices with the participant's consent and later transcribed verbatim for further analysis, which alone was a great amount of work carried out by students and also by the author of this dissertation. The verbatim texts of the interviews serve as the basis for the content analysis. From the text of the answers of the open-ended questions, the typists made a version where only the answers of the participants appeared, the questions and comments of the interviewer did not. The texts were received by 3 independent coders who performed the content analysis, which required great dedication and concentration. The length of the interviews showed great variability: the page count ranged from 3 pages to 38 pages. In this study, we explored the 5 dimensions of PTG defined by Tedeschi and Calhoun. We used a predefined, theory-based coding system developed by the author of this dissertation to encode the texts. Subcategories were also determined within the 5 dimensions of PTG based on the literature (see *Table 1.*). I personally developed the steps of the content analysis and the instructions for the coding. My most important goal was to see how PTG appears when participants are not primed by the topic of positive psychological change, but while they are merely speaking about themselves and their psychological states.

*Table 1.* The 5 dimensions of PTG and their subcategories used in the content analysis in the breast cancer study.

<b>1. Appreciation of Life</b>
1.1. Recognition of small pleasures of life
1.2. Changes in the perception of everyday priorities
1.3. Significant transformation of everyday life
1.4. Sense of being lucky
<b>2. Relationships</b>
2.1. Closer, more meaningful relationships and the re-evaluation of relationships
2.2. Greater empathy for the suffering of the others
<b>3. Personal Strengths</b>
3.1. Increased sense of personal power
3.2. Increased sense of vulnerability
<b>4. New Possibilities</b>
<b>5. Spiritual Change</b>

5.1. Deepening religiousness
5.2. Turning to spirituality and existential issues

Encoders were trained in relevant literature on posttraumatic growth before the content analysis began. They then became familiar with the coding system and asked their questions. The actual content analysis was preceded by a trial process to eliminate possible errors resulting from insufficient knowledge of the literature and clarify issues. On the basis of the coding criteria system, the relevant parts of the text of each interview was coded by the coders, if they found a part that was corresponding to one of the PTG dimensions. After analyzing all of the interviews, the codes found were sorted into a cumulative Excel file independently by coders. The results of the three coders were summarized by me. The resulting parts could only be included in the analysis if at least two of the three coders identified it and administered it to the same domain. As a result, we received the number of times that the experience of posttraumatic growth appeared during the interview per person, and also to which domain it belonged. The steps of content analysis were therefore the following:

1. Multiple readings of the typed interviews to understand the broader context
2. Marking and coding of the parts containing PTG dimensions
3. Collecting the identified PTG codes into the cumulative Excel file
4. Summarizing the codes per participants
5. Comparing the codes of the 3 encoders per participants
6. Creating a final table with accepted codes and the amount of their appearance per participants
7. Reviewing all of the resulting codes to decide whether they are acceptable in the different dimensions of PTG or maybe forming an additional dimension

To globally summarize the study protocol, the frequency of the treatments and interventions, measuring times and related measures see *Figure 3*.

Figure 3. Study protocol, frequency of interventions, measuring times and related measures in the longitudinal trial among breast cancer women.

	T1												T2												T3		T4	T5	T6
	AC treatment												PAC treatment																
Week	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	Year	1	2	3
Chemotherapy																													
Blood tests																													
Hypnosis/Music/Special Attention																													
PICI																													
WHO-QOL																													
PTGI																													
PSDS																													
Life Events List																													
Psychological Interview																													

T1-T6: measuring points (T1-T3 in weeks, T4-T6 in years)

Hypnosis/Music/Special attention: interventions used during the trial

PICI: Psychological Immune Competence Inventory

WHO-QOL: WHO Quality of Life Questionnaire

PTGI: Posttraumatic Growth Inventory

PSDS: Posttraumatic Stress Diagnostic Scale

Life Events Scale

Psychological Interview: content analyses

The original study PSYCHOLOGICAL RESOURCES AND HEALING measured several other variables that are beyond the scope of the present dissertation. A number of physiological indicators were also measured in the study:

1. Full blood count: it was measured before the beginning of the treatment, during each chemotherapy treatment and at the end of the chemotherapy protocol, altogether 21 times.
2. Natural killer (NK) cell activity: it was measured six times - at the same times as PICI and WHO-QOL was measured.
3. Nausea and vomiting as side-effects: they were registered at each chemotherapy treatment, 17 times altogether.

The non-included psychosocial measures were analogous emotional and physical well-being scales (Face Scale and Fit Scale), that were registered every time when meeting with the patients, 25 times altogether. Patients had to choose a face or a body image which expressed their actual emotional and physical feelings the closest and also they had to explain their choice.

#### **3.1.3.4 Data collection and analysis**

In the current study we examined the data from psychological questionnaires registered prior to chemotherapy treatment (T1), at the end of the treatment (T3) (0,5 years after diagnosis) and at the end of the trial (T6) (3 years after diagnosis). PICI and WHOQOL were filled out at T1, T3 and T6. PTGI, PSDS and Life Event List were registered at T6. The content analysis took place regarding the psychological interview at the end of the treatment (T3). The systematization of the data and the execution of statistical procedures were carried out with the help of SPSS: IBM SPSS Version 23.0 (IBM Corp. Released 2015, Armonk, NY: IBM Corp.). Descriptive statistical analyzes (mean, standard deviation, frequency and percentage distribution calculation) were performed to describe the characteristics of the sample. Normality and homogeneity of variance were also tested, there was no need to use robust tests (for the normality and homogeneity of variance tests see *Appendix 1., 2., 3., and 4.*). The differences between the three intervention groups were calculated by using one-way ANOVA, and for pairwise comparisons the Bonferroni post-hoc test was added. For defining effect size,  $\omega^2$  (omega square) was used with Cohen's rule of thumb for interpretation of the results (small from .02; medium from .13; large from .26) (Ellis, 2010). Pearson's correlation method was used to examine the associations between the measured variables and PTG and PTSS. Since several variables were used in the correlation studies, the risk of first species alpha was very high, so Bonferroni corrections were also applied. Linear regression analyses (Enter method) were performed for the complex analysis of the variables determining posttraumatic growth and PTSS.

The details of the qualitative analysis have been listed above.

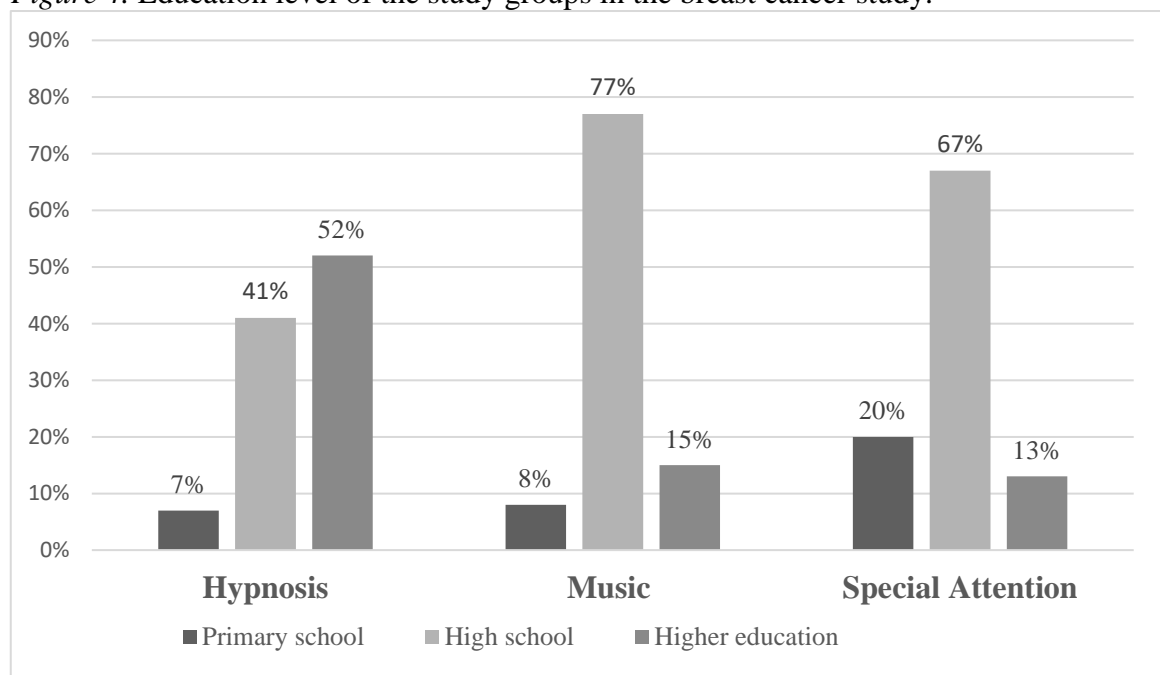
### 3.1.4 Results

#### 3.1.4.1 Descriptive statistics of study groups

71 women completed the 3-year-long study until now, their data are analyzed in the present dissertation. The diagnosis, the time since diagnosis, the treatment protocol (2 patients received different chemotherapy protocol due to allergic reactions) and the risk of the diagnosis were controlled, and the sample is homogenous by disease variables. Also all participants received continuous social support from the research team and from each other.

There was no significant difference in age ( $F(3) = 1.637, p = 0.202$ ) between the three groups. The mean age in the H group was 51.48 (SD=12.06) years, in the M group 55.65 (SD=9.81) years and in the SA group 57.13 (SD=10.88 years). There was no significant difference between study groups regarding marital status ( $\chi^2(8) = 6.738, p = 0.565$ ). The majority (n=46) of the patients were married or lived in a relationship (65%), 4 patients (5.7%) were single, 8 patients (11.4%) were divorced, and 11 patients (15.7%) were widowed. The only difference experienced between the groups regarding descriptive characteristics was in educational level ( $\chi^2(4) = 12.748, p = 0.013$ ). Patients in the H and M groups were significantly higher educated, than patients in the SA group. The distribution of education level in the study groups is summarized in *Figure 4*.

*Figure 4.* Education level of the study groups in the breast cancer study.



### 3.1.4.2 Comparison of study variables among the groups (hypnosis, music, special attention)

Regarding the descriptive statistics and group differences of the PICI cumulative scores (at T1, T3 and T6), PSDS scales (PSDS FR and PSDS ES (frequency and emotional severity of posttraumatic stress symptoms) and the forms of PTSS: avoidance, intrusive thoughts and hyperarousal), Life Events List and WHOQOL-100 domains at T6 see *Table 2*.

The differences between the three intervention groups were compared by using one-way ANOVA and for pairwise comparison the Bonferroni post-hoc test was calculated. For defining effect size,  $\omega^2$  was used with Cohen's rule of thumb for interpretation (small from .02; medium from .13; large from .26) (Ellis, 2010). **There were no significant differences between the groups regarding any of the variables (Table 2.)**

*Table 2.* Descriptive statistics of the study variables in the three groups and group differences in the breast cancer sample.

	Hypnosis		Music		Special Attention		F	p	$\omega^2$
	M	SD	M	SD	M	SD			
PICI cum T1	233.96	31.71	226.00	39.19	236.64	35.43	0.468	0.628	-.02
PICI cum T3	244.16	29.41	231.22	39.30	239.92	39.49	0.778	0.464	-.01
PICI cum T6	245.38	32.24	240.22	46.07	235.83	45.83	0.247	0.782	-.03
PSDS FR T6	10.63	8.70	8.19	11.34	11.20	9.26	0.602	0.550	-.01
PSDS ES T6	11.83	10.67	8.04	11.94	11.27	9.14	0.919	0.404	-.02
QOL SOC T1	16.13	2.14	15.41	2.39	16.11	1.75	0.906	0.409	.00
QOL SPI T1	14.08	3.31	14.92	3.44	15.47	2.61	0.205	0.815	-.02
QOL PHY T1	14.75	2.41	14.51	2.59	14.06	1.98	0.412	0.664	.00
QOL PSY T1	14.10	2.28	13.86	2.96	13.88	2.03	0.075	0.928	-.03
QOL ENV T1	15.70	1.59	15.01	1.97	15.14	1.69	1.175	0.315	.00
QOL LOI T1	15.49	2.78	15.21	3.32	14.06	2.03	0.485	0.618	-.02
QOL SPI T3	16.27	3.32	16.08	2.71	16.64	3.08	0.156	0.856	-.02
QOL SOC T3	15.54	2.45	14.92	2.30	16.53	2.69	1.793	0.175	.02
QOL PHY T3	14.40	2.59	14.26	2.67	13.83	2.34	0.239	0.788	-.02
QOL PSY T3	14.62	2.41	14.65	2.42	14.47	2.56	0.038	0.963	-.01
QOL ENV T3	15.99	1.73	15.50	1.91	15.35	2.09	0.737	0.482	-.01
QOL LOI T3	15.70	2.55	15.07	2.85	14.82	2.50	0.666	0.517	-.01
QOL SPI T6	16.04	2.90	15.42	3.43	16.00	2.56	0.298	0.743	-.02
QOL SOC T6	15.31	2.32	14.97	2.41	14.97	2.28	0.163	0.850	-.03
QOL PHY T6	15.08	2.06	14.26	3.82	13.28	1.43	1.841	0.167	.03

QOL PSY T6	14.81	2.28	14.82	2.99	13.82	2.46	0.712	0.495	-.01
QOL ENV T6	16.02	1.84	15.34	2.13	15.04	2.11	1.277	0.286	.01
QOL LOI T6	16.44	2.25	16.23	3.11	14.46	2.31	2.561	0.086	.05

### 3.1.4.3 Characteristics of PTGI

Patients reported PTG in a minimal to great degree ( $M = 76.07$ ,  $SD = 21.56$ ; PTGI total average score: 3.61,  $SD=1.02$ ). 100% of the H and SA, and 97.2% of the M group experienced some degree of positive change as reflected by a mean PTGI total score above 1 point (higher than very little influence of breast cancer on growth) on the 6 points scale. The mean PTGI total and factor scores were calculated by summing up points on the different items and then dividing them with the number of the items. A considerable amount of studies is using this method to interpret the results from the PTGI (for example: Yi et al, 2015). 80% of the H, 84.3% of the SA and 69.2% of the M group reported moderate to great degree of change. The highest scores were found for Appreciation of Life, followed by Relationships and Personal Strengths in all groups. There were no significant differences between the groups, except Spiritual Change [ $F(2,68) = 4.702$ ,  $p = 0.012$ ,  $\omega^2 = 0.1$ ], in the paired comparisons (via Bonferroni test), significantly higher scores were reported in the SA group than in comparison with the M group regarding the H group the difference was not significant. For the descriptive statistics and group differences regarding PTGI see *Table 3*.

*Table 3.* Group differences in mean PTGI total and PTGI factor scores on the breast cancer sample

	Hypnosis		Music		Special Attention		F	p	$\omega^2$
	M	SD	M	SD	M	SD			
PTGI total score	3.81	0.98	3.33	1.14	3.74	0.81	1.704	0.190	.02
PTGI Appreciation of life	4.3	0.85	4.02	1.16	4.42	0.77	0.956	0.390	-.00
PTGI Relationships	3.85	1.04	3.47	1.24	3.86	0.68	1.062	0.352	.00
PTGI Personal Strengths	4	1.02	3.55	1.28	3.76	1.12	1.080	0.345	.00
PTGI New Possibilities	3.69	1.32	3.06	1.45	3.29	1.21	1.521	0.226	.01
PTGI Spiritual Change	2.85	1.64	1.98	1.44	3.36	1.12	4.702	0.012	.10

For PTGI, average scores are given on the 6 points scale. Above 1 point means small, above 3 points means moderate and above 4 points means great degree of change experienced.

Due to small group sizes and minimal group differences and the fact, that the patients all received social support in addition to medical care during treatment (from the research team and from each other), we merged the groups (see below). In line with this we present a table of the mean PTGI total and mean PTGI factor scores when the groups are merged (see *Table 4*).

The average PTGI total score was generally moderate in the merged group of breast cancer patients (M=3.62; SD=1.02; CI (0.95) = 3.35-3.85).

*Table 4.* Mean PTGI total and PTGI factor scores in the merged group of breast cancer patients

	95% Confidence interval			
	M	SD	Lower	Upper
PTGI total score	3.62	1.02	3.35	3.85
PTGI Appreciation of life	4.22	0.96	3.99	4.45
PTGI Relationships	3.72	1.06	3.43	3.96
PTGI Personal Strengths	3.79	1.14	3.5	4.05
PTGI New Possibilities	3.38	1.36	3.05	3.71
PTGI Spiritual Change	2.64	1.55	2.27	3.04

For PTGI, average scores are given on the 6 points scale. Above 1 point means small, above 3 points means moderate and above 4 points means great degree of change experienced.

#### **3.1.4.4 Correlates of PTGI and PSDS**

Due to small group sizes and minimal group differences and the fact, that the patients all received social support in addition to medical care during treatment (from the research team and from each other), we merged the groups. Pearson correlation analyzes were used to determine the relationship between cumulative PICI (also at T1, T3), QOL domains, PSDS FR and ES, severity of Life events and PTGI at T6 (*Table 5*). Bonferroni correction was used: for the 3 PICI subsystems:  $0.05/3=0.017$ ; for the 6 domains of WHOQOL100:  $0.05/6=0.008$ ; for Life events severity (which is one scale from the two)  $0.05/2=0.025$ ; and for the scales of PSDS:  $0.05/2=0.025$ . A statistically significant result means in this case, that the p-value (with Bonferroni adjusted value) was under the above calculated fixed P limits. In the bivariate correlations, the Psychological domain of QOL (QOL PSY), the Spiritual domain of QOL (QOL SPI), the Environmental domain of QOL (QOL ENV), the cumulative PICI at T3 and T6 were moderately, significantly, positively correlated with PTG. PTG was in a significant, positive, weak association with the other domains of QOL at T6 and with cumulative PICI at T1. The association with the Level



of Independence domain was not significant via the Bonferroni adjusted value. There were no significant associations between the variables of PSDS and between demographic variables and PTGI. Emotional severity of PSDS was significantly, moderately, positively associated with the severity of Life events and was negatively, and mostly moderately associated with QOL domains at T6 and with PICI at T1, T3 and T6.

*Table 5.* Bivariate correlation analyzes of the variables related to posttraumatic growth and to emotional severity of posttraumatic stress symptoms on the merged breast cancer sample.

	PTGI total score		PSDS ES	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Age at diagnosis	-.010	.936	.011	.931
PSDS ES	-.034	.658		
PSDS FR	-.054	.778		
QOL SPI T6	.433	.000	-.528	.000
QOL PHY T6	.393	.001	-.566	.000
QOL PSY T6	.514	.000	-.688	.000
QOL ENV T6	.476	.000	-.474	.000
QOL SOC T6	.368	.003	-.477	.000
QOL LOI T6	.255	.042	-.416	.001
PICI cumulative T1	.390	.001	-.545	.000
PICI cumulative T3	.518	.000	-.529	.000
PICI cumulative T6	.546	.000	-.508	.000
Life events severity	.007	.953	.524	.000

#### **3.1.4.5 Linear regression model for the variables underlying PTGI**

Multivariate linear regression analysis was performed for the complex examination of the explanatory variables of posttraumatic growth with the Entry method. The output variable was the total score of posttraumatic growth. Independent variables (due to theoretical reasons) were the cumulative PICI score (T3), the social support scale from QOL at T6 and PSDS ES (emotional severity). Since PTGI and PSDS questionnaires were administered at T6 (they were included in a later phase in the study) the opportunities were limited to test time factors. Since separate questionnaires were used, multicollinearity was not a problem. PICI at T3 was used because between T1 and T3 the score increased significantly ( $t(58)=-2.389$ ,  $p=0.020$ ,  $g'=0.2$ ) (Hedges  $g'$  was used to measure effect size) and it was hypothesized that the mobilization of resources - which could affect PTG - are higher after treatment. Also due to theoretical assumptions, we suppose, that posttraumatic stress has a nourishing effect on PTG. The severity of Life events score was not used, because it had a strong, significant association PSDS ES (we

wanted to avoid multicollinearity). Although, we did not measure social support with a separate questionnaire, one scale from QOL measures social support – we used it in the regression model. We used the score from T6, because we also measured PTG at T6. In the model (see *Table 6.*) cumulative PICI (T3), the social support scale of QOL at T6 and PSDS ES were all significant predictors, the model explained 33,9% of the variance of PTGI ( $R^2 = 0.339$ ,  $R^2_{adj}=0.299$ ,  $F(3) = 8.547$ ,  $p < 0.001$ ). Thus, we can state that the increased presence of emotional severity of PTSS, the social support experienced and the higher scores on cumulative PICI explain a part of the increased level of posttraumatic growth.

*Table 6.* Regression model for the underlying factors of PTGI in the breast cancer sample

	Unstandardized coefficients		Standardized coefficients	t	p
	B	Standard error	$\beta$		
PICI cumulative T3	.299	.088	.520	3.398	.001
PSDS ES	.641	.285	.355	2.252	.029
QOL social support scale T6	.599	1.197	.333	2.171	.035

#### **3.1.4.6 Results from the qualitative analyses of the psychological interview at the end of the treatment**

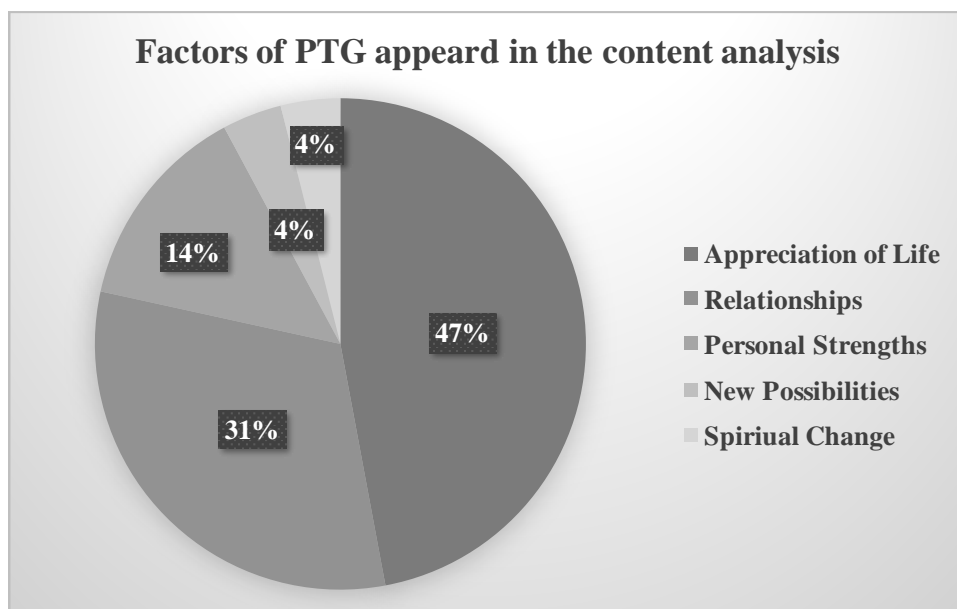
##### **3.1.4.6.1** The appearance of the factors of PTG in the texts of the psychological interviews.

From our sample 65 patient's psychological interviews were analyzed, because at this point of data processing, only these 65 interviews were transcribed and controlled verbatim and so they were ready to be analyzed. In the text of the psychological interviews at the end of the treatment, a total of 212 cases were found by the three coders relating to PTG. Of these, a total of 59 cases had to be excluded, as only one encoder judged that they contained PTG. Thus, **72% of the cases matched between the encoders** (either two or three of them agreed that their content can be put in one dimension of PTG), this 153 cases are analyzed here. This type of content analysis does not make it possible to count inter-rater reliability, but the rule for inclusion of the content (at least two of the coders should find the content for accepting) is really strict. **The experience of PTG appeared at least in one dimension of growth in 83% of our patients** (54 out of 65 subjects) 0.5 years after diagnosis. It is important to determine in advance that the results

of this study design are not capable of supporting differences with statistical tests, rather than using frequency rankings and appearance rates (Curtis et al, 2001).

47% (72 pieces) of all accepted cases (153 pieces) belonged to the **Appreciation of Life** factor, 31% (48 pieces) in the **Relationships** factor, 14% (21 pieces) in the **Personal Strengths**; 4% (6 pieces) in the **New Possibilities** factor and 4% (6 pieces) in the **Spiritual Change** factor. For the frequency of the factors of PTG appeared in the analysis see Figure 5.

*Figure 5.* Factors of PTG appeared in the content analysis of the psychological interviews on the breast cancer sample.



To differentiate by participants, it can be observed, that Appreciation of Life and Relationships appeared in more than half of the participant's interviews. In line with previous quantitative studies also this qualitative study showed that the most pronounced domains of PTG are Appreciation of Life, Relationships and Personal Strengths even just 0.5 years after diagnosis. For more detailed information, see *Table 7*.

Table 7. Factors of PTG appeared by participants (n=65).

	Number of participants	Percentages
<b>Appreciation of Life</b>	41	63%
<b>Relationships</b>	33	50.7%
<b>Personal Strengths</b>	16	24.6%
<b>New Possibilities</b>	6	9.2%
<b>Spiritual Change</b>	3	4.6%

### 3.1.4.6.2 Illustrative examples of the PTG factors from the interviews of the participants

#### I. Appreciation of Life:

##### **Recognizing the joy of life:**

*“Every day I am happy that I am alive, I am happy every day that the sun is rising, I can be happy for every little thing. I think these are the most beautiful things in life when I get up in the morning and the sun is shining on my belly, and I’m one day older again and I live and everything is fine.”*

##### **Changes in Priorities:**

*“I understood now, why they say that we don't live to work, but we work to live.”*

##### **The transformation of everyday life:**

*“I’m trying to eat more fruits, vegetable dishes, etc.. And then sugar, which we have consumed quite a lot, because we are tea-drinkers, I try to minimize it too, because it is supposed to be a cause of cancer.”*

*“I made a clear decision, that at the first appearance of a really small health problem which does not fit into everyday life, I turn immediately to a doctor and so I pay more attention to myself. That is exactly what it means. Not just about health, but about anything. So, in some ways, I’m going to be more selfish. But healthy selfish.”*

##### **The feeling of "I'm lucky":**

*“Well, when you are confronted with the finiteness of life, that can be seen also as a gift.”*

## **II. Relationships**

### **Reassessing the importance of relationships and even other relationships:**

*"My relationship with people has changed completely. I have completely re-evaluated my relationships primarily with my family. I can see clearly now the people who are important to me and those who are not important, the values changed. I had a lot of connections which were quite weak, which did not remain. Which did not contain. Sometimes the family joined together for example, only because the child of my dad's brother had a birthday. But, there was nothing behind these meetings, no real love, nothing. This lesson was very good and people became close to me who I never thought about. I became so important to them and they were such valuable people. I think I got this disease for a reason, this recognition, this was the way to recognize it. "*

### **Greater empathy for the suffering of the others:**

*"I became much more tolerant. In general, I have become more tolerant of the behavior of people in difficult situations, I have understood or understood much better. For example, today a lady was sitting next to me on the bench when I was at the doctor, and I noticed that she was in a much worse shape than me, and so spontaneously I hugged her and encouraged her to hold on."*

## **III. Personal Strengths**

### **Recognizing / increasing the sense of personal power:**

*"And we do not know when, but if I have overcome things so far, then I will do it after too. Because we're warriors. Obviously there is a long way to go and it is not easy to go so far, but everything has to be done to get it done. Only those who have the strong will to live and do I want to stay and live, live, live and not be afraid - we have such a motto, live and not be afraid, then it certainly helps a lot. "*

*"There is practically no problem that could not be solved. You just have to find it. And if you are already determined to go on a road, really towards a goal, you will get help from now on. From the first moment.*

*„It made me stronger in a way, that I think now there isn't any problem which I cannot solve."*

**Excessive sense of vulnerability:**

*"Yes, one thing is that one is confronted with the finality of life, which can be considered as a gift."*

*"So I felt the experience of passing away, I have never felt it before. Well, this is the beginning. Right at the beginning. So that others are gone, it always hit me, yes, it is the law of life, but when one feels herself in this sieve, it sounds quite different. And I always experienced this feeling it in relation to someone else, and it was my duty to help and do it, and more. I changed diapers, and nursed my husband's aunt when she had dementia, it was terrible. So, I always felt that I'm the strong one who can withstand this and can do it all the way and I can help her. And I can also care for my three kids, and to do my job as a leader, and everything. I also pursued a second degree, studying at night. So, I endure everything. And paff, I just got to the state where I have to feel that once I will also be passing."*

**IV. New Possibilities in life**

*"I'm trying to turn off from the job. And it is so interesting that, so I think that if I don't have to do this, then I will have to go in some other direction, if this is the reason and I have to go in a different direction, then God will tell me where. "*

**V. Spiritual and existential Change****Religious deepening or becoming religious:**

*"The truth is that I finally understand a lot of things now, even with my faith and my religion, so much has been achieved. For example, we are talking about it being a difficult road, and that's where it is always that it's a narrow, bumpy road that leads to Jesus or the Lord, and I always thought that I just have to be a good person. And then, how good a person is, contains many things. "*

**Turning to basic existential, spiritual issues**

*"And I am able to stand under a beautiful tree in winter, because I feel that I am getting energy from it also. Even because the tree is full of life. Really, I look at everything as a living being because it is."*

### **An additional 6<sup>th</sup> category: Changes in Health Behavior**

During the summarizing of the cases included in the content analysis it became clear that, some of the cases in the Appreciation of Life factor could be better described as Changes in Health Behavior. The following examples are from the Appreciation of Life factor, but we think that they could be more concretely seen as changes in health behavior.

*“When the treatment is finished, yes, even the wig was on me, I went away and then I thought that something should be done now, to move, to dance. To walk a lot to relax, to try. I never dealt with anything like that before, these things were not important, but are now.”*

*“I decided very strongly, that at the first appearance of a really small health problem which does not fit into everyday life, I turn immediately to a doctor and so I pay more attention to myself. That is exactly what it means. Not just about health, but about anything. So, a little bit, I’m going to be more selfish. But healthy selfish.”*

### 3.1.5 Discussion

The aim of this study was to test the prevalence of PTG, to explore factors contributing to PTG controlling for demographic and disease variables, and to test the hypothesis of positive relation between PTG and QOL in a breast cancer sample after receiving psychological interventions and special attention during chemotherapy treatment. For the deeper understanding of the dimensions of PTG we also used qualitative analysis parallel with the quantitative methods. There has been no combined study of PTG of this group in a Hungarian sample yet - this study attempted to fill this gap and provide a descriptive picture of how PTG appears on a breast cancer sample.

The study is unique from a methodological point of view, because the diagnosis, the time since diagnosis, the treatment protocol and the risk of the diagnosis were controlled, and the sample is homogenous by disease variables. All of these variables could have an effect on PTG, thus controlling them is an opportunity to reach the core predictors of PTG.

**The 1<sup>st</sup> hypothesis** (most of the breast cancer patients are able to experience posttraumatic growth at least at a minimal level at least in one dimension of growth) **has been proven** by our results. According to PTG score, more than 97% of the patients experienced at minimum a small degree of change. The averaged total score of PTG of breast cancer patients was moderate and the total mean score was higher than in other studies including breast cancer patients (Lerolain, 2010, Silva et al, 2012) and containing psychological interventions (Pat-Horenczyk et al, 2015). It can be explained with two inferences: firstly, in the current study psychological interventions and special attention were included, which could have increased the rate of PTG even more (Garland et al, 2007). The social support of the research team and also which was experienced by the patients towards each other could have been an important factor in posttraumatic growth. It is important to mention, that most of our patients have been in touch with each other organizing events to meet and to support every one of them. According to Kulcsár (2005) the social support experienced from the need to belong could have been the starting point for PTG and in my opinion, also one kind of fuel in the process of restoring one's shaken world. Secondly, studies suggest, that PTG increases over time (Danhanuer et al, 2013, Sears et al, 2003) and we measured PTG 3 years after diagnosis with the PTGI questionnaire. In my opinion 3 years after diagnosis patients could be reflecting on the



traumatic time of the diagnosis and treatments with increased appreciation of life as they are already have been fighting for themselves, which could strengthen their self-concept. Also, we can not forget the priming nature of the PTGI questionnaire.

The **2<sup>nd</sup> hypothesis** (breast cancer patients can experience change in all areas of PTG and the most significant dimensions of change experienced will be Appreciation of Life, Relationships and Personal Strength) **has been also proven** by our results. Consistently with previous findings (Cordova et al., 2007; Mols et al, 2009), among the dimensions of PTG, the highest scores were found for Appreciation of Life, followed by Relationships and Personal Strengths in all groups and also when combined. It must also be acknowledged that the scores on the New Possibilities scale were also above moderate. Further research is needed to explore the different processes that can lead to the different dimensions of PTG. Also, several theorists discuss the different processes leading to the different dimensions of growth (for example: Janoff-Bulman, 2004), therefore the process-focused, longitudinal studies would aid in the more accurate understanding of the forming of PTG dimensions. Deeper understanding of the dimensions of PTG in a breast cancer sample would aid in the design of more accurate, target-oriented interventions and clinical work (Stefanic, Caputi, Lane, Iverson, 2015).

It seems, that the Appreciation of Life domain was the most pronounced also in the breast cancer sample. The mean average score for this domain was above moderate, as it displayed a great degree of growth. It can be suggested, that due to the life-threatening nature of cancer which endangers life and physical integrity in a subjective or real manner, the experience is traumatic and while facing death, the patients are re-evaluating the values of life, which concludes most importantly in greater appreciation of life.

Our results supported the fact, that specific areas of PTG (Appreciation of Life, Relationships, Personal Strengths) are more pronounced in a cancer sample, which differentiates the experience of cancer from other traumatic events.

In line with the above discussed quantitative studies also the qualitative study showed that the most pronounced domains of PTG are Appreciation of Life, Relationships and Personal Strengths even just 0,5 years after diagnosis using a different methodology. It seems, that even in the subjective perception of the disease and without PTG specific primed questionnaire items patients report growth similarly.

**The 3<sup>rd</sup> hypothesis** (that age at diagnosis will affect PTG in breast cancer patients, as in younger age would bring higher rates of PTG) **has not been supported by our results.** This may be due to the fact that the mean age in our study was above 50 years in all groups and there was just one patient under the age of 35 years. Thus, we can not really speak about younger patients in our sample, yet we can not differentiate between younger and older patients, because age was used as a continuous variable, thus age groups could not be determined due to the small group size. Some of the studies suggests, that forming age groups, different trajectories of PTG could be detected (Boyle et al, 2016; Danhauer et al, 2015). Future studies should include this line of thought.

The **4<sup>th</sup> hypothesis** has been proven by our results. As we hypothesized positive coping strategies (psychological immune competence) measured after treatment (T3) could predict PTG 3 years after diagnosis. The results showed, that the PICI scores increased significantly between T1 and T3 which could occur due to the mobilization of inner resources with the help of psychological interventions and special attention which could result in increased PTG. The results showed that the cumulative PICI score at T3 together with the emotional severity of PTSS (**proving also our 5<sup>th</sup> hypothesis**) and the **social support scale from QOL at T6** explained one third of PTG variance. Consistently with previous findings, PTSS co-occurs with PTG (Cordova et al, 2007). The model confirms the original belief that the presence of distress is necessary to develop PTG (Calhoun & Tedeschi, 2006). Also, the co-occurrence of PTG and PTSS creates questions about the adaptive function of PTG (Pat-Horenczyk et al 2015). How could PTG be adaptive, if the emergence of PTG is accompanied by PTSS? Consistently with previous findings, the constant cognitive involvement in processing the trauma could be a key factor in the development of PTG. For this process stress is needed (Silva et al, 2012). In my opinion posttraumatic stress is the factor which reminds patients of the vulnerability of people and life, which in the meantime helps to appreciate ourselves and life more.

On the other hand, results of the current study showed, that PTG and QOL domains have moderate to strong, significant associations (except Level of Independence with which the association was weak), **proving our 6<sup>th</sup> hypothesis.** This result could confirm the theory about the adaptive function of PTG, but also raises many questions. Is PTG leading to better well-being (Sawyer et al, 2010) or reciprocal relationships can be cited, as in a

state of stable well-being, people may be more inclined to see more positive changes that are reflected in their well-being notion. The question also arises as could PTG really be differentiated from quality of life as they both are positive psychological constructs? To understand, the complex Janus faces of PTG, Zoellner and Maercker (2006) proposed a two-component model of PTG as discussed in the theoretical background. The illusory component of PTG initially has stronger, positive illusions that help in the processing of emotional stress, but is dysfunctional in the long-term, while the functional component (which is most studied) is constructive and adaptive, bringing a successful growth after the successful coping with trauma.

The **7<sup>th</sup> hypothesis** (PTG would be higher in the intervention groups, than in the SA group) **has not been supported by our results**. There were no significant differences between the intervention groups regarding total PTG score and the factors of PTG, except Spiritual change between M and SA group. Both in the H and M group the spiritual change detected was small, but in the SA group it was above moderate. First, as far as spirituality is concerned, it is important to point out that, there have been no previous studies exploring the relationship between the baseline spirituality/religiousness level of the patients and the spiritual change (Shaw, Joseph, & Linley, 2005). For those with a higher initial level, the change could be less visible. Second, from a methodological point of view, it is also important to emphasize that the Spirituality Scale contains very few items and its reliability is below other scales. Third, spirituality could be culturally affected, so Tedeschi and colleagues (2017) suggested a revision and expansion of PTGI. The new spirituality items reflect on the diversity of perspectives on spiritual and existential thinking represented in different cultures and also solves the problem of few items in the Spirituality Scale. And fourthly, because of the small group sizes the difference could be just a result of statistical analyzes.

There were also no significant differences between the groups regarding the study variables affecting PTG (PICI scales at T1, T3 and T6 and QOL domains, and PSDS scales and Severity of Life Events at T6). Regarding T1, the similar PICI scores can be explained citing two factors: the groups were quite homogenous or, the group size was relatively small. For T3 and T6 the explanation could be more complex than at baseline, because the treatment and the interventions also could have had an effect. First, the patients were receiving the same treatment protocol, but we did not measure the perceived

stress regarding treatment, which could have been individually different. Second, the received social support from the research team and from the other patients could have been more effective than the interventions. The support experienced among our patients towards each other could have had a serious effect which we could not predict early on and therefore have not measured. According to the theoretical and also to the research literature, social support at the time of diagnosis and during treatment is one of the key factors for mobilizing inner resources and even PTG in the long run (Srignaro et al, 2010; Silva et al 2012; Tedeschi & Calhoun, 2006). In line with this thought, the results from the regression model could indicate the important nature of social support. Although using one subscale from the QOL questionnaire raises methodological questions.

Regarding the qualitative analysis of PTG it is important to discuss, that using this method a more detailed and personal experience of PTG could have been detected. The patients explained beautifully and openly without priming questions about PTG how complex and deep is their experience regarding the breast cancer trajectory. From their experience it could be seen also the two-sidedness of the cancer trajectory.

### **3.1.6 Limitations and future directions**

The results should be interpreted with caution, as the variables examined were measured by self-report questionnaires, and the sample size was relatively small, although small sample size in a clinical study with cancer patients is a frequent problem, because of the sensitive nature of the patient's experience. It is also important that participation was voluntary, so the sample is not representative. On the other hand, our research team reached rural Oncology Centers too. It would also be important to assess the perceived severity of the diagnosis and treatment, which would provide useful information on the extent of the threat experienced by the patients. The question also arises as to whether each person in the study considered the disease as a trauma, this topic could be also measured, providing a more detailed picture about the traumatic nature of the cancer disease. Also, regarding the time-sensible nature of PTG it would be useful to measure changes in PTG over time – in the present study we were not able to do that, because the PTGI questionnaire was added after the clinical trial started. For future considerations the content analysis of the psychological interviews at the end of the trial would help to detect changes in PTG over time. This work is having been already started.

Methodologically it could have been interesting to compare the results from the content analysis with the results from the PTGI questionnaire. In the present dissertation the data captured was not enough to execute this comparison.

It is an important question of the present study as to whether the interventions experienced really do not have an effect on PTG or the size of the intervention groups were too small to detect any difference. Another possible explanation and also an important limitation in relation to this topic could be the fact, that actually the study had no control group receiving only the standard medical treatment, so the real differentiation between intervention and no intervention was not possible.

Further research is needed to explore the different processes that can lead to the different dimensions of PTG, therefore the separate analysis of the predicting variables of the dimensions of PTG would be important. Also, several theorists discuss the different processes leading to the different dimensions of growth (for example: Janoff-Bulman, 2004), therefore the process-focused, longitudinal studies would aid in the more accurate understanding of the forming of PTG dimensions.

Not measuring social support is also a limitation of the current study. For future considerations it is also important, that different forms of social support could be measured: emotional, informational and instrumental social support (Schroevers, Helgeson, Sanderman, & Ranchor, 2010). Also for future considerations, it would be useful to measure PTG (and PTG dimensions separately) and PTSS during and after treatment longitudinally, to examine the process of the reintegration of the trauma. Also the content analysis of the psychological interviews could be assessing not just the manifestations of PTG, but parallel the symptoms of posttraumatic stress.

### **3.1.7 Conclusion**

Facing an ongoing trauma such as cancer does not necessarily automatically result in pathological conditions such as the much-researched posttraumatic stress disorder (PTSD), but the struggle with a difficult life situation can potentially lead to personality development, measured by the construct of PTG. As there has not previously been a randomized, longitudinal clinical trial containing both quantitative and qualitative methods in a Hungarian breast cancer sample on posttraumatic growth, the results

described and discussed above are important in framing the experience of Hungarian breast cancer patients in light of the cancer trajectory and the interventions experienced.

As discussed in the theoretical background PTG is a construct which is affected by many variables, most importantly posttraumatic stress symptoms, social support and coping strategies. An important strength of our study is that the in the literature much discussed disease related variables (the diagnosis, the time since diagnosis, the treatment protocol and the risk of the diagnosis) were controlled, thus our sample is homogenous by disease variables. All of these variables could have an effect on PTG, thus controlling them was an opportunity to reach the core predictors of PTG. Our research strongly supports, that for the emergence of PTG, stress is needed and more importantly the subjective, emotional severity of the posttraumatic stress symptoms could have a facilitating effect on PTG together with positive coping mechanisms and social support.

Despite limitations, our research provides useful information for planning future interventions. PTG was higher in the current study than in other breast cancer samples, even when intervention was used (Lerolain, 2010; Silva et al, 2012, Pat-Horenczyk et al, 2015). It is clear from the results that it's worthwhile to help people who have undergone breast cancer not only individually, but also in terms of psychological interventions using and facilitating social support and suggestive techniques. Also, using qualitative techniques, studies can measure PTG more deeply and the subjective descriptions of the patients could help in the understanding of the traumatic and also of the positively facilitating nature of cancer simultaneously. The current study confirms the fact, that positive coping strategies and emotional severity of PTSS are contributing to PTG and PTG has moderate association with quality of life. Therefore, facilitating PTG could be cost effective. Nonetheless, the present dissertation is not stating that PTG is the only good outcome possibility, psychologically dealing with trauma-related experiences.

### **3.2 RETROSPECTIVE STUDY: Posttraumatic growth among adult survivors of childhood cancer and parents of childhood cancer survivors**

#### **3.2.1 Research questions**

This part of the doctoral dissertation is aimed to analyze posttraumatic growth from two perspectives: firstly, the experience of young adults who were treated with cancer in their childhood. Secondly, the study will also focus on parents of childhood cancer survivors. The purpose of the **retrospective study** was to explore the factors that influence posttraumatic growth in both young adult survivors of childhood cancer and parents of childhood cancer survivors. Despite the fact that international research has been more focused on PTG in recent years regarding the experience of young adult survivors of childhood cancer (Arpawong et al, 2013; Gianiazzi et al, 2016; Yi et al, 2015), in the case of parents of childhood cancer survivors, the examination of the predicting variables of PTG is underrepresented, as just few studies have explored this topic (for example: Hungerbuehler et al, 2011; Picoraro et al, 2014). To date, there has not been a comprehensive study of this groups in a Hungarian sample yet - this study attempts to fill this gap and provide a descriptive picture of how PTG appears in these groups and how underlying factors are associated with it. The few Hungarian studies regarding childhood cancer have focused on other aspects of the childhood cancer trajectory (for example: Szentesi, 2018: illness representation of childhood cancer patients; Molnár et al, 2013: cognitive schemas and the development of relationships of childhood cancer survivors). In the retrospective study we examined the following questions:

- Do young adult survivors of childhood cancer and parents of childhood cancer survivors experience posttraumatic growth? If so, what is the frequency of PTG in these groups?
- What are the most significant dimensions of change experienced regarding posttraumatic growth in adult survivors of childhood cancer and parents of childhood cancer survivors?
- How do the PTG scores relate to PTG scores studied abroad in the group of young adult survivors of childhood cancer and the parents of childhood cancer survivors?

- Does gender, age, educational level or marital status have an affect on PTG in childhood cancer survivors?
- Does time since diagnosis play a role in PTG in childhood cancer survivors and in parents of childhood cancer survivors?
- Does the perceived objective severity of the diagnosis have an affect on PTG in childhood cancer survivors and in parents of childhood cancer survivors?
- Is there a positive relationship between social support and PTG in both groups?
- Is there a positive relationship between posttraumatic stress symptoms and PTG in both groups?
- Is there a relationship between well-being and PTG?
- Is there a relationship between emotion regulation types (self-focused and emotion-focused rumination and dampening of positive emotions) and PTG in both groups?
- Could there be a complex model explaining the factors influencing PTG in both groups?
- Are the factors influencing PTG different in the dimensions of PTG in both groups?

### 3.2.2 Research hypotheses

Despite the fact that the present study is exploratory and the results regarding the factors influencing PTG in these study groups are contradictory in the current literature and using different methodologies, research hypotheses were formulated.

1. **Hypothesis:** The present dissertation outlines that most of the young adult survivors of childhood cancer and the parents of childhood cancer survivors are able to experience posttraumatic growth at a minimal level at least in one dimension of growth. This hypothesis is supported by previous studies (for example: Arpawong et al, 2013; Gianiazzi et al, 2016; Picoraro et al, 2014).
2. **Hypothesis:** In line with previous research abroad we argue that young adult survivors of childhood cancer can experience change in all areas of PTG. However, we suppose, that the most significant dimensions of change experienced



will be greater appreciation of life and the need for more meaningful relationships (Gianiazzi et al., 2016; Yi et al., 2015). Regarding the parents, the study is exploratory, but we suggest, that the most significant domains of change experienced will also be greater appreciation of life and the need for more meaningful relationships, because the nature of the experience.

3. **Hypothesis:** We suggest, that gender and the age at diagnosis will affect PTG in the group of young adult survivors of childhood cancer. The results of previous studies suggest that women (Arpawong et al., 2013; Gianiazzi et al., 2016; Yi et al., 2015) and patients who are older at the time of diagnosis (Barakat et al., 2006; Devine et al, 2010; Yi et al., 2015) can experience higher levels of PTG. Regarding parents, we mostly examined mothers, so statistical differentiation is not possible, but some studies suggest that mothers experience greater growth than fathers (Hungerbuehler et al, 2011).
4. **Hypothesis:** We suppose, that time since diagnosis plays an important role in PTG in both groups, but the results regarding the association are contradictory in the current literature. We suggest, that a longer time duration since diagnosis will be in a negative relationship with PTG, as proven by some studies (Barakat et al, 2006; Yi & Kim, 2014), because as posttraumatic stress fades PTG could also decrease.
5. **Hypothesis:** We strongly suppose, that general social support is one of the key factors influencing PTG. We hypothesize, that social support is in a positive relationship with PTG in both groups, which is also supported by previous studies (Ekim & Ocakci, 2015; Gunst et al, 2016; Yi et al, 2015).
6. **Hypothesis:** We hypothesize that the perceived objective severity of the diagnosis and posttraumatic stress symptoms are in a positive relationship with PTG as discussed above and supported by several studies in both groups (Arpawong et al., 2013; Barakat et al., 2006; Gunst et al, 2016; Hungebuehler et al, 2011).

- 7. Hypothesis:** We hypothesize, that well-being and posttraumatic growth will be in a positive relationship, as supported by previous studies (Kamibeppu et al, 2010; Zebrack & Chesler, 2002) in the group of young adult survivors of childhood cancer, but as discussed before, the direction of the association is not clear.

Regarding emotion regulation in both groups and well-being in the group of parents we could not make a hypothesis, because there are no studies exploring the first association and regarding well-being the results are contradictory and are influenced by posttraumatic stress. Generally, we think that the factors influencing posttraumatic growth should be explored together, because most of the factors are in relationship with each other. Taking this into account, multiple regression modelling is crucial.

### **3.2.3 Methods**

#### **3.2.3.1 Study framework**

We asked young adults (aged 18-35) who underwent childhood cancer and have been in remission to take part in the retrospective study. In addition, we examined parents of childhood cancer survivors without age restriction. We asked participants to take part in the study not through health organizations, but through supporting organizations and foundations in relation to children and their parents who had undergone cancer (Bátor Tábor Foundation/Serious Fun camp; Érintettek Egyesület/Association of patients affected by childhood cancer). The design of the collaboration with the organizations took a great amount of time and work, but the organizations were really helpful and open to the study. We are really thankful to them, not just for their participation in the study, but for the tremendous work and care they are providing during the treatment period and also in the rehabilitation of the pediatric cancer patients. Their contribution is essential in the support of the whole family. We have provided access to our study questionnaires to organizations that are involved with young adult survivors of cancer and parents of childhood cancer survivors. Our online questionnaire was available on LimeSurvey online platform (for the complete questionnaire packages for young adults and for parents see *Appendix 5.* and *6.*). Organizations circulated our online questionnaire to those affected. The completion of questionnaires was anonymous and voluntary, and the contact details and identity of the participants remained anonymous. Participants could have stopped the participation or refused to answer questions at any time, without

required justification. The contact details of a professional psychologist were provided in the informational consent form in case any questions or concerns arose – if so, the consultation was to be free of charge. The young adult survivors of childhood cancer and parents of childhood cancer survivors who participated in the study could not have been matched, because of the anonymity, and also because of the fact that more parents filled out the questionnaires than young adults.

The study was conducted with the permission of ELTE-PPK Research Ethics Committee. License code: ELTE PPK Research Research Request\_201410. (Principal investigator: Adrien Rigó, PhD). After the preparation phase (licence approval, preparing the questionnaire packages for both groups, organization of the collaboration with the foundations) we started the data collection in 2016 and finished in 2017.

### **3.2.3.2 Subjects**

The parent sample originally contained 202 participants, but 90 data samples were excluded because incomplete responses resulting of 112 participants. The sample of young adult survivors contained originally 100 participants, but after filtering out the highly incomplete forms, we were able to analyze the data of 53 participants.

A total of 53 young adults with a history of childhood cancer were enrolled in our sample, with an average age of 27.5 (SD = 5.4), 17 men and 36 women. 88.7% of young adults finished secondary school and more than half of them are working actively. 62.3% of them have an average financial status and the same percent of them live in a relationship. Of the young adult survivors, 17 had leukemia (ALL=Acute lymphoid leukemia, AML=Acute myeloid leukemia, CML=Chronic myeloid leukemia), 14 lymphomas (HL=Hodgkin's lymphoma, NHL=Non-Hodgkin lymphoma, BL=Burkitt lymphoma), 4 osteosarcomas, 2 neuroblastomas, 2 ovarian tumors, and the remaining 14 patients experienced different cancers. Among them, 49 (88.7%) received chemotherapy, 27 (47.2%) received radiotherapy, 24 had surgery (47.2%) and 4 received transplantation (7.5%). Among the young adult survivors, 20 reported long-term consequences (for example: visual disturbances, menstrual problems, weight problems, paralysis). The average age of young adults at the time of diagnosis was 10.77 years (SD = 5.76), with an average of 16.5 (SD = 5.6) years since diagnosis. Among them, there were 5, who were 0-3 years at diagnosis, but they have not been excluded due to developmental differences, because despite their cognitive ability to process the trauma of cancer may not have been fully developed at the time of treatment, when entering adulthood and

gaining the cognitive ability to process the trauma, their risk of psychological difficulties increase, because it includes plans of employment, spouse selection and parenthood, which could have been affected by the late effects of cancer (Schwartz et al, 2010).

The average age of parents of survivors of childhood cancer is 44.9 years (SD = 6.7), 9 men and 103 women. 86.6% of parents have a secondary school degree and 75% are actively working, and 91.2% of them are of average or better financial status. More than 90% of parents live in a relationship. The average age of their child at the time of diagnosis was 7.32 (SD = 4.44), with an average of 8.1 (SD = 4.72) years since diagnosis. The few male parents were not excluded, because there were no gender differences in the examined variables and the size of the sample would further decrease (See later, in *Table 12.*). The demographic and disease-related variables are shown in *Table 8-9.*

*Table 8.* Sample characteristics of young adult survivors of childhood cancer (demographic and disease-related variables)

<b>YOUNG ADULT SURVIVORS OF CHILDHOOD CANCER</b>			
<b>n</b>	53	<b>Relationship status (n,%)</b>	
<b>Age (mean, SD)</b>	27.5 (4.7)	Single	20 (37.7)
<b>Gender (n, %)</b>		In a relationship/Married	33 (62.3)
Male	17 (32.1)	Divorced	0 (0)
Female	36 (67.9)	Widowed	0 (0)
<b>Education (n,%)</b>		<b>Cancer related variables</b>	
Less than 8 grades	0 (0)	<b>Objective severity of diagnosis (n,%)</b>	
8 grades	2 (3.8)	Small tumor, not metastasized	13 (24.5)
Vocational school	4 (7.5)	Slightly larger tumor, metastasized in closer lymph nodes	14 (26.4)
Secondary school	29 (54.7)	Larger tumor, metastasized also in distant lymph nodes	8 (15.1)
Higher education	18 (34)	Large tumor, metastasized in distant organs	0 (0)
<b>Employment (n,%)</b>		No information	18 (34)
Student	15 (28.3)	<b>Age at diagnosis (mean, SD)</b>	10,77 (5.76)
Employed	30 (56.6)	<b>Years since diagnosis (mean, SD)</b>	16,51 (5.6)
Housewife/Homemaker	3 (5.7)	<b>Treatments</b>	
Unemployed	5 (9.4)	Chemotherapy (received n, %)	47 (88.7)
Retired	0 (0)	Radiation (received n, %)	25 (47.2)
<b>Income (n,%)</b>		Surgery (received n, %)	25 (47.2)
Worse than average	6 (11.3)	Transplant (received n,%)	4 (7.5)
Average	33 (62.3)		
Better than average	14 (26.4)		

Table 9. Sample characteristics of parents of survivors of childhood cancer (demographic and disease-related variables)

PARENTS OF CHILDHOOD CANCER SURVIVORS			
<b>n</b>	112	<b>Relationship status (n,%)</b>	
<b>Age (mean, SD)</b>	44.9 (6.7)	Single	4(3.6)
<b>Gender (n, %)</b>		In a relationship/Married	102(91.1)
Male	9(8)	Divorced	4(3.6)
Female	103(92)	Widowed	2(1.8)
<b>Education (n,%)</b>		<b>Variables related to the child's cancer</b>	
Less than 8 grades	1(0.9)	<b>Objective severity of diagnosis (n,%)</b>	
8 grades	2(1.8)	Small tumor, not metastasized	24(21.4)
Vocational school	12(10.7)	Slightly larger tumor, metastasized in closer lymph nodes	25(22.3)
Secondary school	42(37.5)	Larger tumor, metastasized also in distant lymph nodes	15(13.4)
Higher education	55(49.1)	Large tumor, metastasized in distant organs	3(2.7)
<b>Employment (n,%)</b>		No information	15(13.4)
Student	0(0)	<b>Age at diagnosis (mean, SD)</b>	7.32(4.44)
Employed	84(75)	<b>Years since diagnosis (mean, SD)</b>	8.1(4.72)
Housewife/Homemaker	21(18.8)	<b>Treatments</b>	
Unemployed	2(1.8)	Chemotherapy (received n, %)	105 (93.8)
Retired	5(4.5)	Radiation (received n, %)	21 (18.8)
<b>Income (n,%)</b>		Surgery (received n,%)	50 (44,6)
Worse than average	11(9.8)	Transplant (received n,%)	17 (15.2)
Average	70(62.5)		
Better than average	31(27.7)		

### **3.2.4 Measures**

#### **3.2.4.1 Demographic data**

Demographic data included gender, age, educational level, marital status, employment status and income of the study subjects.

#### **3.2.4.2 Disease variables**

Diagnosis, perceived objective severity of diagnosis (size of the tumor, presence of metastasis), date of diagnosis, time since diagnosis, age of the person at the time of diagnosis were assessed among the variables related to the disease. We explored the type and characteristics of the treatment, the history of surgery or transplantation. We also asked about relapse and the long-term consequences of the disease and treatment.

#### **3.2.4.3 Posttraumatic Growth Inventory**

To measure posttraumatic growth, the original and most often used form of the Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996, 2004) was used. The internal consistency of the normative sample was high (Cronbach- $\alpha$ : 0,9). The Hungarian version (translated by the Department of Personality and Health Psychology of ELTE) of PTGI also provided high reliability (Cronbach- $\alpha$ =0,94) (Kovács et al, 2012). A detailed description of the PTGI is already written regarding the first study (see before). The reliability of the sub-scales was also good in the present study, with Cronbach- $\alpha$  0.74 for Appreciation of Life, 0.87 for Relationships, 0.81 for Personal Strengths and 0.79 for New Possibilities, except for the factor Spiritual Change that fell behind the expected criterion (Cronbach- $\alpha$  = 0.57).

#### **3.2.4.4 Social Support Questionnaire (SSQ)**

Social support was measured with a shortened, Hungarian version of Support Dimension Scale (Tandari-Kovács, 2010) developed by Caldwell Pearson and Chin (1987), which measures the **perceived degree of social support** (Kopp & Skrabski, 1992) on a 4 point Likert scale. The participants had to decide how much they could count on the help of the people in their social environment during the illness, or generally. The scores ranged from *Could not count at all (0)* to *Could very much count (4)* on the help of the people in their social environment. In the present study, the questionnaire was used in two versions for both young adult survivors of childhood cancer and parents of childhood cancer survivors. One questionnaire had to be filled out about the time of the illness and the other one generally. In the case of young adults, regarding the time of the illness, we measured

the perceived social support from parents, schoolmates, neighbors, friends, relatives, supporting professionals, church groups, help organizations, and fellow patients. In terms of general social support, this list was complemented by a colleague, child and partner or spouse, but a fellow patient was not included, because generally (without the trauma experience) it is hardly interpretable. In the case of parents, the questions regarding the time of illness and general social support were the same. The amount of social support was based on the total score following Caldwell and his colleagues' (1987) guideline. The higher score indicated higher social support perceived. The reliability of the questionnaire is acceptable based on previous studies (Nyulászi & Rigó, 2014). In the present study, Cronbach- $\alpha$  was 0.65 for parents, and 0.70 for young adults regarding social support during the illness. The Cronbach- $\alpha$  for general social support was 0.62 for parents, and 0.60 for young adults. Because of the nature of the questionnaire, we did not expect a close relationship between the items, so they were considered acceptable.

#### **3.2.4.5 Impact of Events Scale Revised (IES-R)**

To measure posttraumatic stress symptoms, the Hungarian and revised version (Perczel-Forintos, Ajtay, Barna, Kiss, & Komlósi 2012), of the Impact of Events Scale (developed by Horowitz Wilner and Alvarez, 1979) was used. The 22 item self-reported questionnaire measures the level of subjective distress symptoms regarding a traumatic event on a 5-point Likert-scale. Each item should be answered following the question: "*How much have you been distressed or bothered by these difficulties?*". The answers are ranging between *Not at all* (0) and *Extremely* (4). The revised version of the Impact of Event Scale (IES-R) has seven additional questions and a scoring range of 0 to 88. In addition to the original two subscales (avoidance, intrusive thoughts) the 7 new items reflect on the hyperarousal symptoms, therefore a third subscale is included (Weiss & Marmar, 1997). The respondents had to determine how much they have been distressed by the illness. A higher score means a higher subjective distress level regarding the negative life event. The questionnaire also had good internal consistency in the present study (Cronbach- $\alpha$  = 0.87), the Cronbach- $\alpha$  value was 0.79 for hyperarousal, 0.85 for the intrusive thoughts subscale, and 0.66 for avoidance.

#### **3.2.4.6 Responses to Positive Affect Questionnaire (RPAQ)**

We used the Hungarian version of Responses to Positive Affect Questionnaire developed by Feldman, Joormann and Johnson (2008) for the measurement of emotion regulation,

especially with regard to rumination. Since the validation of the questionnaire is still ongoing in Hungary (by the research team of Gyöngyi Kökönyei at the Department of Clinical Psychology and Addictology of ELTE), we used the original three-factor structure. The questionnaire measures three cognitive, response-focused emotion regulation strategies (intensity and length of emotion) to positive affects, on a 4-points Likert scale. When answering the question “*When I'm happy,*” participants have to decide how often they have the feelings and thoughts in general listed in the questionnaire between the endpoints *Almost never (0)* and *Almost always (3)*. Two positive strategies (emotional-focused and self-focused rumination) and a negative (dampening of positive emotions) can be measured with the 17-item questionnaire.

- An example of an emotional-focused strategy: *When you feel good (happy), how often do you think “I can do anything”?*
- An example of a self-focused strategy: *When you feel good (happy), how often do you think “I'm ready to do anything”?*
- An example of dampening of positive emotions: *When you feel good (happy), how often do you think “it's too good to be true”?*

Based on a validation study with the original questionnaire, the internal reliability of the measuring instrument is adequate (Feldman et al., 2008). The Hungarian version proved to be reliable in our study (Cronbach- $\alpha$  = 0.79), the Cronbach- $\alpha$  value was 0.74 for self-focused rumination, 0.82 for emotion-focused rumination and 0.80 for dampening of positive emotions.

### **3.2.4.7 WHO Well-being Questionnaire**

For measuring the current (regarding the past two weeks) psychological well-being of young adult survivors of childhood cancer and parents of childhood cancer survivors, the WHO Well-being Questionnaire was used. The original 22-item Well-being Index (WBI), developed in 1982, was revised and shortened for 5 items by Bech, Gudech and Johansen (1996) for an easy use in healthcare. The 5-item Hungarian version of the WHO Well-Being Questionnaire was validated in 2006, according to which the internal consistency of the questionnaire is appropriate (Susánszky, Konkoly Thege, Stauder, & Kopp, 2006). The participants have to decide on a 4-point Likert scale between the endpoints *Not at all (0)* and *Completely (3)* regarding the 5 questions. A higher score



indicates a better general well-being. The reliability of the questionnaire was also excellent in this study (Cronbach- $\alpha$  = 0.86).

### **3.2.5 Statistical analyses**

Sharing and completing the questionnaire packages and downloading the data was done on the LimeSurvey online application interface. The systematization of the data and the execution of statistical procedures were carried out with the help of SPSS: IBM SPSS Version 23.0 (IBM Corp. Released 2015, Armonk, NY: IBM Corp.). Normality and homogeneity of variance were tested; the application of robust tests were not necessary (for the normality and homogeneity of variance tests see *Appendix 7.*, *8.* and *9.*). Descriptive statistical analyzes (mean, standard deviation, frequency and percentage distribution calculation) were performed to describe the characteristics of the sample. Independent samples t-test was used to test gender differences in PTGI in both groups. Pearson's correlation method was used to examine the associations of the variables examined separately in the two groups. Multiple linear regression analyses (stepwise regression, backward elimination) were performed for the complex analysis of the variables determining posttraumatic growth in both groups and also separately for the different dimensions of posttraumatic growth. The comparison between the two groups was not possible, due to methodological reasons: the subjects in two groups could not be matched and several variables could not be controlled.

### **3.2.6 Results**

#### **3.2.6.1 *Characteristics of posttraumatic growth in both groups and gender differences in PTGI***

The large majority of young adult survivors (97.9%) experienced some degree of positive change as reflected by a mean PTGI total score above 1 point (higher than very little influence of childhood cancer on growth) on the 6 points scale. 66.7% of childhood cancer survivors experienced moderate change (mean PTGI total score above 3 points). The averaged total score of PTG of young adult survivors of childhood cancer was moderate ( $M = 3.18$ ;  $SD = 0.97$ ;  $CI(0.95) = 2.9-3.45$ ). It was higher than in an American study ( $M = 2.73$ ;  $SD = 1.21$ ) regarding young adult survivors of childhood cancer where, similarly to our study, on average, more than 10 years passed since the diagnosis and participants have experienced various childhood cancer diseases (Yi et al., 2015). At the same time, the average total score of PTG of young adult survivors was lower than in a sample study focusing on breast cancer patients ( $M = 4.51$ ;  $SD = 0.92$ ) (Brunet, McDonough, Hadd,

Crocker, & Sabiston, 2010), but higher than in a study focusing on stomach cancer patients (Sim, Lee, Kim, & Kim, 2015) ( $M = 2.9$ ;  $SD = 1.2$ ).

Also, the large majority of parents of childhood cancer survivors (93%) experienced some degree of positive change as reflected by a mean PTGI total score above 1 point, while 61% reported at least moderate growth (PTGI total score above 3 points). The average total PTG score of parents was also moderate ( $M = 3.15$ ;  $SD = 0.98$ ;  $CI (0.95) = 2.94-3.33$ ). It was higher than what was observed in an American study ( $M=2,83$ ;  $SD=1,13$ ), where similarly to our study, on average more than 8 years passed since the child's diagnosis (Turner-Sack, Menna, Setchell, Maan, & Cataudella, 2016). At the same time, the average total PTG score of parents was nearly the same as in another study where the PTG of the parents ( $M=3,09$ ;  $SD=0,9$ ) was measured in relation to their child's complex chronic health condition (for example: epileptic encephalopathy, neuromuscular diseases, and so on) (Stephenson et al, 2017). It appears that the chronic nature of the disease could be an important factor regarding PTG.

The highest scores were found for Appreciation of Life in both groups. For young adults, this was followed by Relationships, Personal Strength and New Possibilities, represented by moderate positive changes, while for Spiritual Change the scores were lower. In the group of parents Appreciation of Life was followed by Personal Strength and Relationships represented by moderate positive changes, followed by New Possibilities and Spiritual Change with lower scores. The results are summarized in *Table 10*.

*Table 10.* Mean PTGI total and PTGI factor scores in the group of young adult survivors of childhood cancer and parents of childhood cancer survivors.

	Young adult survivors of childhood cancer				Parents of childhood cancer survivors			
	95% Confidence interval						95% Confidence interval	
	M	SD	Lower	Upper	M	SD	Lower	Upper
<b>PTGI total score</b>	3.18	0.97	2.88	3.44	3.15	0.98	2.94	3.33
<b>PTGI</b>	3.7	1.17	3.32	4.02	4.03	0.95	3.85	4.21
<b>Appreciation of Life</b>								
<b>PTGI</b>	3.3	1.15	2.94	3.6	3.22	1.09	2.99	3.42
<b>Relationships</b>								
<b>PTGI Personal Strengths</b>	3.29	1.16	2.93	3.62	3.28	1.19	3.04	3.49
<b>PTGI New Possibilities</b>	3.19	1.08	2.85	3.45	2.83	1.19	2.56	3.07
<b>PTGI Spiritual Change</b>	1.79	1.59	1.32	2.25	2.13	1.49	1.85	2.42

There were no significant gender differences in any of the groups regarding PTGI, except for the Appreciation of Life dimension of PTGI in the group of parents. For detailed data see *Table 11.* and *12.*

*Table 11.* Gender differences in PTGI total and factor scores in the group of young adult survivors.

	Male			Female			F	p
	N	M	SD	N	M	SD		
PTGI	15	3.038	0.945	32	3.420	1.242	.270	0.298
Relationships								
PTGI	15	3.311	1.094	32	3.311	1.094	.605	0.112
Appreciation of Life								
PTGI Personal Strengths	15	3.896	1.178	32	3.896	1.178	1.591	0.407
PTGI New Possibilities	15	3.083	1.335	32	3.083	1.335	.003	0.215
PTGI Spiritual Change	15	3.391	1.092	32	3.391	1.092	1.105	0.288
PTGI: total score	15	2.880	0.953	32	2.880	0.953	.008	0.169

*Table 12.* Gender differences in PTGI total and factor scores in the group of parents of childhood cancer survivors.

	Male			Female			F	p
	N	M	SD	N	M	SD		
PTGI	8	2.661	0.566	92	3.270	1.114	2.492	.130
Relationships								
PTGI	8	2.958	1.201	92	4.127	0.877	1.977	.011
Appreciation of Life								
PTGI Personal Strengths	8	2.500	1.541	92	3.353	1.145	1.195	.520
PTGI New Possibilities	8	2.275	1.146	92	2.880	1.233	.416	.184
PTGI Spiritual Change	8	2.188	1.223	92	2.130	1.522	1.960	.918
PTGI: total score	8	2.536	0.898	92	3.207	0.975	.666	.630

### **3.2.6.2 Related variables to PTG in both groups, correlation studies**

Statistical differentiation between the groups was not possible, the scores allow only descriptive examination regarding the scores on the study variables. Both forms of the Social Support Questionnaire (SSQ) showed higher scores in the group of parents. The IES-R total score was high in the group of parents (mean score was 55.21 from 88 points). The well-being scores were nearly the same in both groups.

Regarding the descriptive statistics of the variables used in the correlation studies see *Table 13.* and 14.

*Table 13.* Descriptive statistics of the variables used in correlation studies in the group of young adult survivors of childhood cancer

<b>Young adult survivors of childhood cancer</b>						
	95% Confidence interval					
	Min	Max	M	SD	Lower	Upper
<b>SSQ: illness</b>	6	24	17.79	4.23	16.67	19.10
<b>SSQ: in general</b>	6	27	16.21	5.13	14.71	17.42
<b>IES-R:</b>	0	20	10.19	5.66	8.65	11.3
<b>intrusive thoughts</b>						
<b>IES-R:</b>	0	15	6.23	4.38	4.92	7.13
<b>hyperarousal</b>						
<b>IES-R:</b>	0	22	9.98	5.20	7.63	10.41
<b>avoidance</b>						
<b>IES-R: total score</b>	0	54	26.41	12.8	22.72	29.31
<b>RPAQ: self-focused rumination</b>	0	11	6.26	2.51	5.54	6.95
<b>RPAQ:</b>						
<b>emotion-focused rumination</b>	0	15	10	3	9.13	10.89
<b>RPAQ:</b>						
<b>dampening of positive emotions</b>	0	18	7.45	4.72	6.13	8.84
<b>WHO well-being</b>	0	15	8.67	3.39	7.71	9.69

*Table 14.* Descriptive statistics of the variables used in correlation studies in the group of parents of survivors of childhood cancer

<b>Parents of childhood cancer survivors</b>						
	Min	Max	M	SD	95% Confidence interval	
					Lower	Upper
<b>SSQ: illness</b>	2	27	26.46	9.46	24.62	28.48
<b>SSQ: in general</b>	6	33	32.26	13.34	29.69	35.03
<b>IES-R:</b>	1	21	22.09	4.75	21.12	23.05
<b>intrusive thoughts</b>						
<b>IES-R:</b>	0	18	15.72	4.47	14.79	16.63
<b>hyperarousal</b>						
<b>IES-R:</b>	0	20	17.29	4.42	16.34	18.24
<b>avoidance</b>						
<b>IES-R: total score</b>	5	57	55.21	11.01	5.,09	57.26
<b>RPAQ: self-focused rumination</b>	0	12	5.93	2.54	5.37	6.48
<b>RPAQ:</b>	0	15	9.72	3.08	9.07	10.34
<b>emotion-focused rumination</b>						
<b>RPAQ:</b>	0	20	6.79	3.68	5.97	7.65
<b>dampening of positive emotions</b>						
<b>WHO well-being</b>	0	15	8.82	3.74	8.05	9.65

Pearson correlation analyzes were used to determine the relationship between the variables related to the total score of PTGI. Bonferroni correction was used: for the 3 IES-R subscales:  $0.05/3 = 0.017$  and for the 3 subscales of RPQA  $0.05/3 = 0.017$ . A statistically significant result means in this case, that the p-value (with Bonferroni adjusted value) was under the above calculated fixed P limits. In the group of young adult survivors of childhood cancer, in the bivariate correlations, emotional-focused rumination and well-being were moderately, significantly, positively correlated with PTG. Social support experienced during illness, general social support and self-focused rumination were weakly, significantly, positively correlated with posttraumatic growth. Intrusive thoughts (from posttraumatic stress symptoms) was also in a weak relationship with PTG, but with

the Bonferroni adjusted value, the association was not strongly significant. Hyperarousal (from posttraumatic stress symptoms), and total score of posttraumatic stress symptoms, and dampening of positive emotions (from emotion regulation strategies), were in a weak, positive, relationship with posttraumatic growth, but the associations were not significant. The time since diagnosis showed a weak, negative, significant relationship with PTG, but with the Bonferroni adjusted value, the association was not strongly significant. Avoidance from posttraumatic stress symptoms was in a weak, negative relationship with PTG, but the association was not significant. The perceived objective severity of the diagnosis and the age at diagnosis was not in a significant relationship with PTG.

In the sample of parents, the self-focused rumination was in a moderate, positive, significant relationship with posttraumatic growth. Emotional-focused rumination (from emotion regulation strategies), hyperarousal (from posttraumatic stress symptoms), intrusive thoughts (from posttraumatic stress symptoms) and the total score of posttraumatic stress symptoms and well-being were in a weak, positive, significant relationship with PTG. Dampening of positive emotions (from emotion regulation strategies) was also in a weak, significant association with PTG, but with the Bonferroni adjusted value, the association was not strongly significant. Time since diagnosis, the two forms of social support, avoidance from posttraumatic stress symptoms were in a positive relationship with PTG, but the associations were not significant. The objective severity of the diagnosis and the child's age at diagnosis was not in a significant relationship with PTG. The results of the correlation studies are summarized in *Table 15*.

Table 15. Bivariate correlations of the variables related to the total score of posttraumatic growth (PTGI) in the group of young adult survivors of childhood cancer and parents of childhood cancer survivors

	Young adult survivors		Parents of survivors	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
SSQ: illness	<b>.360</b>	<b>.013</b>	.037	.713
SSQ: in general	<b>.392</b>	<b>.006</b>	.183	.069
(Child's) age at diagnosis	.234	.118	-.082	.420
Time since diagnosis	<b>-.323</b>	<b>.027</b>	.024	.846
Perceived, objective severity of the diagnosis	-.027	.857	-.095	.433
IES-R: intrusive thoughts	.295	.044	<b>.275</b>	<b>.006</b>
IES-R: hyperarousal	.214	.149	<b>.322</b>	<b>.001</b>
IES-R: avoidance	-.118	.431	.191	.057
IES-R: total score	.156	.296	<b>.334</b>	<b>.001</b>
RPQA: self-focused rumination	<b>.398</b>	<b>.006</b>	<b>.421</b>	<b>.000</b>
RPQA: emotion-focused rumination	<b>.570</b>	<b>.000</b>	<b>.339</b>	<b>.000</b>
RPQA: dampening of positive emotions	.160	.287	.215	.034
WHO: well-being	<b>.512</b>	<b>.000</b>	<b>.311</b>	<b>.004</b>

Notice, that significant correlations are written with bold numbers

### 3.2.6.3 Exploratory variables of posttraumatic growth

#### 3.2.6.3.1 The group of young adult survivors of childhood cancer

Multivariate linear regression analysis was performed for the complex examination of the explanatory variables of posttraumatic growth. The output variable was the total score of post-traumatic growth. Based on literature considerations and the previous correlation studies the explanatory input variables included the **time since diagnosis, age at diagnosis, two forms of social support, emotion-focused, and self-focused rumination, dampening of positive emotions** and from posttraumatic stress symptoms **intrusive thoughts, avoidance and hyperarousal** and **gender** and **well-being**. Stepwise regression modelling was used, because in the final model the estimation of the  $\beta$  coefficients could be more precise and reliable as if I used Enter method.

After the stepwise regression (backward elimination), in the final model well-being, dampening of positive emotions, and intrusive thoughts remained significant explanatory variables. Well-being had the greatest explanatory power. In the case of general social support, the significance was on a tendency level ( $p = 0.055$ ), but we determined, that it was approaching an acceptable level of significance and on the other hand, the

explanatory power of the model would have been greatly reduced by excluding it. The final model explained 50.7% of PTG variance ( $R^2 = 0.507$ ;  $R^2_{adj} = 0.459$ ;  $F(4) = 10.562$ ;  $p = 0.001$ ). The results are summarized in *Table 16*. Thus, we can state that the higher level of **general social support**, **dampening of positive emotions**, and the increased presence of **intrusive thoughts**, as well as the higher level of subjective feeling of **well-being** are associated with higher levels of posttraumatic growth. For the non-significant, excluded variables in the stepwise regression modelling of the explanatory variables of PTGI see *Appendix 10*.

*Table 16.* The final stepwise regression model of the underlying variables of posttraumatic growth in the sample of young adult survivors of childhood cancer

	Unstandardized coefficients		Standardized coefficients	t	p
	B	Standard error	$\beta$		
SSQ: in general	.917	.465	.234	1.971	.055
RPAQ: dampening of positive emotions	1.097	.497	.253	2.205	.033
IES-R: intrusive thoughts	1.312	.404	.374	3.25	.002
WHO well-being	3.743	.703	.622	5.324	.000

For the dimensions of PTG (Appreciation of Life, Relationships, Personal Strengths, New Possibilities and Spiritual Change), separate stepwise regression analyses were performed with the same input variables. After the stepwise regression (backward elimination) the significant explanatory variables are discussed here. Compared to the PTG total score model, the gender of the respondents was also an explanatory factor in the **Appreciation of Life dimension** (PTG was higher for women), but social support did not have significant explanatory power. In terms of the **Relationships dimension**, social support experienced during the time of illness took over the role of general social support, and the dampening of positive emotions did not appear in the final model. In terms of **Personal Strengths dimension**, only well-being had an explanatory role. In the domain of **New Possibilities**, avoidance (from posttraumatic stress symptoms) and time since diagnosis had also a role in addition to the variables explaining the total score of PTG, but the direction of the relationship was negative. In the case of **Spiritual Change dimension**, dampening of positive emotions and well-being were excluded from the model. Final explanatory models of PTG dimensions are summarized in *Table 17*.



Table 17. Final stepwise regression models for the underlying variables of the dimensions of PTG in the group of young adult survivors of childhood cancer

Regression MODELS		Unstandardized coefficients		Standardized coefficients		
<b>1. Posttraumatic growth: Predicting variables of <i>Appreciation of Life</i></b>		B	Standard error	$\beta$	t	p
<b>R<sup>2</sup>=0,45</b>						
	Emotion regulation: dampening of positive emotions	0.227	0.088	0.304	2.586	0.013
	Posttraumatic stress symptoms: intrusive thoughts	0.232	0.071	0.384	3.262	0.002
	WHO well-being	0.521	0.124	0.501	4.195	<0.000
	Gender	2.126	0.879	0.28	2.418	0.020
<b>2. Posttraumatic growth: Predicting variables of <i>Relationships</i></b>		Unstandardized coefficients B	Standard error	Standardized coefficients $\beta$	t	p
<b>R<sup>2</sup>=0,431</b>						
	Social support experienced during illness	0.623	0.231	0.327	2.696	0.010
	Posttraumatic stress symptoms: intrusive thoughts	0.478	0.17	0.342	2.814	0.007
	WHO well-being	0.988	0.289	0.412	3.414	0.001
<b>3. Posttraumatic growth: Predicting variables of <i>Personal Strengths</i></b>		Unstandardized coefficients B	Standard error	Standardized coefficients $\beta$	t	p
<b>R<sup>2</sup>=0,393</b>						
	WHO well-being	0.876	0.163	0.627	5.336	<0.001
<b>4. Posttraumatic growth: Predicting variables of <i>New Possibilities</i></b>		Unstandardized coefficients B	Standard error	Standardized coefficients $\beta$	t	p
<b>R<sup>2</sup>=0,439</b>						
	Emotion regulation: dampening of positive emotions	0.334	0.138	0.292	2.412	0.021
	Posttraumatic stress symptoms:	0.336	0.126	0.363	2.667	0.011

<b>intrusive thoughts</b>	<b>Posttraumatic stress symptoms: avoidance</b>	-0.284	0.138	-0.277	-2.058	0.046
	<b>WHO well-being</b>	0.656	0.201	0.412	3.27	0.002
	<b>Time since diagnosis</b>	-0.248	0.119	-0.26	-2.078	0.044
<b>5. Posttraumatic growth: Predicting variables of <i>Spiritual Change</i></b>		Unstandardized coefficients		Standardized coefficients		
<b>R<sup>2</sup>=0,347</b>		B	Standard error	β	t	p
	<b>Social support in general</b>	0.209	0.078	0.338	2.678	0.011
	<b>Posttraumatic stress symptoms: hyperarousal</b>	0.225	0.108	0.294	2.082	0.044
	<b>Posttraumatic stress symptoms: avoidance</b>	-0.302	0.087	-0.495	-3.473	0.001

### 3.2.6.3.2 The group of parents of survivors of childhood cancer

The input variables of the linear regression analysis performed on the sample of the parents included the posttraumatic stress symptoms (avoidance, hyperarousal and intrusive thoughts), the emotion regulation strategies (emotion-focused and self-focused rumination, and dampening of positive emotions), social support experienced during the child's illness and in general, risk at diagnosis and well-being. After the stepwise regression (backward elimination) in the final model, self-focused rumination, hyperarousal from posttraumatic stress symptoms and well-being remained significant explanatory variables. The final model explained 26.5% of PTG variance ( $R^2 = 0.265$ ;  $F(3) = 6.799$ ;  $p = 0.001$ ). The results are summarized in *Table 18*. Thus, we can state that the increased presence of hyperarousal symptoms, the more pronounced use of self-focused rumination and the increased level of the subjective feeling of well-being are associated with increased level of posttraumatic growth. For the non-significant, excluded variables in the stepwise regression modelling of the explanatory variables of PTGI see *Appendix 11*.

*Table 18.* The final stepwise regression model of the underlying variables of posttraumatic growth in the sample of parents of childhood cancer survivors.

	Unstandardized coefficients		Standardized coefficients	t	p
	B	Standard error	$\beta$		
IES-R: hyperarousal	2.064	.636	.396	3.244	.002
RPQA: self-focused rumination	2.903	1.175	.31	2.27	.017
WHO well-being	1.699	.78	.275	2.139	.037

For the dimensions of PTG (Appreciation of Life, Relationships, Personal Strengths, New Possibilities and Spiritual Change), separate stepwise regression analyzes were performed with the same input variables. After the stepwise regression (backward elimination) the significant explanatory variables are discussed here. Compared to the PTG total score model, the significant explanatory variables of the **Appreciation of Life dimension** included dampening of positive emotions, but none of the posttraumatic stress symptoms played a significant role in the final model. Regarding the **Relationship dimension**, well-being did not play a role compared to the original model. In terms of **Personal Strengths dimension**, only self-focused rumination had a role. Regarding **New Possibilities dimension**, however, self-focused rumination was eliminated, and only hyperarousal and well-being played a role. In terms of **Spiritual Change dimension**, social support experienced during the child's illness had a negative effect, while general social support had a positive effect, and hyperarousal proved to have a lesser impact. The final explanatory models of PTG dimensions are summarized in *Table 19*.

*Table 19.* Final stepwise regression models for the underlying variables of the domains of PTG in the group of parents of childhood cancer survivors.

Regression MODELS		Unstandardized coefficients		Standardized coefficients	t	p
		B	Standard error	$\beta$		
<b>1. Posttraumatic growth:</b>						
<b>Predicting variables of</b>						
<b><i>Appreciation of Life</i></b>						
<b>R<sup>2</sup>=0,293</b>						
<b>Emotion regulation:</b>						
<b>Self-focused rumination</b>		0.412	0.151	0.341	2.721	0.009
<b>Emotion regulation:</b>						
<b>dampening of</b>		0.294	0.086	0.409	3.407	0.001

	positive emotions WHO-Well-being	0.226	0.097	0.289	2.336	0.023
<b>2. Posttraumatic growth: Predicting variables of Relationships</b> <b>R<sup>2</sup>=0,161</b>		Unstandardized coefficients		Standardized coefficients		
		B	Standard error	$\beta$	t	p
	Posttraumatic stress symptoms: hyperarousal	0.534	0.241	0.277	2.216	0.031
	Emotion regulation: Self-focused rumination	1.266	0.433	0.365	2.921	0.005
<b>3. Posttraumatic growth: Predicting variables of Personal Strengths</b> <b>R<sup>2</sup>=0,125</b>		Unstandardized coefficients		Standardized coefficients		
		B	Standard error	$\beta$	t	p
	Emotion regulation: Self-focused rumination	0.764	0.266	0.353	2.876	0.006
<b>4. Posttraumatic growth: Predicting variables of New Possibilities</b> <b>R<sup>2</sup>=0,25</b>		Unstandardized coefficients		Standardized coefficients		
		B	Standard error	$\beta$	t	p
	Posttraumatic stress symptoms: hyperarousal	0.634	0.186	0.412	3.401	0.001
	WHO-Well-being	0.801	0.217	0.447	3.691	0.001
<b>5. Posttraumatic growth: Predicting variables of Spiritual Change</b> <b>R<sup>2</sup>=0,294</b>		Unstandardized coefficients		Standardized coefficients		
		B	Standard error	$\beta$	t	p
	Social support experienced during illness	-0.543	0.14	-0.783	-3.89	<.001
	Social support in general	0.396	0.111	0.718	3.561	0.001
	Posttraumatic stress symptoms: hyperarousal	0.216	0.078	0.316	2.781	0.007

### 3.2.7 Discussion

The aim of our study was to investigate variables affecting posttraumatic growth among young adult survivors of childhood cancer and parents of childhood cancer survivors in Hungarian samples. In addition to demographic and disease variables, we also examined the effect of posttraumatic stress symptoms, emotional regulation strategies, well-being, general social support and social support experienced during the illness in both parents and young adult survivors of childhood cancer.

**The 1<sup>st</sup> hypothesis** (most of the young adult survivors of childhood cancer and parents of childhood cancer survivors are able to experience posttraumatic growth at least at a minimal level at least in one dimension of growth) **has been proven** by our results. In line with current literature, posttraumatic growth was identified in more than 90% of both young adults and parents, at least in one dimension of growth, in our sample study. This result is consistent with the findings of recent literature, that the experience of a serious illness and the struggle with trauma can also have positive consequences (Arpawong et al., 2013; Barakat et al., 2006; Gianinazzi et al., 2016). Moreover, the young adult survivors and their parents also experienced growth in all areas of PTG to least at a minimal level. The averaged total score of PTG of young adult survivors of childhood cancer was moderate and was higher than in an American study where, similarly to our study, on average, more than 10 years passed since the diagnosis and participants have experienced various childhood cancer diseases (Yi et al., 2015). At the same time, the average total score of PTG of young adult survivors was lower than in a sample study focusing on breast cancer patients (Brunet et al, 2010), but higher than in a study focusing on stomach cancer patients (Sim, Lee, Kim, & Kim, 2015). These kind of differences could be suggesting, that the degree of PTG could be different by cancer types. Another important factor is, that the subjects of the present study were recruited via organizations which are focusing on the therapeutic recreation of the pediatric cancer patients, so they received some kind of psychological and social support, which could lead to increased levels of PTG.

The average total PTG score of parents was also moderate and was higher than what was observed in an American study where similarly to our study, on average more than 8 years passed since the child's diagnosis (Turner-Sack et al, 2016). At the same time, the average total PTG score of parents was nearly the same as in another study where the PTG of the parents was measured in relation to their child's complex chronic health condition (for

example: epileptic encephalopathy, neuromuscular diseases, and so on) (Stephenson et al., 2017). It appears that the chronic nature of the disease could be an important factor regarding PTG.

As in the results have been shown PTG depends on various factors, so the difference among the various cancer typologies could not be explained simply and also methodological questions should be considered. Besides, different cancer types have different psychological consequences. In addition, the comparison of various cancer types regarding PTG could help to frame the experience of childhood cancer survivors and the parents of childhood cancer survivors and can provide a basis for further cross-sectional research.

The **2<sup>nd</sup> hypothesis** (young adult survivors of childhood cancer can experience change in all areas of PTG and the most significant domains of change experienced will be greater appreciation of life and the need for more meaningful relationships) **has been also proven** by our results. In line with previous research abroad, young adult survivors of childhood cancer can experience change in all areas of PTG, which was reflected in our sample. The most significant dimensions of change experienced were greater Appreciation of Life and Relationships, similar to other studies (Gianiazzi et al., 2016; Yi et al., 2015), but it is important to mention that Personal Strengths and New Possibilities factor closely followed the first two (the average score was above 3 for all four factors). Lower scores were shown only by the Spirituality factor in the sample of young adults. One possibility to explain the lower scores could be cultural differences; the religious context in which the child was brought up could be a determinant (Kilmer et al., 2009). In addition, the cognitive developmental level of the child at the time of illness may also be a significant factor (Hendricks-Ferguson, 2006) which was not explored during our study.

Regarding the factors of PTG for parents, the study was exploratory because this area has not been widely researched. The highest scores were found also for Appreciation of Life, followed by Personal Strengths and Relationships (average score above 3), followed by a lower level of growth in the New Possibilities and Spirituality factor.

It seems, that both in childhood cancer survivors and their parents the Appreciation of Life domain was the most pronounced. In the group of parents, the mean average score for this dimension of PTG was above moderate, as it displayed a great degree of growth. It can be suggested, that due to the life-threatening nature of cancer which endangers life

and physical integrity in a subjective or real manner or in learning that one's child has a life threatening illness, the experience is traumatic and while facing (the child's) death, the survivors and parents are re-evaluating the values of life, which concludes most importantly in greater appreciation of life.

As far as spirituality is concerned (in both groups), it is important to note that it has not yet been investigated how the level of the person's (pre-trauma) spirituality / religiosity is related to spiritual change (Shaw, Joseph, & Linley, 2005). For those with a higher initial level, the change could be less visible. From a methodological point of view, it is important to emphasize that the Spirituality scale contains very few items and its reliability is below the other scales. The fact that spirituality could be culturally affected inspired Tedeschi and colleagues (2017) to suggest a revision and expansion of PTGI. The new spirituality items incorporate the diversity of perspectives on spiritual and existential thinking represented in different cultures and helps to solve the problem of the relatively few items in the Spirituality Scale. Future research should consider the application of this new measurement.

**The 3<sup>rd</sup> hypothesis** (that age at diagnosis and gender will affect PTG in the sample of young adult survivors) **has not been supported by our results**. In the sample of young adults, the age at diagnosis and the gender were not in a significant relationship with PTG and there were no significant gender differences regarding PTG in this group. In the sample of parents, the child's age at diagnosis was not in a significant relationship with PTGI and there were also no gender differences regarding PTGI total score, but in the dimension of Appreciation of Life, women reached higher scores, than men.

This results could have been occurred due to methodological reasons. The gender ratio was not balanced in either of the groups, the retrospective analysis may deprive the age of diagnosis, and the sample size was small, which could weaken the statistical strength, but in many studies these variables and PTG were also unrelated. (Arpawong et al., 2013; Turner-Sack et al., 2012). Additionally, age was used as a continuous variable, thus age groups could not be determined, because the group sizes would be really small. At the same time, another possible explanation for the results is supporting a different line of thought in the literature stating that the demographic variables have no significant role in the explanation of PTG (Arpawong et al., 2013; Devine et al., 2010). In the present dissertation it could be explained with the above listed methodological reasons supplemented by the priming effect of the PTGI, which could hide the differences.

Therefore, qualitative analysis of the experiences of childhood cancer survivors would be also useful.

Of the cancer-related variables, only the time elapsed since diagnosis was in a negative, significant relationship with PTG in the group of young adult survivors, **proving our 4<sup>th</sup> hypothesis**. That means that the less time since diagnosis indicates higher levels of PTG. It is important to note that an average of 16.51 years has passed since the diagnosis, and the standard deviation was 5.6 years, so even for those with less time, we are referring to about 10 years. This result is consistent with the results of several recent studies (for example: Barakat et al., 2006; Yi & Kim, 2014), although in a study where a longer time since diagnosis has elapsed (more than 10 years) no significant relationship with PTG has been found (Klosky et al., 2014). Also, a longitudinal examination did not reveal any significant change in PTG at 6, 12, 24 months after diagnosis on an adolescent sample (Husson et al., 2017). It can be suggested that longitudinal studies examining longer periods of time after the diagnosis could be more meaningful in relation to the process of PTG. The treatment for adolescents generally takes 1-2 years depending on the type of the cancer. It would be worthwhile to examine PTG long after the completion of treatment. To conclude, the explanation of the mixed results may also be accredited to methodology.

In the sample of young adult survivors of childhood cancer, general social support, dampening of positive emotions, intrusive thoughts and well-being remained significant explanatory variables of PTG, **proving our 5<sup>th</sup>** (social support in a positive relation with PTG), **6<sup>th</sup>** (perceived objective severity of the diagnosis and posttraumatic stress symptoms in a positive relation to PTG) and **7<sup>th</sup> hypothesis** (well-being in a positive relation to PTG). The model explained 50% of the variance of posttraumatic growth, which is a very high ratio compared to the similar literature (for example it was 9.5% in the study of Yi et al., 2015) and even compared to the field of psychology. It is important to note, that the perceived objective severity of the diagnosis was not in a significant relationship with PTG, just the posttraumatic stress symptoms had a role.

As previously discussed, **social support is fundamentally important** for the main mechanisms of coping with the trauma, thus the role of general social support is unquestionable. It is also not surprising that general social support has an affect on PTG, rather than social support experienced during the illness, because the emergence of PTG



is a process for which social support is longitudinally needed. It is also important that during the illness and hospital stay children are isolated from their everyday environment and can experience less social interaction and support than before – they could not meet their friends, their wider family and also their close family has been seen less often. Usually, during hospital stay, the social support experienced in appearance is limited for the presence of the mother. Therefore, it is not surprising that social support experienced in general (after treatments and hospital stay) would have had a greater importance in the process of PTG.

The questionnaire (Feldman et al., 2008) measuring ruminative thinking has distinguished emotional-focused and self-focused rumination and dampening of positive emotions based on responses to positive emotional states. The **dampening of positive emotions** can be associated with the process of cognitive restructuring (Calhoun & Tedeschi, 2006) related to the integration of trauma. The experience of a serious illness shatters a person's belief that only good things can happen and can result in a more realistic worldview, the person no longer naïvely thinks that only good things could happen and adopts a more balanced approach about positive life events. Feldman and his colleagues (2008) found in their original research that dampening of positive emotions could be used to maintain a sense of predictability and stability. At the same time, there is a risk of pathologies, and this type of emotional regulation can also be associated with a decrease in self-confidence (Feldman et al., 2008). It is important to note, however, that the regression studies on the factors of PTG have shown that dampening of positive emotions was only relevant to the factors Appreciation of Life and New Possibilities. It is possible that a person will be less in need of definitive positive emotions and events in order to appreciate life, and to be happy with small things. Perhaps by trying to dampen positive emotions, the person will spare themselves of further disappointments. In addition, the security of stability can help improve appreciation of life and more anxious testing of life's possibilities, as the person already possesses a cautious awareness of that negative events.

Regarding **intrusive thoughts**, it is important to note that they are not only intrusive thoughts about cancer as a trauma, but may also include future fears of possible recurrence of the disease (Kangas et al., 2002). The presence of these symptoms can maintain the perceived threat of the trauma, which can affect posttraumatic growth through rumination processes and social support (Meyerson, Grant, Carter, & Kilmer, 2011: a model explaining the development of post-traumatic growth regarding children

underwent traumatic experiences). In light of this line of thought, it would also be interesting to see how the sixth factor - positive changes in health behavior, more appreciation of health - recently emerged in the literature of posttraumatic growth (Stanton, Bower, & Low, 2006) can be related to the frequency of intrusive thoughts.

The **positive relationship between PTG and posttraumatic stress symptoms** (in this case: intrusive thoughts) proves the assumption that for positive psychological change stress is needed (Silva et al, 2012), even if one could suppose that a positive construct, like PTG would be correlating with other positive constructs (Kovács et al, 2012). The memories of the trauma and the anticipatory nature of the cancer disease could be reminding the survivors repeatedly to appreciate life, relationships, themselves and the possibilities that life can offer. In this way suffering can have an adaptive function in the long term. This line of thought also contradicts the idea that strictly positive thinking is necessary to cope with traumatic events. The traumatic experience should be legitimized as shattering, therefore the reconstruction of one's world view could mean real change.

In terms of **well-being**, the original validation study of the 5-item WHO questionnaire (Susánszky et al., 2006) had an average score of 8.5 points for the 18-44 age group, whereas in this sample, this result was 8.65, indicating that the quality of life of young adult survivors of childhood cancer does not differ from the population. This is also confirmed by the literature (for example: Kamibeppu et al., 2010). However, it is important to note that since the diagnosis of our subjects, an average of 16.51 years has elapsed, which may explain the average well-being. PTG showed a clear and strong relationship with well-being in the case of young adult survivors of childhood cancer, also when examining the factors of PTG individually (only examining Spirituality had no role). However, the role of well-being in our explanatory model raises many questions. Does PTG lead to better well-being (for example, female breast cancer patients: Morill et al., 2008) or more positive family relationships have an impact on well-being (for example, in child cancer survivors: Orbuch, Parry, Chesler, Fritz, & Repetto, 2005)? Maybe it can be inferred that in reciprocal relationships, as in a state of stable well-being, people may be more inclined to see more positive changes that are reflected in their well-being vision. In the research area of young adult survivors of childhood cancer, this area is still very neglected, most of the studies explore the well-being and posttraumatic stress symptoms of childhood cancer patients and young adult survivors (for example: Quinn,

Goncalves, Sehovic, Bowman, & Reed, 2015), but regarding the relationship of PTG and well-being little research has been done.

In the case of parents, posttraumatic stress symptoms and all forms of emotional regulation were in a significant, positive relationship with posttraumatic growth, but only the **hyperarousal, self-focused rumination and well-being** remained in the final explanatory regression model. The model confirms the original idea (which was also the case for young adult survivors of childhood cancer) that the presence of distress is necessary to develop posttraumatic growth (Calhoun & Tedeschi, 2006). According to a longitudinal study, the symptoms of stress experienced by parents (mainly due to their nature, intrusive thoughts and hyperarousal) may be more sustained over time (Pöder, Ljungman, & von Essen, 2008). This may explain that the posttraumatic stress symptoms are still pronounced in the present study after 8.1 years on average, when they have to recall the trauma. In addition, parents are more objectively able to judge the severity of the life-threatening nature of the disease because of their cognitive capacity (Kazak et al., 2004; Landolt Vollrath, Ribi, Gnehm, & Sennhauser, 2003) and are more likely to be afraid of the recurrence of the disease.

While social support had a role for young adult survivors, for parents the belief in themselves and their own strength was an important factor. Regarding **self-focused rumination**, the recurring automatic thoughts are associated with a positive self-image, which can be beneficial in difficult situations. Also my personal experience is that parents of children undergoing cancer cannot focus on themselves (as in the need for social support), while concentrating on ways to support their child. A significant personal experience for me in the pediatric oncology setting was, that as psychologists we can only support parents if we are able to help their child first. Thus, perhaps social support is experienced by parents through their child, which indicates that dyadic analyses would be useful in future research.

The role of **well-being** is also important in the case of parents regarding PTG, which can be due to the decrease of the perceived threat (healed child).

Regarding parents, the question arises as why just 26% of PTG was explained by the study variables. It is possible that future studies would have to examine more factors related to the child in terms of posttraumatic growth while carrying out dyadic analyses.

Theoretically comparing the results of the young adult survivors of childhood cancer and the group of parents, it can be concluded that **well-being has played a role in both groups regarding PTG.**

At the same time, there is an **important difference in emotional regulation processes:** for young adult survivors, the dampening of positive emotions, and for parents the role of self-focused rumination was dominant. This may be due to the fact that at the time of illness the child and the parent experience trauma at different levels of cognitive development. Parents are more sensitive to the objective life-threatening nature of the disease with mature cognitive capacity (Yalug et al., 2011), so they are faced with the real experience of the trauma in parallel to their primary task of supporting their child. The literature also shows that the strongest supporters of children are the parents (Trask et al., 2003), which is also a source of additional stress for the parent. Thus, parent's belief in themselves, and in their own strength is an obvious factor, both in coping with trauma, in supporting their child, and in terms of PTG. This is also supported by the fact that in the group of parents only the self-focused rumination has an effect on the Personal Strengths factor of PTG.

The average age of young adult survivors of childhood cancer at the time of illness was 10.77 years, but the sample also included subjects who were 0-3 years old at the time of the disease, so they could be less affected by the trauma from a developmental psychology perspective compared to the parents. The level of self-reflection of children, their internal representations and their basic beliefs, as well as their basic working methods, are still developing at this age, so emotional regulation is still not that conscious (Kilmer et al., 2014). It is likely that children did not attain the level of abstraction at the time of illness that could help in the rumination process of trauma, while their current average age (27.5 years) already assumes the level of adult cognitive development. However, since on average 16 years have passed since the diagnosis and the retrospective nature of the study makes it difficult to explain this thought. However, based on a new direction of research (Nashiro, Shakaki, & Mather, 2012), older adults' emotional control functions may be better with age, due to better processing of positive stimuli than negative ones (changes in attention and memory functions). Accordingly, while emotional control techniques for dampening positive emotions may be more pronounced in younger adults, older adults' (like parents in our study) rumination processes strengthening positive impact could be more important.

Our results indicate that certain domains of PTG require different predicting variables in both groups. This finding suggests that PTG is a multidimensional construct, as the different areas of PTG are forming through different processes, but in relation to each other. It would be interesting and useful to explore the paths of development of the different domains longitudinally.

### **3.2.8 Limitations and Strengths**

Our results should be interpreted with caution, as the variables examined were measured by self-reporting questionnaires, and the sample size was not too broad, which is a common phenomenon in this disease population.

It is also important to note that the participation was voluntary, so the sample is not representative. At the same time, reaching the study subjects through different non-health organizations could result in greater heterogeneity. However, the question of group effects regarding high levels of PTG also arises. The question is whether study subjects who turn to non-health care organizations are more open to accepting outside support.

An important limitation of our study is that the appearance of different disease groups was not balanced in the sample, and we were not able to study the disease-related variables because the group was heterogeneous.

It would also be important to assess the perceived severity of the diagnosis, which would provide useful information on the extent of the threat. The question also arises as to whether each person in the study considered the disease as a trauma.

An important strength of our study is that there has not been a comprehensive study of these target groups in a Hungarian sample yet. This study provided a descriptive picture of how PTG appears in these groups and how underlying factors are associated with it. Regarding the young adult survivors of childhood cancer, the study succeeded to identify 50% of the PTG variance, which is a high percentage given the fact that emotions and thoughts are hard to predict. It was proven, that PTG could be described through several underlying factors in a complex relationship.

In addition to these, our research provides useful information for planning future interventions. It is clear from the results that it would be worthwhile to help people with childhood cancer not only individually but also with regard to family functioning, to strengthen and facilitate their social support system during treatment and recovery, and to help integrate trauma with cognitive therapeutic techniques according to their age if the clinician thinks it is adequate. Meanwhile, of course the treatment of stress symptoms

is crucial. Intervention protocols have also been developed regarding this line of thinking in foreign practice (Brier, Schwartz, & Kazak, 2015; Kazak, 2005).

### **3.2.9 Conclusion and future directions**

Facing an ongoing trauma such as cancer does not necessarily automatically result in pathological conditions such as the much-researched posttraumatic stress disorder (PTSD), but the struggle with a difficult life situation can potentially lead to personality development, measured by the construct of PTG. As there has not previously been a comprehensive study of these target groups in a Hungarian sample on posttraumatic growth, the results described and discussed above are important in framing the experience of Hungarian childhood cancer survivors and parents of childhood cancer survivors in light of the cancer trajectory.

As discussed in the theoretical background, PTG is a construct which is affected by many variables, most importantly posttraumatic stress symptoms, social support and coping strategies. Our research strongly supports, that for the emergence of PTG, stress is needed and, to cope with various stressors, social support is essential. In the present dissertation several variables affecting posttraumatic growth among young adult survivors of childhood cancer and parents of childhood cancer survivors were investigated. In addition to demographic and disease-related variables, we also examined the effect of posttraumatic stress symptoms, emotional regulation strategies, well-being, general social support and social support experienced during the illness in both parents and young adult survivors of childhood cancer, which makes the present study very unique, not solely in Hungary. The present dissertation was aimed to examine the complex nature of PTG and succeeded.

The results of the study showed, that the experience of a serious illness and the struggle with an ongoing trauma, like childhood cancer can also have positive consequences: PTG was experienced by more than 90% of the young adult survivors of childhood cancer and also by the parents of cancer survivors. As our study was retrospective (for young adults more than 10 years, for parents more than 8 years have passed since the cancer diagnosis), these results are important regarding the longitudinal aspects of PTG.

Our results supported the fact, that specific areas of PTG (Appreciation of Life, Relationships, Personal Strengths) are more pronounced in a cancer sample and also in a parent sample, which differentiate the experience of cancer from other traumatic events.

Our results regarding the dimensions of PTG in both study groups supported the idea that PTG is a multidimensional construct, indicating that the different domains of PTG are affected by different underlying variables. Future studies should examine the changes in these domains through time and in light of other serious life events.

Our results showed that there are important differences in the experience of the young adult survivors of cancer and of the parents of childhood cancer survivors regarding the factors influencing PTG. Although we succeeded to describe more than 50% of the PTG variance in the group of young adult survivors of childhood cancer, for parents it was just 26%, which raises the questions as to whether different variables would be determinant in this group.

It is possible that future studies would have to examine more factors related to the child regarding the experience of the parents, in terms of posttraumatic growth while carrying out dyadic analyses (examining the experiences of the children and their parents together). In the sample of young adult survivors of childhood cancer, general social support, dampening of positive emotions, intrusive thoughts and well-being remained significant explanatory variables of PTG. Regarding the parents, self-focused rumination, hyperarousal and well-being remained significant explanatory variables of PTG. The different mechanisms and underlying explanations have been discussed before, but it is important here to conclude that posttraumatic stress symptoms, cognitive emotion regulation strategies (self-focused rumination and dampening of positive emotions) and well-being have a role in both groups. For young adult survivors of childhood cancer social support was also crucial, but for the parents it did not have a significant role. Thus, it can be inferred that social support is experienced by the parents through their child, that's why dyadic analyses would be useful in future research.

The role of posttraumatic stress symptoms in PTG proved our original suspicion, that the cancer experience is two-sided. From one side, cancer is a specific ongoing trauma and process and in the meantime from another perspective, a potential to grow and experience

posttraumatic growth. In this way suffering can have an adaptive function in the long term and stress serves as a reminder for constant re-evaluation.

Researchers abroad are urging for the integration of psychological knowledge and clinical practice in research based interventions in the pediatric oncology setting (Kazak & Noll, 2015). Regarding to Kazak (2005) psychological intervention research in pediatric oncology contains 4 main areas: **reducing procedural pain** (for example: cognitive and behavioral approaches, such as desensitization, imagery, relaxation), **realizing long-term consequences** (for example: reducing posttraumatic stress symptoms, improving quality of life, treating late effects), **appreciating distress at diagnosis and over time** (for example: treating negative psychological consequences) and **knowing the importance of social relationships** (for example: social skills training, guided family intervention).

Our results indicate that the long-term wellbeing of young adult survivors of childhood cancer and the parents of childhood cancer are in a moderate relationship with PTG. It is clear from the results that PTG requires several individual, social and stress-related factors to appear. Regarding the facilitation of PTG to occur, it would be worthwhile to provide assistance to people with childhood cancer not only individually but also with regard to family functioning, to strengthen and facilitate their social support system during treatment and recovery, and to help integrate trauma with cognitive therapeutic techniques according to their age if the clinician thinks it is adequate. The cognitive emotional regulation strategies are less researched in relation to PTG, but it is clear from our research, that they could have great effect on PTG both for parents and young adult survivors of childhood cancer. Meanwhile, of course the treatment of stress symptoms is crucial, if they reach a pathological stage. For more focused interventions, further variables should be examined (cancer-related variables, personality factors, dyadic analyzes) in a longitudinal and cross-sectional design. Also, the application of a pre-post design would be crucial regarding PTG, because of the specific condition changes of the cancer disease.



## **4 GENERAL CONCLUSION**

Generally, both of the studies of the present dissertation found, that most of the cancer patients can experience posttraumatic growth 0,5 years or 3 years after diagnosis or even retrospectively. Also, parents of childhood cancer survivors experienced a similar amount of PTG retrospectively.

Both of the studies supported the fact, that specific areas of PTG (Appreciation of Life, Relationships, Personal Strengths) are more pronounced in a cancer sample, which differentiates the experience of cancer from other traumatic events. Also, both of the studies found that cancer patients and survivors and also close relatives experience PTG generally at a moderate level. Both of the studies and also the qualitative analysis supported the fact, that Appreciation of Life is the most pronounced domain of PTG on a cancer sample.

Our results indicate that certain dimensions of PTG are related to different predicting variables in both groups. This finding suggests that PTG is a multidimensional construct, as the different areas of PTG are forming through different processes, but in relation to each other. It would be interesting and useful to explore the paths of development of the different dimensions longitudinally.

Regarding the factors underlying PTG both of the studies suggested, that different forms of posttraumatic stress symptoms, coping and emotion regulation strategies and social support are the core predictors of PTG controlled for disease-related variables or even when not controlled. However, we did not have information about the subjective perception of the cancer trajectory (for example: perceived severity of the threat). Quality of life was also an important factor regarding PTG, but the direction and the nature of the association is still not clear. The more critical line of theorists are also considering the fact that, before the beneficial relationship between PTG and physical well-being (which is difficult to detect) is proven to be evident, it would be important to design studies that examine immune functions, and the progression of cancer and mortality in the context of PTG (Gorin, 2010). In our breast cancer longitudinal study we measured immune functions (white blood counts and NK activity), but the data processing is not in the stage which would allow me to discuss it here.

In addition to these our research provides useful information for planning future interventions. It is clear from the results that it is would be worthwhile to help people with cancer not only individually but also with regard to family functioning, to strengthen and facilitate their social support system during treatment and recovery, and facilitate coping strategies and to help integrate trauma with cognitive therapeutic techniques according to their age if the clinician thinks it is adequate. Meanwhile, of course the treatment of stress symptoms is crucial.

Both of the studies drew attention to the importance of the psychological rehabilitation of the cancer patients, as PTG was examined years after diagnosis. Based on my own experience, the psychological rehabilitation after treatments end could be as important as the coping with the disease-related psychological consequences during treatment. There are several rehabilitation programs available also in Hungary. For childhood cancer survivors usually Foundations and supporting organizations could provide therapeutic recreation (Serious Fun Children's Organization camps/Bátor Tábor Alapítvány; Together for Children with Pediatric Cancer Foundation/Együtt a Daganatos Gyermekekért Alapítvány; Guardians Foundation/Őrzők Alapítvány; Playhouse Foundation/Játszóház Alapítvány; Smile Foundation/Mosoly Alapítvány and so on) for example therapeutic recreation camps, family days, group therapy, psychodrama groups and so on. For adults, there are organized, psychological rehabilitation programs in the Oncology Centers in Hungary.

Regarding our study with the breast cancer patients containing intervention, a last, rhetorical question arises as to the type of intervention or the social support received through intervention is more important?

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## 7 APPENDICES

### 7.1 Normality and homogeneity of variance tests for the used measures in the breast cancer study.

#### 7.1.1 Appendix 1. Normality tests for the used measures in the hypnosis group in the breast cancer study.

	Hypnosis			
	M	SD	Z	p
PICI cum T1	233.96	31.71		
PICI cum T3	244.16	29.41		
PICI cum T6	245.38	32.24		
PTSS FR T6	10.63	8.70		
PTSS ES T6	11.83	10.67		
QOL SOC T1	16.13	2.14	.679	.746
QOL SPI T1	14.08	3.31	.679	.745
QOL PHY T1	14.75	2.41	.470	.980
QOL PSY T1	14.10	2.28	.653	.787
QOL ENV T1	15.70	1.59	.520	.949
QOL LOI T1	15.49	2.78	.538	.934
QOL SPI T3	16.27	3.32	1.468	.027
QOL SOC T3	15.54	2.45	.663	.771
QOL PHY T3	14.40	2.59	.572	.899
QOL PSY T3	14.62	2.41	1.077	.197
QOL ENV T3	15.99	1.73	.431	.993
QOL LOI T3	15.70	2.55	.774	.587
QOL SPI T6	16.04	2.90	.919	.369
QOL SOC T6	15.31	2.32	.429	.993
QOL PHY T6	15.08	2.06	.578	.892
QOL PSY T6	14.81	2.28	.700	.711
QOL ENV T6	16.02	1.84	.730	.660
QOL LOI T6	16.44	2.25	.934	.347
PTGI total score	3.81	0.98	1.035	.235
PTGI				
Appreciation of life	4,3	0.85	1.453	.029
PTGI Relationships	3.85	1.04	1.137	.151
PTGI Personal Strengths	4	1.02	1.084	.191
PTGI New Possibilities	3.69	1.32	1.089	.187
PTGI Spiritual Change	2.85	1.64	.929	.354

**7.1.2 Appendix 2. Normality tests for the used measures in the music group in the breast cancer study.**

	Music			
	M	SD	Z	p
PICI cum T1	226.00	39.19		
PICI cum T3	231.22	39.30		
PICI cum T6	240.22	46.07		
PTSS FR T6	8.19	11.34		
PTSS ES T6	8.04	11.94		
QOL SOC T1	15.41	2.39	.414	.996
QOL SPI T1	14.92	3.44	.826	.502
QOL PHY T1	14.51	2.59	.581	.889
QOL PSY T1	13.86	2.96	.743	.638
QOL ENV T1	15.01	1.97	.464	.983
QOL LOI T1	15.21	3.32	.745	.636
QOL SPI T3	16.08	2.71	1.119	.163
QOL SOC T3	14.92	2.30	.918	.368
QOL PHY T3	14.26	2.67	.555	.918
QOL PSY T3	14.65	2.42	.964	.311
QOL ENV T3	15.50	1.91	.431	.993
QOL LOI T3	15.07	2.85	.785	.568
QOL SPI T6	15.42	3.43	.660	.776
QOL SOC T6	14.97	2.41	.622	.834
QOL PHY T6	14.26	3.82	.783	.572
QOL PSY T6	14.82	2.99	.902	.390
QOL ENV T6	15.34	2.13	.617	.842
QOL LOI T6	16.23	3.11	.938	.342
PTGI total score	3.81	0.98	.703	.706
PTGI				
Appreciation of life	3.33	1.14	1.024	.245
PTGI Relationships	4.02	1.16	1.096	.181
PTGI Personal Strengths	3.47	1.24	.696	.717
PTGI New Possibilities	3.55	1.28	.688	.732
PTGI Spiritual Change	3.06	1.45	.911	.377

**7.1.3 Appendix 3. Normality tests for the used measures in the special attention group in the breast cancer study.**

	Special Attention			
	M	SD	Z	p
PICI cum T1	236.64	35.43		
PICI cum T3	239.92	39.49		
PICI cum T6	235.83	45.83		
PTSS FR T6	11.20	9.26		
PTSS ES T6	11.27	9.14		
QOL SOC T1	16.11	1.75	.782	.574
QOL SPI T1	15.47	2.61	.888	.410
QOL PHY T1	14.06	1.98	.594	.842
QOL PSY T1	13.88	2.03	.706	.701
QOL ENV T1	15.14	1.69	.494	.978
QOL LOI T1	14.06	2.03	.554	.919
QOL SPI T3	16.64	3.08	.905	.386
QOL SOC T3	16.53	2.69	.593	.873
QOL PHY T3	13.83	2.34	.811	.526
QOL PSY T3	14.47	2.56	.477	.977
QOL ENV T3	15.35	2.09	.447	.988
QOL LOI T3	14.82	2.50	.482	.974
QOL SPI T6	16.00	2.56	.402	.997
QOL SOC T6	14.97	2.28	.752	.624
QOL PHY T6	13.28	1.43	.783	.572
QOL PSY T6	13.82	2.46	.465	.982
QOL ENV T6	15.04	2.11	.678	.747
QOL LOI T6	14.46	2.31	.453	.986
PTGI total score	3.74	0.81	.760	.610
PTGI				
Appreciation of life	4.42	0.77	.929	.354
PTGI Relationships	3.86	0.68	.943	.336
PTGI Personal Strengths	3.76	1.12	.799	.546
PTGI New Possibilities	3.29	1.21	.785	.568
PTGI Spiritual Change	3.36	1.12	.941	.338



**7.1.4 Appendix 4. Homogeneity of variance tests for the used measures in the breast cancer study**

	Levene's Test for Equality of Variances	
	F	p
PICI cum T1	.162	.85
PICI cum T3	1.206	.307
PICI cum T6	1.849	.167
PTSS FR T6	.451	.639
PTSS ES T6	.098	.907
QOL SOC T1	.675	.513
QOL SPI T1	1.048	.356
QOL PHY T1	.224	.8
QOL PSY T1	1.204	.306
QOL ENV T1	1.048	.356
QOL LOI T1	1.344	.268
QOL SPI T3	.365	.695
QOL SOC T3	.664	.518
QOL PHY T3	.664	.518
QOL PSY T3	.122	.886
QOL ENV T3	.324	.724
QOL LOI T3	.38	.685
QOL SPI T6	1.142	.326
QOL SOC T6	.319	.728
QOL PHY T6	9.049	.915
QOL PSY T6	.372	.691
QOL ENV T6	.593	.556
QOL LOI T6	2.317	.107
PTGI total score	1.214	.303
PTGI	.826	.442
Appreciation of life		
PTGI	1.742	.183
Relationships		
PTGI Personal	.908	.408
Strengths		
PTGI New	.33	.72
Possibilities		
PTGI Spiritual	1.204	.306
Change		

## 7.2 Questionnaire packages in the retrospective study in the group of young adult survivors of cancer and parents of childhood cancer survivors

### 7.2.1 Appendix 5. Questionnaire package for parents in the retrospective study

#### I. Demográfiai adatok

1. Neme: 1. férfi ☐ 2. nő ☐
2. Születési éve: |\_|\_|\_|\_|
3. Testmagassága: |\_|\_|\_| cm
4. Testtömege: |\_|\_|\_| kg
5. Lakhely:
1. ☐ főváros 3. ☐ vidéki kisváros  
2. ☐ vidéki nagyváros 4. ☐ község, falu
6. Legmagasabb iskolai végzettsége:
1. ☐ kevesebb, mint 8 általános  
2. ☐ 8 általános  
3. ☐ szakmunkásképző  
4. ☐ érettségi  
5. ☐ diploma (főiskolai/egyetemi)
7. Családi állapota:
1. ☐ egyedülálló  
2. ☐ párkapcsolatban él  
3. ☐ házas/élettársi kapcsolatban él  
4. ☐ elvált  
5. ☐ özvegy
8. Munkaügyi státusza:
1. ☐ diák, tanuló  
2. ☐ aktív, fő állású dolgozó  
3. ☐ háztartásbeli (+ GYES, GYED)  
4. ☐ munkanélküli  
5. ☐ nyugdíjas (betegség miatt nyugdíjas)
9. Anyagi helyzetét milyennek ítéli?
1. ☐ az átlagosnál sokkal rosszabb  
2. ☐ az átlagosnál rosszabb  
3. ☐ átlagos  
4. ☐ az átlagosnál jobb  
5. ☐ az átlagosnál sokkal jobb
10. Hány gyermeke van?
- |\_|\_| gyermek

#### II. Gyermeke betegségével kapcsolatos kérdések

1. Gyermeke diagnózisa (daganat típusa): \_\_\_\_\_
2. Kockázata/stádiuma a diagnóziskor: 1 ☐ kis méretű tumor, még nem terjedt sehová  
2 ☐ kissé nagyobb méretű tumor, csak a közeli nyirokcsomók  
vagy szövetek felé terjedt  
3 ☐ nagyobb tumor, s távolabbi nyirokcsomókra/szervekre is  
áttért  
4 ☐ nagy méretű tumor, igen távoli szervekbe is áttétet adott  
5 ☐ nincs róla pontos információ
3. Diagnózis ideje: |\_|\_|\_|\_| év |\_|\_| hónap
4. Gyermeke életkora a diagnóziskor: |\_|\_| év
5. Kezelés befejezése: |\_|\_|\_|\_| év |\_|\_| hónap
6. Kezelés típusa: 1. ☐ kemoterápia  
- hossza: |\_|\_| (hány hónap)

- típusa (protokol): \_\_\_\_\_
2. ☐ sugárterápia; hossza: |\_\_|\_\_(hány hónap)
3. ☐ műtét; ideje: |\_\_|\_\_|\_\_|\_\_év\_\_|\_\_hónap
4. ☐ transzplantáció; ideje |\_\_|\_\_|\_\_|\_\_év\_\_|\_\_hónap
7. Volt-e visszaesés?
0. ☐ nem
1. ☐ igen; dátum: |\_\_|\_\_|\_\_|\_\_év\_\_|\_\_hónap
8. A betegségnek/kezelésnek vannak-e hosszú távú következményei a gyermekére nézve? Ha igen, mik ezek?
0. ☐ nem
1. ☐ igen:
- \_\_\_\_\_
9. Ön járt-e valamilyen terápiás, segítő csoportba/pszichológushoz, azzal a céllal, hogy támogatást kapjon ebben a helyzetben?
0. ☐ nem
1. ☐ igen
- Ha igen, hova? 1. ☐ pszichológushoz a kórházban
2. ☐ pszichológushoz egyénileg
3. ☐ csoport, ha igen hova: \_\_\_\_\_
10. Gyermeke gyógyulása után részt vett-e valamilyen önkéntes, segítő tevékenységben? Ha igen, miben?
0. ☐ nem
1. ☐ igen: \_\_\_\_\_

### III. Társas Támogatás Kérdőív-1

**Gondoljon vissza arra az időszakra, amikor diagnosztizálták gyermekénél a betegséget, s kezelés alatt állt!**

**Abban az élethelyzetben mennyire számíthatott az alábbiak segítségére?**

Kérem, hogy válaszait a megfelelő szám bekarikázásával jelezze!

A nem releváns választ csak abban az esetben válassza, ha az a forrás nem állhatott rendelkezésére (pl. nem volt akkor házastársa/élettársa, stb.)

	Egyáltalán nem	Keveset	Átlagosan	Nagyon	Nem releváns
1. szülő	0	1	2	3	9
2. házastárs/élettárs	0	1	2	3	9
3. iskolatárs	0	1	2	3	9
4. szomszéd	0	1	2	3	9
5. munkatárs	0	1	2	3	9
6. barát	0	1	2	3	9
7. gyermek	0	1	2	3	9
8. rokonok (édesanya, édesapa, nagyszülők, testvérek, más fontos rokon)	0	1	2	3	9
9. segítő foglalkozású (pl. orvos, nővér)	0	1	2	3	9
10. egyházi csoport	0	1	2	3	9
11. egyesület, segítő szervezet	0	1	2	3	9

### IV. Társas Támogatás Kérdőív-2

**Nehéz élethelyzetben általában mennyire számíthat az alábbiak segítségére?**

Kérem, hogy a válaszait a megfelelő szám bekarikázásával jelezze!

A nem releváns választ csak abban az esetben válassza, ha az a forrás nem állhat rendelkezésére (pl. nincs házastársa, élettársa, stb.)

	Egyáltalán nem	Keveset	Átlagosan	Nagyon	Nem releváns
1. szülő	0	1	2	3	9

2. házastárs/élettárs	0	1	2	3	9
3. iskolatárs	0	1	2	3	9
4. szomszéd	0	1	2	3	9
5. munkatárs	0	1	2	3	9
6. barát	0	1	2	3	9
7. gyermek	0	1	2	3	9
8. rokonok (édesanya, édesapa, nagyszülők, testvérek, más fontos rokon)	0	1	2	3	9
9. segítő foglalkozású (pl. orvos, nővér)	0	1	2	3	9
10. egyházi csoport	0	1	2	3	9
11. egyesület, segítő szervezet	0	1	2	3	9

## V. Poszttraumás stressz tünetek

Kérjük, gondoljon arra az időszakra, amikor gyermeke még kezelés alatt állt, vagy éppen befejeződött a kezelés! Minden tételnél jelölje meg, milyen gyakran voltak jellemzőek Önre ezek a megállapítások gyermeke akkori betegségével kapcsolatban.

	Egyáltalán nem	ritkán	néha	gyakran
1. Akkor is gondoltam rá, amikor nem akartam.	1	2	3	4
2. Nem hagytam, hogy felidegesítsen, amikor erre gondoltam, vagy emlékeztetett rá.	1	2	3	4
3. Próbáltam kitörölni az emlékezetemből.	1	2	3	4
4. Problémát okozott az elalvás vagy az alvás, mert képek és gondolatok jutottak eszembe róla.	1	2	3	4
5. Hullámokban erős érzések törnek rám az eseménnyel kapcsolatban.	1	2	3	4
6. Álmodtam róla.	1	2	3	4
7. Elkerültem az erre emlékeztető dolgokat.	1	2	3	4
8. Úgy éreztem, mintha meg sem történt volna, vagy nem a valóságban történt volna.	1	2	3	4
9. Megpróbáltam nem beszélni róla.	1	2	3	4
10. Képek jutottak az eszembe róla.	1	2	3	4
11. Más dolgok folyton eszembe juttatták.	1	2	3	4
12. Tudatában voltam, hogy még mindig sok érzésem van ezzel kapcsolatban, de nem foglalkoztam velük.	1	2	3	4
13. Próbáltam nem gondolni rá.	1	2	3	4
14. Bármilyen emlékeztető, visszahozta az ezzel kapcsolatos érzéseket.	1	2	3	4
15. Egyfajta tompaságot éreztem ezzel kapcsolatban.	1	2	3	4
16. Nehézségeim voltak a koncentrálással.	1	2	3	4
17. Ingerlékeny és dühös voltam.	1	2	3	4
18. Izgatott voltam és mindentől könnyen megrémültem.	1	2	3	4
19. Az eseményre emlékeztető dolgok heves testi reakciót váltottak ki nálam (pl. izzadás, nehézlégzés, émelygés, gyors szívverés).	1	2	3	4
20. Állandóan résen voltam és figyeltem.	1	2	3	4
21. Nehézségeim voltak az elalvással.	1	2	3	4

## VI. Poszttraumás növekedés Kérdőív

Kérem, gondoljon gyermeke betegségére! Minden alábbi állítással kapcsolatban értékelje egy hatfokozatú skálán (0–5), hogy az adott változás milyen mértékben következett be az Ön életében gyermeke betegsége miatt.

Kérem, hogy a válaszait az állítások előtt található vonalra írja!

0: nem tapasztaltam ezt a változást; 3: közepes mértékben tapasztaltam a változást;

1: nagyon kis mértékben tapasztaltam ezt a változást; 4: nagymértékben tapasztaltam a változást;

2: kis mértékben tapasztaltam a változást; 5: nagyon nagymértékben tapasztaltam ezt a változást

1.	Ez az esemény megváltoztatta a véleményemet arról, hogy mi fontos igazán az életben.	0	1	2	3	4	5
2.	Jobban értékelem a saját életemet.	0	1	2	3	4	5
3.	Új dolgok iránt kezdtem érdeklődni.	0	1	2	3	4	5
4.	Jobban bízom önmagamban.	0	1	2	3	4	5
5.	Jobban megértem a spirituális dolgokat.	0	1	2	3	4	5
6.	Tisztábban látom, hogy támaszkodhatok másokra nehéz időkben.	0	1	2	3	4	5
7.	Új irányt szabtam az életemnek.	0	1	2	3	4	5
8.	Közelebb érzem magam másokhoz.	0	1	2	3	4	5
9.	Inkább kifejezem az érzéseimet, mint korábban.	0	1	2	3	4	5
10.	Biztosabb vagyok benne, hogy képes vagyok kezelni a nehézségeket.	0	1	2	3	4	5
11.	Jobb dolgokra vagyok képes az életemben.	0	1	2	3	4	5
12.	Jobban el tudom fogadni a dolgok alakulását.	0	1	2	3	4	5
13.	Jobban értékelek minden egyes napot.	0	1	2	3	4	5
14.	Új lehetőségek nyíltak meg előttem, amelyekkel különben nem találkoztam volna.	0	1	2	3	4	5
15.	Jobban együtt érzek másokkal.	0	1	2	3	4	5
16.	Több erőfeszítést teszek a kapcsolataimért.	0	1	2	3	4	5
17.	Sokkal inkább törekszem, hogy megváltoztassam azokat a dolgokat, amelyek változásra szorulnak.	0	1	2	3	4	5
18.	Megerősödött a vallásos hitem.	0	1	2	3	4	5
19.	Rájöttem, hogy erősebb vagyok, mint gondoltam.	0	1	2	3	4	5
20.	Rájöttem, hogy milyen nagyszerűek az emberek.	0	1	2	3	4	5
21.	Jobban elfogadom, hogy szükségem van másokra.	0	1	2	3	4	5

## VII. Érzelemszabályozási Kérdőív

Az emberek sokféle dolgot tesznek és gondolkodnak, HA JÓL ÉRZIK MAGUKAT (BOLDOGOK). Kérjük, olvassa el az alábbi állításokat, és jelölje, hogy milyen gyakran – soha, néha, gyakran, mindig – gondolkodik így vagy tesz így, ha **BOLDOG (VIDÁM)**, **IZGATOTT VAGY LELKES**. Kérjük, azt jelölje, ahogy általában gondolkodik vagy tesz, és nem pedig azt, ahogy Ön szerint tennie kellene.

Amikor jól érzi magát (boldog), milyen gyakran.....

(Minden sorban egy választ adjon!)	szinte soha	néha	gyakr an	szinte mind ig
1. ...észleli, hogy mennyire tele van energiával.	0	1	2	3
2. ...élvezi is az adott pillanatot.	0	1	2	3
3...gondolja, hogy "bármire képes vagyok"	0	1	2	3
4...gondolja, hogy kész vagyok bármit megtenni.	0	1	2	3

5....gondolja azt, hogy "az adottságaimnak/képességeimnek megfelelően élek".	0	1	2	3
6....gondolja azt, hogy "ez túl szép ahhoz, hogy igaz legyen".	0	1	2	3
7. ...gondol arra, hogy mennyire jól érzi magát (boldog).	0	1	2	3
8. ...gondol arra, hogy mennyire erősnek érzi magát.	0	1	2	3
9...gondol olyan dolgokra, amik rosszul sikerülhetnek.	0	1	2	3
10. ...emlékezteti magát arra, hogy ez csak egy múltó érzés.	0	1	2	3
11...gondolja, hogy "az emberek azt fogják hinni, hogy hencegek".	0	1	2	3
12...gondol arra, hogy mennyire nehéz koncentrálni.	0	1	2	3
13...gondolja azt, hogy "mindent el fogok érni".	0	1	2	3
14. ...gondolja azt, hogy "Ezt nem is érdemlem meg".	0	1	2	3
15...gondolja azt, hogy "a szerencse-sorozatam hamarosan véget ér".	0	1	2	3
16...gondol arra, hogy milyen büszke magára.	0	1	2	3
17. ...gondol azokra a dolgokra, amik eddig nem sikerültek.	0	1	2	3

### VIII. WHO Jól-lét kérdőív 5 tételes magyar változata

Kérem, válaszoljon az alábbiak szerint:

0. egyáltalán nem jellemző      1. alig jellemző      2. jellemző      3. teljesen jellemző

**Az elmúlt két hét során érezte magát...**

1. ... vidámnak és jókedvűnek?
2. ... nyugodtnak és ellazultnak?
3. ... aktívnak és élénknek?
4. ... ébredéskor frissnek és élénknek?
5. ....a napjai tele voltak számára érdekes dolgokkal?

### 7.2.2 Appendix 6. Questionnaire package for the young adults in the retrospective study

#### I. Demográfiai adatok

1. Neme: 1 ☐ férfi      2 ☐ nő
2. Születési éve: |\_\_|\_\_|\_\_|
3. Testmagassága: |\_\_|\_\_|\_\_| cm
4. Testtömege: |\_\_|\_\_|\_\_| kg
5. Lakhely:      1 ☐ főváros      3 ☐ vidéki kisváros  
2 ☐ vidéki nagyváros      4 ☐ község, falu
6. Legmagasabb iskolai végzettsége:      1 ☐ kevesebb, mint 8 általános  
2 ☐ 8 általános  
3 ☐ szakmunkásképző  
4 ☐ érettségi  
5 ☐ diploma (főiskolai/egyetemi)
7. Családi állapota:      1 ☐ egyedülálló  
2 ☐ párkapcsolatban él  
3 ☐ házas/élettársi kapcsolatban él  
4 ☐ elvált  
5 ☐ özvegy
8. Munkaügyi státusza:      1 ☐ diák, tanuló  
2 ☐ aktív, fő állású dolgozó  
3 ☐ háztartásbeli (+ GYES, GYED)  
4 ☐ munkanélküli  
5 ☐ nyugdíjas (betegség miatt nyugdíjas)
9. Anyagi helyzetét milyennek ítéli?      1 ☐ az átlagosnál sokkal rosszabb  
2 ☐ az átlagosnál rosszabb

- 3 ☐ átlagos  
 4 ☐ az átlagosnál jobb  
 5 ☐ az átlagosnál sokkal jobb

10. Van gyermeke? Ha igen, hány gyermeke van?

0 ☐ nincsen gyermekem

1 ☐ van gyermekem (|\_|\_| gyermek)

## II. Betegséggel kapcsolatos kérdések

1. Diagnózis (daganat típusa): \_\_\_\_\_

2. Kockázata/stádiuma a diagnózisakor: 1 ☐ kis méretű tumor, még nem terjedt sehová  
 2 ☐ kissé nagyobb méretű tumor, csak a közeli nyirokcsomók

vagy szövetek felé terjedt

3 ☐ nagyobb tumor, s távolabbi nyirokcsomókra/szervekre is

átterjedt

4 ☐ nagy méretű tumor, igen távoli szervekbe is áttétet adott

5 ☐ nincs róla pontos információ

3. Diagnózis ideje: \_\_\_\_\_

|\_|\_|\_|\_| év |\_| hónap

4. Életkor a diagnózisakor: \_\_\_\_\_

|\_|\_| év

5. Kezelés befejezése: \_\_\_\_\_

|\_|\_|\_|\_| év |\_| hónap

6. Kezelés típusa: 1 ☐ kemoterápia

- hossza: |\_|\_| (hány hónap)

- típusa (protokol): \_\_\_\_\_

2 ☐ sugárterápia; hossza: |\_|\_| (hány hónap)

3 ☐ műtét; ideje: |\_|\_|\_|\_| év |\_| hónap

4 ☐ transzplantáció; ideje |\_|\_|\_|\_| év |\_| hónap

7. Volt-e visszaesés?

0 ☐ nem

1 ☐ igen; dátum: |\_|\_|\_|\_| év |\_| hónap

8. A betegségnek/kezelésnek vannak-e hosszú távú következményei? Ha igen, mik ezek?

0 ☐ nem

1 ☐ igen:

9. Járt-e valamilyen terápiás, segítő csoportba/pszichológushoz azzal a céllal, hogy támogatást kapjon ebben a helyzetben?

0 ☐ nem 1 ☐ igen

Ha igen, hova?

1 ☐ pszichológushoz a kórházban

2 ☐ pszichológushoz egyénileg

3 ☐ Bátor Tábor: - hányszor? |\_|

- milyen típusú táborban?

1 ☐ családi tábor

2 ☐ tesó tábor

3 ☐ nyári

tábor

4 ☐ egyéb tábor, ha igen hova: \_\_\_\_\_

5 ☐ csoport, ha igen hova: \_\_\_\_\_

10. Gyógyulása után részt vett-e valamilyen önkéntes, segítő tevékenységben? Ha igen, miben?

0 ☐ nem

1 ☐ igen:

## III. Társas Támogatás Kérdőív-1

Kérjük, gondoljon vissza arra az időszakra, amikor diagnosztizálták Önnél a betegséget, s kezelés alatt állt! Abban az élethelyzetben mennyire számíthatott az alábbiak segítségére?

Kérjük, hogy a válaszait a megfelelő szám bekarikázásával jelölje.

	Egyáltalán nem	Keveset	Átlagosan	Nagyon		Egyáltalán nem	Keveset	Átlagosan	Nagyon

1. szülő	0	1	2	3	6. segítő foglalkozású (pl. orvos, nővér)	0	1	2	3
2. iskolatárs	0	1	2	3	7. egyházi csoport	0	1	2	3
3. szomszéd	0	1	2	3	8. egyesület, segítő szervezet	0	1	2	3
4. barát	0	1	2	3	9. sorstársak	0	1	2	3
5. rokonok (édesanya, édesapa, nagyszülők, testvérek, más fontos rokon)	0	1	2	3					

#### IV. Társas Támogatás Kérdőív-2

**Nehéz élethelyzetben általában mennyire számíthat az alábbiak segítségére?**

Kérem, hogy a válaszait a megfelelő szám bekarikázásával jelezze!

A nem releváns választ csak abban az esetben válassza, ha az a forrás nem állhat rendelkezésére (pl. nincs házastársa, élettársa, stb.)

	Egyáltalán nem	Keveset	Átlagosan	Nagyon	Nem releváns
1. szülő	0	1	2	3	9
2. házastárs/élettárs	0	1	2	3	9
3. iskolatárs	0	1	2	3	9
4. szomszéd	0	1	2	3	9
5. munkatárs	0	1	2	3	9
6. barát	0	1	2	3	9
7. gyermek	0	1	2	3	9
8. rokonok (édesanya, édesapa, nagyszülők, testvérek, más fontos rokon)	0	1	2	3	9
9. segítő foglalkozású (pl. orvos, nővér)	0	1	2	3	9
10. egyházi csoport	0	1	2	3	9
11. egyesület, segítő szervezet	0	1	2	3	9

#### V. Poszttraumás stressz tünetek

Kérjük, gondoljon arra az időszakra, amikor gyermeke még kezelés alatt állt, vagy éppen befejeződött a kezelés! Minden tételnél jelölje meg, milyen gyakran voltak jellemzőek Önre ezek a megállapítások gyermeke akkori betegségével kapcsolatban.

	Egyáltalán nem	ritkán	néha	gyakran
1. Akkor is gondoltam rá, amikor nem akartam.	1	2	3	4
2. Nem hagytam, hogy felidegesítsen, amikor erre gondoltam, vagy emlékeztettek rá.	1	2	3	4



3. Próbáltam kitörölni az emlékezetemből.	1	2	3	4
4. Problémát okozott az elalvás vagy az alvás, mert képek és gondolatok jutottak eszembe róla.	1	2	3	4
5. Hullámokban erős érzések törnek rám az eseménnyel kapcsolatban.	1	2	3	4
6. Álmodtam róla.	1	2	3	4
7. Elkerültem az erre emlékeztető dolgokat.	1	2	3	4
8. Úgy éreztem, mintha meg sem történt volna, vagy nem a valóságban történt volna.	1	2	3	4
9. Megpróbáltam nem beszélni róla.	1	2	3	4
10. Képek jutottak az eszembe róla.	1	2	3	4
11. Más dolgok folyton eszembe juttatták.	1	2	3	4
12. Tudatában voltam, hogy még mindig sok érzésem van ezzel kapcsolatban, de nem foglalkoztam velük.	1	2	3	4
13. Próbáltam nem gondolni rá.	1	2	3	4
14. Bármilyen emlékeztető, visszahozta az ezzel kapcsolatos érzéseket.	1	2	3	4
15. Egyfajta tompaságot éreztem ezzel kapcsolatban.	1	2	3	4
16. Nehézségeim voltak a koncentrációval.	1	2	3	4
17. Ingerlékeny és dühös voltam.	1	2	3	4
18. Izgatott voltam és mindentől könnyen megrémültem.	1	2	3	4
19. Az eseményre emlékeztető dolgok heves testi reakciót váltottak ki nálam (pl. izzadás, nehézlégzés, émelygés, gyors szívverés).	1	2	3	4
20. Állandóan résen voltam és figyeltem.	1	2	3	4
21. Nehézségeim voltak az elalvással.	1	2	3	4

## VI. Poszttraumás növekedés Kérdőív

**Kérem, gondoljon gyermeke betegségére! Minden alábbi állítással kapcsolatban értékelje egy hatfokozatú skálán (0–5), hogy az adott változás milyen mértékben következett be az Ön életében gyermeke betegsége miatt.**

**Kérem, hogy a válaszait az állítások előtt található vonalra írja!**

0: nem tapasztaltam ezt a változást; 3: közepes mértékben tapasztaltam a változást;

1: nagyon kis mértékben tapasztaltam ezt a változást; 4: nagymértékben tapasztaltam a változást;

2: kis mértékben tapasztaltam a változást; 5: nagyon nagymértékben tapasztaltam ezt a változást

1.	Ez az esemény megváltoztatta a véleményemet arról, hogy mi fontos igazán az életben.	0	1	2	3	4	5
2.	Jobban értékelem a saját életemet.	0	1	2	3	4	5
3.	Új dolgok iránt kezdtem érdeklődni.	0	1	2	3	4	5
4.	Jobban bízom önmagamban.	0	1	2	3	4	5
5.	Jobban megértem a spirituális dolgokat.	0	1	2	3	4	5
6.	Tisztábban látom, hogy támaszkodhatok másokra nehéz időkben.	0	1	2	3	4	5
7.	Új irányt szabtam az életemnek.	0	1	2	3	4	5
8.	Közelebb érzem magam másokhoz.	0	1	2	3	4	5
9.	Inkább kifejezem az érzéseimet, mint korábban.	0	1	2	3	4	5
10.	Biztosabb vagyok benne, hogy képes vagyok kezelni a nehézségeket.	0	1	2	3	4	5
11.	Jobb dolgokra vagyok képes az életemben.	0	1	2	3	4	5
12.	Jobban el tudom fogadni a dolgok alakulását.	0	1	2	3	4	5
13.	Jobban értékelek minden egyes napot.	0	1	2	3	4	5
14.	Új lehetőségek nyíltak meg előttem, amelyekkel különben nem találkoztam volna.	0	1	2	3	4	5
15.	Jobban együtt érzek másokkal.	0	1	2	3	4	5
16.	Több erőfeszítést teszek a kapcsolataimért.	0	1	2	3	4	5
17.	Sokkal inkább törekszem, hogy megváltoztassam azokat a dolgokat, amelyek változásra szorulnak.	0	1	2	3	4	5

18.	Megerősödött a vallásos hitem.	0	1	2	3	4	5
19.	Rájöttem, hogy erősebb vagyok, mint gondoltam.	0	1	2	3	4	5
20.	Rájöttem, hogy milyen nagyszerűek az emberek.	0	1	2	3	4	5
21.	Jobban elfogadom, hogy szükségem van másokra.	0	1	2	3	4	5

## VII. Érzelemszabályozási Kérdőív

Az emberek sokféle dolgot tesznek és gondolnak, HA JÓL ÉRZIK MAGUKAT (BOLDOGOK). Kérjük, olvassa el az alábbi állításokat, és jelölje, hogy milyen gyakran – soha, néha, gyakran, mindig – gondolkodik így vagy tesz így, ha **BOLDOG (VIDÁM), IZGATOTT VAGY LELKES**. Kérjük, azt jelölje, ahogy általában gondolkodik vagy tesz, és nem pedig azt, ahogy Ön szerint tennie kellene.

Amikor jól érzi magát (boldog), milyen gyakran.....

(Minden sorban egy választ adjon!)	szint e soha	néha	gyak ran	szint e mind ig
1. ...észleli, hogy mennyire tele van energiával.	0	1	2	3
2. ...élvezi is az adott pillanatot.	0	1	2	3
3...gondolja, hogy “bármire képes vagyok”	0	1	2	3
4...gondolja, hogy kész vagyok bármit megtenni.	0	1	2	3
5....gondolja azt, hogy “az adottságaimnak/képességeimnek megfelelően élek”.	0	1	2	3
6....gondolja azt, hogy“ ez túl szép ahhoz, hogy igaz legyen”.	0	1	2	3
7. ...gondol arra, hogy mennyire jól érzi magát (boldog).	0	1	2	3
8. ...gondol arra, hogy mennyire erősnek érzi magát.	0	1	2	3
9...gondol olyan dolgokra, amik rosszul sikerülhetnek.	0	1	2	3
10. ...emlékezteti magát arra, hogy ez csak egy múló érzés.	0	1	2	3
11...gondolja, hogy “az emberek azt fogják hinni, hogy henecegek”.	0	1	2	3
12...gondol arra, hogy mennyire nehéz koncentrálni.	0	1	2	3
13...gondolja azt, hogy “mindent el fogok érni”.	0	1	2	3
14. ...gondolja azt, hogy “Ezt nem is érdemlem meg”.	0	1	2	3
15...gondolja azt, hogy “a szerencsesorozatom hamarosan véget ér”.	0	1	2	3
16...gondol arra, hogy milyen büszke magára.	0	1	2	3
17. ...gondol azokra a dolgokra, amik eddig nem sikerültek.	0	1	2	3

## VIII. WHO Jól-lét kérdőív 5 tételes magyar változata

Kérem, válaszoljon az alábbiak szerint:

0. egyáltalán nem jellemző      1. alig jellemző      2. jellemző      3. teljesen jellemző

Az elmúlt két hét során érezte magát...

1. ... vidámnak és jókedvűnek?
2. ... nyugodtnak és ellazultnak?
3. ... aktívnak és élénknek?
4. ... ébredéskor frissnek és élénknek?
5. ....a napjai tele voltak számára érdekes dolgokkal?

### 7.3 Normality and homogeneity of variance tests for the used measures in the retrospective study

#### 7.3.1 Appendix 7. Normality tests for the used measures in the sample of young adults.

	N	Min	Max	M	SD	Skewness		Kurtosis	
						Statistic	Std. Error	Statistic	Std. Error
SSQ: illness	53	6.00	24.00	17.79	4.23	-.873	.327	.631	.644
SSQ: in general	52	6.00	27.00	16.21	5.13	.153	.330	-.456	.650
IES-R: intrusive thoughts	51	.00	20.00	10.19	5.66	-.051	.333	-1.042	.656
IES-R: hyperarousal	51	.00	15.00	6.23	4.38	.398	.333	-1.070	.656
IES-R: avoidance	51	.00	22.00	9.98	5.20	.061	.333	-.642	.656
IES-R: total score	51	.00	54.00	26.41	12.80	.123	.333	-.396	.656
PTGI: Relationships	47	.00	4.86	3.29	1.15	-1.030	.347	.700	.681
PTGI: Appreciation of Life	47	.00	5.00	3.70	1.17	-1.131	.347	.993	.681
PTGI: Personal Strengths	47	.00	5.00	3.29	1.16	-.866	.347	.384	.681
PTGI: New Possibilities	47	.00	5.00	3.17	1.08	-.740	.347	.827	.681
PTGI: Spiritual Change	47	.00	5.00	1.79	1.59	.508	.347	-.793	.681
PTGI: total mean score	47	.00	4.86	3.18	.97	-1.078	.347	1.657	.681
RPAQ: emotion-focused rumination	46	.00	11.00	6.26	2.51	-.668	.350	.082	.688
RPAQ: emotion-focused rumination	46	.00	15.00	10.00	3.00	-.689	.350	1.475	.688
RPQA: dampening of positive emotions	46	.00	18.00	7.45	4.72	.450	.350	-.523	.688
WHO: well-being	46	.00	15.00	8.67	3.39	-.452	.350	.344	.688

### 7.3.2 Appendix 8. Normality tests for the used measures in the sample of parents.

	N	Min	Max	M	SD	Skewness		Kurtosis	
						Statistic	Std. Error	Statistic	Std. Error
SSQ: illness	112	2.00	27.00	17.65	4.85	-.479	.228	.403	.453
SSQ: in general	108	6.00	33.00	19.72	5.11	.056	.233	.099	.461
IES-R: intrusive thoughts	104	1.00	21.00	14.76	4.90	-.713	.237	-.253	.469
IES-R: hyperarousal	104	.00	18.00	9.71	4.52	-.046	.237	-.761	.469
IES-R: avoidance	104	.00	20.00	9.74	4.49	.008	.237	-.593	.469
IES-R: total score	104	5.00	57.00	34.21	11.01	-.232	.237	-.498	.469
PTGI: Relationships	100	.00	5.00	3.22	1.09	-.787	.241	.394	.478
PTGI: Appreciation of Life	100	.33	5.00	4.03	0.95	-1.416	.241	2.121	.478
PTGI: Personal Strengths	100	.00	5.00	3.29	1.20	-1.064	.241	.668	.478
PTGI: New Possibilities	100	.00	5.00	2.83	1.23	-.321	.241	-.489	.478
PTGI: Spiritual Change	100	.00	5.00	2.14	1.50	.094	.241	-1.072	.478
PTGI: total mean score	100	.14	4.90	3.15	0.98	-.764	.241	.581	.478
RPAQ: emotion-focused rumination	97	.00	12.00	5.79	2.60	-.008	.245	-.495	.485
RPAQ: emotion-focused rumination	97	.00	15.00	9.58	3.14	-.493	.245	-.070	.485
RPQA: dampening of positive emotions	97	.00	20.00	6.72	3.98	.627	.245	.382	.485
WHO: well-being	86	.00	15.00	8.83	3.75	-.168	.260	-.749	.514

### 7.3.3 Appendix 9. Homogeneity of variance tests for the used measures in the retrospective cancer study.

	Levene's Test for Equality of Variances	
	F	p
SSQ: illness	1.424	0.235
SSQ: in general	0.034	0.853
IES-R: intrusive thoughts	2.152	0.144
IES-R: hyperarousal	0.011	0.917
IES-R: avoidance	1.757	0.187
IES-R: total score	1.182	0.279
PTGI: Relationships	0.575	0.449
PTGI: Appreciation of Life	3.192	0.076
PTGI: Personal Strengths	0.062	0.803
PTGI: New Possibilities	1.601	0.208
PTGI: Spiritual Change	0.150	0.699
PTGI: total score	0.081	0.777
RPAQ: self-focused rumination	0.186	0.667
RPQA: emotion-focused rumination	0.466	0.496
RPQA: dampening of positive emotions	2.977	0.087
WHO well-being	2.814	0.096

## 7.4 Excluded variables in the stepwise regression modelling of the explanatory variables of PTGI in the retrospective study

### 7.4.1 Appendix 10. Excluded variables in the stepwise regression modelling of the explanatory variables of posttraumatic growth in the sample of young adult survivors of childhood cancer

Model		Beta In	t	p	Partial Correlation	Collinearity Statistics Tolerance
2	IES-R hyperarousal	.034	.213	.833	.037	.379
3	IES-R hyperarousal SSQ: illness	.020 .147	.126 1.111	.901 .274	.022 .187	.381 .526
4	IES-R hyperarousal SSQ: illness	.034 .134	.212 .992	.833 .328	.036 .165	.383 .529

	RPAQ: self-focused rumination	-.243	-1.513	.139	-.248	.358
5	IES-R hyperarousal	.050	.313	.756	.052	.385
	SSQ: illness	.096	.717	.478	.119	.547
	RPQA: self-focused rumination	-.212	-1.304	.201	-.212	.364
	Gender	.146	1.328	.192	.216	.798
6	IES-R hyperarousal	.066	.408	.685	.067	.387
	SSQ: illness	.028	.215	.831	.035	.618
	RPQA: self-focused rumination	-.194	-1.181	.245	-.191	.366
	Gender	.119	1.083	.286	.175	.817
	Age at diagnosis	-.201	-1.352	.184	-.217	.445
7	IES-R hyperarousal	.056	.337	.738	.055	.388
	SSQ: illness	.075	.586	.561	.095	.651
	RPQA: self-focused rumination	-.004	-.030	.977	-.005	.519
	Gender	.151	1.368	.179	.217	.847
	Age at diagnosis	-.204	-1.340	.188	-.212	.445
	RPQA: emotion-focused rumination	.245	1.758	.087	.274	.514
8	IES-R hyperarousal	-.009	-.051	.960	-.008	.405
	SSQ: illness	.106	.813	.421	.129	.664
	RPQA: self-focused rumination	-.043	-.292	.772	-.047	.530
	Gender	.196	1.830	.075	.281	.923
	Age at diagnosis	-.202	-1.282	.208	-.201	.445
	RPQA: emotion-focused rumination	.201	1.394	.171	.218	.525
	IES-R: avoidance	-.219	-1.870	.069	-.287	.770
9	IES-R hyperarousal	.012	.068	.946	.011	.407
	SSQ: illness	.168	1.313	.197	.203	.721
	RPQA: self-focused rumination	-.063	-.416	.680	-.066	.533
	Gender	.229	2.134	.039	.320	.956

Age at diagnosis	.054	.449	.656	.071	.852
RPQA: emotion-focused rumination	.172	1.145	.259	.178	.530
IES-R: avoidance	-.205	-1.676	.102	-.256	.773
Time since diagnosis	-.229	-2.009	.051	-.303	.858

#### 7.4.2 Appendix 11. Excluded variables in the stepwise regression modelling of the explanatory variables of posttraumatic growth in the sample of parents of childhood cancer survivors

Model		Beta	t	p	Partial Correlation	Collinearity Statistics Tolerance
<b>2</b>	Risk at diagnosis	-.030	-.251	.803	-.036	.924
<b>3</b>	Risk at diagnosis	-.030	-.252	.802	-.036	.924
	IES-R: avoidance	-.040	-.309	.759	-.044	.773
<b>4</b>	Risk at diagnosis	-.025	-.216	.830	-.030	.926
	IES-R: avoidance	-.040	-.309	.759	-.043	.773
	IES-R: intrusive thoughts	.135	.859	.394	.119	.513
<b>5</b>	Risk at diagnosis	-.021	-.180	.858	-.025	.929
	IES-R: avoidance	-.036	-.278	.782	-.039	.775
	IES-R: intrusive thoughts	.082	.560	.578	.077	.594
	RPQA: emotion-focused rumination	-.103	-.650	.519	-.090	.502
<b>6</b>	Risk at diagnosis	-.019	-.163	.871	-.022	.929
	IES-R: avoidance	-.070	-.543	.589	-.074	.796
	IES-R: intrusive thoughts	.086	.581	.564	.080	.594
	RPQA: emotion-focused rumination	-.115	-.715	.478	-.098	.503
	SSQ: illness	-.353	-1.729	.090	-.231	.299
<b>7</b>	Risk at diagnosis	-.012	-.100	.921	-.014	.935
	IES-R: avoidance	-.070	-.545	.588	-.074	.796
	IES-R: intrusive thoughts	.080	.543	.589	.074	.595
	RPQA: emotion-focused rumination	-.107	-.671	.505	-.091	.505
	SSQ: illness	-.035	-.303	.763	-.041	.958
	SSQ: in general	.090	.776	.441	.105	.954
<b>8</b>	Risk at diagnosis	-.017	-.141	.889	-.019	.936
	IES-R: avoidance	-.053	-.409	.684	-.055	.802
	IES-R: intrusive thoughts	.101	.678	.501	.091	.601



RPQA: emotion-focused rumination	-.122	-.753	.454	-.101	.507
SSQ: illness	-.026	-.218	.828	-.029	.960
SSQ: in general	.080	.682	.498	.092	.957
RPQA: dampening of positive emotions	.207	1.531	.132	.202	.698

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