

Making sense of resilience: A review from the field of paediatric psycho-oncology and a proposal of a model for its study

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Título: Explicando la resiliencia: una revisión desde la psico-oncología pediátrica y una propuesta de modelo para su estudio.

Resumen: En el presente artículo se pretende hacer una revisión del concepto de resiliencia desde el ámbito de la psico-oncología pediátrica. Se analizará su origen, sus distintas definiciones y adecuación de la misma aplicada al ámbito de las enfermedades físicas graves como el cáncer. También se tratará de diferenciar la resiliencia de otros conceptos como el crecimiento postraumático o los beneficios percibidos, comúnmente asociados o confundidos con ésta. Por último, se plantea una propuesta de modelo integrador de resiliencia en cáncer infanto-juvenil.

Palabras clave: resiliencia; cáncer infanto-juvenil; psico-oncología; crecimiento postraumático; beneficios percibidos.

Abstract: This article is intended to review the concept of resilience from the scope of paediatric psycho-oncology. The origin, its different definitions and its suitability of application in the field of serious physical illness – such as cancer – will be analyzed. Furthermore, the differences between resilience and other concepts commonly associated or confused with it, such as post-traumatic growth or benefit finding, will be discussed. Finally, a proposal for a comprehensive model of resilience in paediatric cancer will be put forward.

Key words: resilience; childhood cancer; psycho-oncology; post-traumatic growth; benefit finding.

Introduction: The concept of resilience

The term resilience comes from the Latin word “*resilio*” which means “*to go back*” (Kotliarenco, Cáceres & Fontecilla, 1997). Although the word “*resilience*” did not appear until recently in the Dictionary of the Royal Spanish Academy (Diccionario de la Real Academia Española), other Anglo-Saxon sources actually date it to ancient times (Munist et al., 1998; Oxford English Dictionary, 2009). However, the exact definition will always depend on the specific discipline in which it is used. Originally, the term resilience is understood to refer to the ability of a substance or an object to resist and bounce back into its original shape after suffering a blow or a deforming pressure (Kotliarenco et al., 1997). It is for this reason that it is a concept frequently used in physics, mechanics and metallurgy, and ultimately adapted by social sciences and humanities.

Historical development of the concept of resilience from the scope of social sciences and humanities

The classic works of Garmezy and his colleagues are considered to be the forerunners in the proposition and scientific study of resilience from the standpoint of psychology (Garmezy, 1971; 1974; 1993; Garmezy, Masten & Tellegen, 1984; Garmezy & Streitman, 1974). In the 1940's and 1950's, Garmezy developed a study group called “*Project competence*”, which included children at risk of developing psychopathology, from which they evaluated the role that determining factors such as personal confidence, self-esteem and auton-

omy could play in affecting their history and prognosis (Garmezy & Rodnick, 1959; Masten & Garmezy, 1985). As a result of his studies, the latter author offered a first definition of the concept, understanding it as “*a declaration of competence developed by children, in spite of their exposure to extremely stressful situations*” (Garmezy, 1993). Garmezy was already indicating that the terms *resilience* and *competence* were not equivalent terms. Competence is a term that describes a wide variety of behavior considered as adaptive. For its part, resilience would clearly be competence, but always in adverse situations. Garmezy asserted that one cannot speak about resilience without the presence of severe stress; it could perhaps be from the existence of a single, specific source of extreme stress (acute stress) – for example, natural disasters or the death of very close persons –; or perhaps through the successive accumulation of significant stressful factors (chronic stress), – for example, situations of extreme poverty, war or extremely severe illness (Garmezy, 1993) –.

Another key author who, like Garmezy, contributed to the historical development of resilience in psychology is the evolutionary psychologist Emmy Werner (Werner, 1989; Werner & Smith, 1982; 1992; 2001). Werner conducted a prospective longitudinal study with a cohort of 698 children born in 1955 in Kauai, a Hawaiian Island. These children lived in extreme poverty and grew up with alcoholic parents, parents who suffered from severe mental illness or who were unemployed without economic resources. In her study, Werner noted that once these children grew up, two thirds of them exhibit disruptive behaviors – such as substance abuse, unemployment or early pregnancies among girls –. However, in spite of everything, the remaining third of these children were able to adapt and show competent behaviors in adulthood. Werner called those in this group “*resilient*”. One of the obvious questions which arises from this work is: Why do individuals who have grown up in such adverse conditions manage to adapt so differently? Werner tried to

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answer this question by describing some of the key features of the young resilient group. Specifically, she noted that it was a question of one group of individuals who, despite having gone through a high-risk situation, had managed to function properly, in part, thanks to external support sources and to a certain inherent temperament, which she called “resistance”.

Both Werner and Garmezy constitute the first generation of resilience researchers who, opening the way to its study, tried to identify risk and protective factors in relation to adaptation after experiencing different severe adverse situations (Johnson & Wiechelt, 2004). Therefore, the origin of the study of resilience in psychiatry and psychology started when trying to understand the etiology and development of psychopathology, especially among children at risk for maladjustment (Cicchetti, 2003). Michael Rutter and Louis Murphy (Masten & Wright, 2009) also belong to this first generation of researchers interested in resilience. In the mid-90s new streams began to emerge focusing on several researches: firstly, trying to comprehend and explain different processes from which resilience arises (second generation of researchers); secondly, could resilience be promoted by means of different interventions? (third generation of researchers); and lastly, how resilience works across the life span of an individual, from the micro and individual levels to the macro and socio-cultural (fourth generation of researchers); (Masten & Wright, 2009).

Another important source of literature on resilience can be found in humanists' writings. In general, these are autobiographical accounts from people who have gone through various traumas or extreme experiences at some point in their lives, but who, nevertheless, have managed to survive and thrive physically and psychologically after such situations. We find, for instance, Boris Cyrulnik texts (Cyrulnik, 2002; 2004; 2005), a Russian Jew who at age of 6 escaped from a Nazi concentration camp where his parents died. After the war, Cyrulnik went through various youth centers, orphanages and foster families to finally end up in a charity farm. Currently, he is a highly regarded neurologist, psychiatrist and psychologist besides being considered the “father of human ethology”. In his writings, Cyrulnik explains not only his example but also that of many other people who, after experiencing extreme situations such as his, have been able to reorganize their lives and carry on successfully (Cyrulnik, 2002; 2004; 2005).

Another example, perhaps more famous and yet close to the Cyrulnik narrative, is that of Viktor Frankl (1905-1997), a renowned Viennese Jewish psychiatrist creator of the logotherapy. Frankl was imprisoned by the Nazis in 1942, deported and sent to Auschwitz and then to Dachau. Viktor survived this horror and on the 27th of April of 1945 was set free by the U.S. Army after losing his wife and parents in the concentration camps. After his release, he returned to Vienna and wrote the book “... trotzdem Ja zum Leben sagen: Ein Psychologe erlebt das Konzentrationslager” (Frankl, 1946) in which he describes his life as a prisoner (literal translation of the ti-

tle: “... saying yes to life: a psychologist surviving the concentration camp”). The English translation was first published in the States in 1959 under the title “*Man's Search for Meaning*”. In this book he argues that people can find meaning to their existence, even in the most extreme situations of dehumanization and suffering (for further explanations of the concept of resilience from a humanistic approach, see: Cyrulnik, 2001; 2004; Guénard, 2003; Manciaux, 2003; Vanistendael & Lecomte, 2002).

Current perspective of resilience and main definitions

Although we have already mentioned that from the social and human sciences scope and, specifically, from psychology, the concept of resilience has been used in a way that could be considered an analogy to its meaning in physics; to date, there is still no consensus with regard to its concrete definition. As shown in Table 1, we can find as many definitions as number of authors working in this field and, in some cases, some contradictions can be noted: personality trait versus behavioral pattern, process versus result, innate competence versus individual-environment interaction and a long list of discrepancies (Luthar, Cicchetti & Becker, 2000). However, although there is no agreed definition of resilience, some commonalities exist between different approaches.

All the definitions considered present two constants: on the one hand, the presence of an adversity risk, threat or intense stressful situation, whose key feature is a high probability that leads individuals to maladjustment; on the other hand, positive adaptation, usually defined as a cognitive-behavioral manifested competence with regard to a particular issue or the capacity to recover from a trauma. Both features constitute the essence of the construct of resilience.

The term “adversity” can designate a constellation of many risk factors or even a life situation with specific problems. Adversity can be objectively defined through standardized measures or expert criteria (e.g. healthcare professionals), whereas subjectively, adversity is defined by means of protagonist's perceptions and narratives of each situation. The definition of resilience provided by Luthar and Cicchetti could be considered an operative one: “*Adversity, also referred to a risk, typically encompasses negative life circumstances that are known to be statistically associated with adjustment difficulties*” (Luthar & Cicchetti, 2000, p.856).

In the present study, adaptation refers to the state in which an individual establishes a balanced relationship, lacking in conflicts with regard to his/her psychosocial context (also known as “psychological adjustment”). In many research of resilience, the mere absence of behavioral or emotional maladjustment in front of specific stressors has been considered positive adaptation or overcoming to an adversity (Luthar et al., 2000; Luthar & Cicchetti, 2000; Rutter 1990). However, positive adaptation includes both positive

outcomes after a potential trauma and the way the individual reacts and copes with a concrete situation. This may involve changes in the individual to adjust to the environment or

even, changes provoked by the individual in the environment to adjust it to him/her.

Table 1. Definitions of resilience.

Author(s) and year	Definition of resilience
Beardslee, 1989.	Ability to adapt and restore balance. It consists of self-confidence, curiosity, self-discipline, self-esteem and confidence over the environment.
Richardson, Niger, Jensen & Kumpfer, 1990.	Coping process of wrenching life events, stressful or challengers, in a way that provides the individual protection and additional coping skills, as compared with that previously resulting of a breakdown from the event.
Garmezy, 1991.	Ability to recover and maintain an adaptive behavior after abandonment or initial inability after stressful event happened.
Rutter, 1992.	Set of social and intrapsychic processes that enable a healthy life, living in an insane environment. These processes take place over time, giving lucky combinations between attributes of the child and his/her family, social and cultural environment. Thus, resilience cannot be thought of as an attribute, which children are born with, or that children acquire during their development. This would be an interactive process between them and their environment.
Osborn, 1993.	Generic concept that refers to a wide range of risk factors and results of competences (...), it is the product of a conjunction between environmental and personal factors.
Milgran & Pati, 1993.	Resilient children are defined as those exhibiting resilient adaptive coping, despite environmental stressors to which they are subjected in the formative years of their life.
Institute on Child Resilience & Family, 1994.	Ability to emerge from adversity, to adapt, to recover and to access a meaningful and productive life.
Vanistendael, 1994.	Resilience distinguishes two components. On the one hand, resistance to destruction, understood as the ability to protect one's integrity under pressure. On the other hand, beyond endurance, the ability to build a positive sense of life despite difficult circumstances.
Suárez, 1995.	Resilience refers to a combination of factors that enable a child and/or a human face and overcome the problems and adversities of life.
Grotberg, 1995.	Universal human capacity to cope with life's adversities, overcome them, and even turned out from them. Resilience is part of the evolutionary process and should be promoted since childhood.
Luthar, Cicchetti & Becker, 2000.	Dynamic process encompassing positive adaptation within the context of a significant adversity.
Fergus & Zimmerman, 2005.	Process of overcoming the negative effects of exposure to risk, successful coping with traumatic experiences, and the avoidance of negative trajectories associated with risk. In order to speak of resilience there must be present both risk factors and protective that, on balance, these help achieving a positive outcome, or reduce or avoid a negative outcome.

Source: adapted from Becoña, 2006 and Luthar et al., 2000.

Concepts related to the experience of trauma

Post-traumatic stress disorder (PTSD) and post-traumatic growth (PTG)

Several concepts have been related to experiencing traumatic situations and consequently, to resilience. In this section, we will address two constructs that have been occasionally considered as core elements of resilience, either by complementarity or equality – as the case of post-traumatic growth –, or by contrast – as in the case of post-traumatic stress disorder, which could be considered the antithesis of resilience –.

Post-traumatic stress disorder (hereinafter, PTSD) was introduced for the first time in the third version of the *Diagnostic and Statistical Manual of Mental Disorders* in 1980 (American Psychiatric Association [APA], 1980). This diagnostic category was meant to be applied to those individuals who, after being exposed to highly aversive, threatening or poten-

tially traumatic situations, suffered a complex reaction. This complex reaction follows certain patterns with specific features: re-experiencing the event (e.g. flashbacks or intrusive memories), exaggerated hypervigilance (e.g. irritability or difficulty in sleeping), and avoidance of internal or external stimuli associated in some way to the event (e.g. avoidance of certain thoughts or activities or difficulty remembering some aspects of the event). Furthermore, these features are followed by certain criteria of duration and intensity over time. Thus, the definition of trauma had two implied ideas. Firstly, it was a unique and extreme experience that would irremediably have psychological effects to any human undergoing it (e.g. overwhelming them or emotionally shaking them) and secondly, that for all these reasons, people who were “victims” of such events had to be protected.

However, epidemiological data show that in front of potential traumatic situations (no matter the nature of the event), the majority of those affected are able to display adaptive responses. The prevalence of PTSD does not usually exceed 5%. Moreover, a favorable evolution over time will

be showed since symptoms remit gradually in most cases (Miguel-Tobal, Gozález-Ordí & López-Ortega, 2002; Vázquez 2005; Vázquez, Pérez-Sales & Matt, 2006).

Clinical and health psychology models of vulnerability have been developed to explain human reactions in front of difficulties. Simultaneously, other type of models, usually called as “resistance” or “strength’s models”, have been developed to try to explain the mechanisms that activate a process of certain “immunity” in front of adversity. This new approach of human endurance in front of adversities carries a major change in the conceptualization of traumatic events. Either in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* [DSM-V; APA, 1994] and the revised version [DSM-IV-TR], a traumatic event is defined as: “all extreme human experience that constitutes a severe threat to physical integrity of self or others and in front of which, the common response is intense fear, helplessness or horror” (APA, 2000, pp. 518-525). Therefore, the idea of universality disappears and it is pointed out that not all the people (not even the majority of them) will react in a pathological manner in front of extreme adversity situations’. This leads to a growing body of research, which reveals that many trauma survivors also experience positive psychological changes after this experience. Different terms have been used to describe this phenomenon: *stress-related growth* (Park, Cohen & Murch, 1996; Park & Hegelson, 2006), *flourishing* or *thriving* (Ryff & Singer, 1998; Seligman, 2003), *benefit finding* (Affleck & Tennen, 1996; Harrington, Gurk & Llewellyn, 2008), *post-traumatic growth* (Calhoun & Tedeschi, 2006; Hefferon, Grealy & Mutrie, 2009) or *positive psychological changes* (Yalom & Lieberman, 1991), among others. One of the terms that has been largely accepted is *post-traumatic growth* (hereinafter, PTG), since it seems to adequately capture the idea that there is a “growth”, or a development beyond the level of functioning prior to the event. Moreover, the “post-traumatic” factor is also emphasized, referring to the change that occurs because of the event and not as a part of other minor stressors or as a part or other kind of personal developmental processes not related to the trauma itself (Zoellner & Maercker, 2006).

Following Richard Tedeschi & Lawrence Calhoun, two of the leading researchers in the field of PTG, this can be defined as “a construct of positive psychological change that occurs as the result of one’s struggle with a highly challenging, stressful, and traumatic event” (Calhoun & Tedeschi, 2006).

Regarding PTG, it should be considered that a normal response in front of a potentially traumatic or highly threatening situation is pain or negative feelings. The fact that some people could obtain certain positive values after experiencing a traumatic situation does not mean that they do not experience negative changes in other domains. This idea of coexistence of positive and negative emotions is very important to understand the genesis of PTG. At first, Calhoun & Tedeschi did not include the emotional element in their work, as they considered that PTG belonged to the cognitive. In other words, PTG is a process of reflection and an active search for meaning of the experience, as well as from

the new narrative of personal life story developed to integrate the experience.

However, in recent years, Tedeschi and Calhoun (Tedeschi & Calhoun, 2004), as well as other authors (Hefferon et al., 2009; Vázquez & Páez, 2010; Zoellner & Maercker, 2006), highlighted the major role of emotions in the development of PTG. In this sense, the coexistence of positive and negative emotions in the individual could be an essential requisite to experience PTG. Nevertheless, there are still few empirical studies that include both factors supporting this hypothesis (Aspinwall & Tedeschi, 2010; Bostock, Sheikh & Bartom, 2009). After the experience of a highly aversive event, the individual’s life can change, because his/her way of thinking and/or reacting can be modified. Change is usually the key element in the aftermath of trauma and this could imply both positive and negative consequences. Furthermore, it is not a universal response because not everyone will be able to learn from their own experiences. Hence, Calhoun and Tedeschi (Calhoun & Tedeschi, 2006) stated that undergoing a traumatic experience can generate three types of changes leading to PTG, not mutually exclusive, nor all of them required:

1. Changes in one-self. For instance, people report to feel stronger and more able to cope with difficult situations in life.
2. Changes in interpersonal relationships. For instance, increasing altruistic behaviors, feelings of intimacy, understanding or empathy for others’ suffering or even, strengthening social relationships.
3. Changes in spirituality or life philosophy. For instance, modifying conceptions or fundamental ideas from which a person has built his/her life (values, principles). This is the most commonly reported change. For many people, to be more conscious of their own mortality and finiteness offers them an opportunity to rebuild their life philosophy to a better one.

Different research has been focused on identifying personality traits that could foster or hamper the development of a positive change in the aftermath of trauma. Optimism (Bostock et al., 2009; Ho et al., 2010), hope (Ai, Cascio, Santangelo & Evans-Campbell, 2005; Ho et al., 2010), spirituality or certain religious beliefs (Ai et al., 2005; Cadell, Regehr & Hemsworth, 2003; Thombre, Sherman & Simonton, 2010), extraversion (Tedeschi & Calhoun, 1996), as well as a problem-focused coping (Bussell & Naus, 2010; Dirik & Karanci, 2008), are some features that most commonly have been associated to a high likelihood of PTG. It is generally assumed that most of the empirical evidence on the existence of PTG has been based from single-case studies with exceptionally mentally-strong or extraordinary people (Masten, 2001). Nevertheless, systematic research studies, that analyze larger samples, provide empirical evidences that this phenomenon is relatively common (Aspinwall & Tedeschi, 2010; Bostock et al., 2009).

It is important to note that sometimes PTG can be confused with resilience and, in fact, some authors consider both terms to be synonyms (Manciaux, 2003). In general, there is a trend called “French school”, because of its mainly French origins, that tends to consider both concepts as equivalents (Manciaux, 2003). However, it is worth remembering that a resilient response, as defined above, is the one that succeeds to achieve that the traumatic event does not interfere with the daily life of the individual, avoiding the experience of psychopathological symptoms (Luthar et al., 2000). In contrast, the PTG would imply a transformational element in the individual, characterized by a better performance compared to that prior to the traumatic event (Calhoun & Tedeschi, 2006). Moreover, in some cases PTG may even occur in the presence of functional and psychopathological disturbance.

Benefit finding

As discussed in previous sections, lately more attention has been paid to the fact that many trauma survivors experience positive consequences in the aftermath of trauma. This phenomenon is often interchangeably treated as PTG (*post-traumatic growth*) or as *benefit finding* (hereinafter, BF). This has led to several problems. Firstly, for many people, speaking on “growing” after a trauma could be unacceptable or even offensive. Secondly, the use of the term BF instead of PTG has been preferred in many occasions by healthcare scientific literature scope, due to the humanistic connotation of PTG and the few operational definitions of the term. Moreover, using the term BF facilitates a more operational definition and, at the same time, avoids the transformational features of the PTG. In other words, having positive consequences as a result of a traumatic event, it is not necessarily related to a higher performance compared to that prior to the trauma.

In this sense, research with childhood population exposed to traumatic or significantly adverse situations tends to use the term BF because of its substantial advantages compared to PTG. Due to the intrinsic characteristics of childhood and adolescence life stages, it would be extremely difficult to distinguish how many of the changes stated by the individual are explicitly due to the experience of the traumatic event itself, and how many changes are due to the maturation process typical to their developmental stage. Furthermore, depending on the age and their maturity, many individuals might not be able to differentiate what they were like before such event happened or they might not recall memories (Coyne & Tennen, 2010; Gorin, 2010).

Although the difference between one concept and the other is still a matter of debate (Kinsinger et al., 2006; Park & Hegelson, 2006), certain authors tend to assume that PTG is a type of perceived benefit (BF); (Kinsinger et al., 2006; Siegel, Schrimshaw & Pretter, 2005). Thus, in these studies BF is defined as: *the fact to find benefits (or positive consequences) in personal, social, psychological and/or spiritual domains, after having*

suffered a trauma or having experienced a highly adverse situation (Kinsinger, et al., 2006).

In several studies with patients having chronic diseases, a direct relationship has been found between the occurrence of BF and their general health status. Specifically, in one study there was an improvement in the prognosis of patients who had suffered a heart attack but reported BF (Affleck, Tennen, Croog & Levine, 1987). Other example is the reduction of mortality observed in HIV-positive men reporting BF (Bower, Kemeny, Taylor & Fahey, 1998). Although this relationship seems plausible, very few studies have analyzed the concrete mechanisms by which BF would act in improving overall health and quality of life (Barskova & Osterreich, 2009). It has been suggested that BF might be related to the fact of using a more adaptive coping or, in other words, using better coping strategies in front of adverse situations; ultimately, that would be what really influences overall health status of individuals (Barskova & Osterreich, 2009; Calhoun & Tedeschi, 2006).

Thus, the nature of BF could be interpreted from two different approaches. On the one hand, this can be seen as a *result* after displaying a set of coping strategies – what could lead to certain benefits despite the adverse situation. On the other hand, BF could be understood as a strategy itself (*process*). That is, the person would use this search of benefit to cope with the situation (Sears, Stanton & Danoff-Burg, 2003).

Resilience in health contexts. The specific scenario of psycho-oncology

Although initially research on resilience was focused on children experiencing traumatic situations and their outcomes in terms of adaptation, at present, resilience has become a construct susceptible to be applied to the entire life span of an individual (Melillo, Suárez-Ojeda & Rodríguez, 2004). Anybody, at any life stage and in any life domain, may face a highly adverse situation, which tests his/her ability to effectively cope and thrive. So far, the most studied adverse life events have been: parental divorce, extreme poverty situations, traumatic stressors such as abuse or harm (physical or psychological), abandonment, parental pathology, wars or natural disasters (Luthar & Cicchetti, 2000). However, since the 90s, severe diseases with vital threat were added to this list. Thus, in 1994, the fourth edition of the DSM included cancer for the first time and other serious medical conditions such as adverse events potentially related to adjustment difficulties.

At this point, it is worth noting that cancer differs markedly from other known stressors likely to cause PTSD (e.g. rapes, military combats, high-risk surgical procedures or natural disasters). Cancer is not a discrete event limited in time, on the contrary, it is a chain of stressful events which begins with the oncological diagnosis, extends along the whole medical treatment, therapies, rehabilitation and even in the

ulterior follow-up appointments after remission. Consequently, it is difficult to delimitate in time when the threat has already ended (see Table 2). On the other hand, unlike acute stressors, cancer is an event on which the patient and his/her social environment may exert certain control

measures (e.g. active participation in decision-making, management of the disease, etc.). Moreover, the precipitant stressor may vary from one individual to another and this may be unique or be composed by multiple variables related to the oncological experience.

Table 2. Differences between an acute traumatic event and cancer.

Element	Acute traumatic stressor	Cancer
Stressor	From simple and unobtrusive nature. The stressor is easily identifiable by the individual.	Complex in nature. The individual has difficulty identifying the stressor or set of stressors that cause traumatic response.
Source	Stressor of external nature with regard to the individual.	Stressor of internal nature with regard to the individual.
Temporary characteristics	The traumatic experience (its beginning and end) is clearly circumscribed in time (past a certain point the individual).	The traumatic experience is still present (current and future threat). There is a progressive and uncertain threat with threatening stimuli. The individual has difficulty defining the beginning and end of the traumatic event.
Perceived control	Low perception of control by the individual regarding to the nature and consequences of the traumatic event.	There is some perception of control by the individual regarding to the stressor (involvement in treatment, adherence to medical guidelines, monitoring, preventive actions, etc.).

Source: adapted from Sumalla et al., 2009.

It is commonly assumed that paediatric cancer is a potentially traumatic experience for both patients and their families. The set of stressors they will have to face throughout the disease process (e.g. physical threat, adverse effects, invasive medical-surgical procedures and separation from peer group and change in social and/or family roles), uncertainty about prognosis or relapse as well as possible late effects, put this population at high risk for experiencing psychological difficulties at both short and long term (Bragado, 2009). However, empirical evidences obtained in recent years seem to suggest that a high percentage of adolescents surviving childhood cancer do not have worse health-related quality of life (Castellano et al., 2009) or greater psychopathological disturbances (Bragado, Hernández-Lloreda, Sánchez-Bernards & Urban, 2008) than a healthy peer group with no history of cancer. Thus, to explain these outcomes, seemingly counterintuitive, it could be useful to adopt the theoretical framework of resilience. Although some models have been put forward to the study of resilience in adolescents exposed to adverse situations, many of these models are not very operational and still do not have enough empirical evidences supporting them (Haase, 2004; Noeker, 2012). Moreover, the authors of the current paper have no knowledge of models of resilience in childhood cancer or even in any other general models of resilience that have been proved suitable for implementation in paediatric oncology contexts. Finally, although psychological distress and social dysfunctions appear to be more the exception than the rule, there is scientific literature that documents such dysfunctions and this is something to be taken in consideration.

Post-traumatic stress disorder (PTSD) and paediatric psycho-oncology

Currently, in paediatric oncology a survivor is a young person – up to 18 years old – who has been diagnosed and

treated for a malignancy, and is currently free of disease (even if physical or psychological consequence exists) and free of oncological treatments for a period ≥ 2 -5 years (this last time criterion varies depending on the specific type of neoplasm). The standard period of 5 years is set as a reference to establish a relative long-term survival, because it has been shown that cancer recurrences are more frequent in the first five years post-diagnosis.

Several studies with adult samples have confirmed the suitability of using a PTSD research model to assess the psychological impact experienced by cancer survivors (Alter et al., 1996; Cordova & Andrykowski, 2003; Hobbie et al., 2000; Jim & Jacobsen, 2008; Kangas, Henry & Bryant, 2002; 2005; 2007; Rourke, Hobbie, Schwartz & Kazak, 2007; Smith, Redd, Peyser & Vogl, 1999; Taieb, Moro, Baubert, Lévy & Flament, 2003). Although less research has been carried out with childhood population, moderate to high levels of PTSD symptoms have been described in 5-20% of adolescent survivors of childhood cancer who had spent more than five years out of treatment (Alderfer, Navsaria & Kazak, 2009; Erickson & Steiner, 2001; Meeske, Ruccione, Globe & Stuber, 2001; Ozone et al., 2007; Wiener et al., 2006). These symptoms were characterized by avoidance of stimuli associated to the cancer experience, defensive personality, hospital anxiety, intrusive thoughts related to the disease and/or concerns about health issues (e.g. vulnerability and fear of recurrence). Additionally, survivors who suffered cancer during adolescence are more likely to experience post-traumatic symptoms in comparison to the group of survivors who had cancer in childhood (Hobbie et al., 2000). This could be explained because, during adolescence, the search for personal independence and autonomy is higher and cancer interferes with the success of such stage-developmental milestones (Castellano et al., 2010). Similarly, evidences of post-traumatic symptoms have been described (e.g. hypervigilance in front of possible signs or symptoms

of disease recurrence) in parents of paediatric cancer survivors when attending follow-up appointments once their children are free of treatment (Brown, Swain & Lambert, 2003; Bruce, 2006; Norberg & Boman, 2008; Ozone et al., 2007; Wijnberg-Williams, Kamps, Klip-Weebers & Hoekstra, 2006).

Post-traumatic growth (PTG), Benefit finding (BF) and paediatric psycho-oncology

Although there is research and several assessment tools aimed at exploring PTG in the paediatric population exposed to traumatic situations (Clay, Knibbs & Joseph, 2009), or even, specifically in adolescent survivors of childhood cancer (Park, Chmielewski & Blank, 2009), the vast majority of questionnaires and scales have been adapted from tools designed for an adult population. Thus, although many of these instruments have acceptable psychometric properties, to date, there are not enough empirical evidences to support their use in paediatric population (Clay et al., 2009). Therefore, it is required to develop more sensitive and specific measurement tools for childhood population exposed to an adverse situation. Only by doing this, it would be possible to determine to what extent growth has been the result of the traumatic experience, and to what extent as a result of the regular development and maturation of the adolescent (Clay et al., 2009).

Hence, it seems more appropriate to use the term BF in survivors of childhood cancer. Although recently, the study of BF has gained attention from the scope of psycho-oncology, most studies have focused on adult patients (Antoni et al., 2001; Bower & Segerstrom, 2004; Carver & Antoni, 2004; Cordova, Cunningham, Carlson & Andrykowski, 2001; Cruess et al., 2000; Lechner, Antoni & Zakowski, 2002; Lechner, Carver, Antoni, Weaver & Phillips, 2006; Lechner, Zakowski & Antoni, 2003; McGregor et al. 2004; Mols, Vingerhoets, Coebergh & van den Poll-France, 2009; Reiker et al., 1985; Sears et al. 2003; Thornton, 2002; Tomich & Helgeson, 2004; Weaver, Llabre, Lechner, Penedo & Antoni, 2008). The results of these studies have shown that most of the survivors report positive consequences such as: the development of closer bonds with relatives and/or friends, a more sensitive approach or greater interest in religion and/or spirituality, as well as a more positive life scope. However, there are also studies that do not find significant relationships between quality of life and perceived benefits (Tomich & Helgeson, 2004).

Despite these results, BF research with childhood cancer survivors' samples is still scarce (Castellano et al., 2010; Eiser

et al., 2000; Michel, Taylor, Absolom & Eiser, 2010; Phipps, Long & Ogden, 2007; Zebrack & Chesler, 2002). So far, obtained results suggest that the vast majority of adolescent cancer survivors are able to report both positive and negative consequences as a result of the oncological experience, with different effects on their quality of life and adjustment in survivorship (Engvall, Cernvall, Larsson, von Essen & Mattsson, 2011; Mattsson et al., 2007; Maurice-Stam, Grootenhuis, Caron & Last, 2007; Sundberg et al., 2009). One of the few scales that have satisfactory psychometric properties to assess BF in adolescent samples is the *Benefit and Burden Scale for Children* (BBSC: Currier, Hermes & Phipps, 2009) based on the *Benefit Finding Scale for Children* (BFSC: Phipps et al., 2007). However there is no Spanish adaptation for this scale – there is only a Spanish translation for Mexican population – and few studies have used it in childhood cancer survivors' samples so far (Maurice-Stam et al., 2010). For these reasons, the few studies that have addressed this issue have done it through semi-structured interviews or by means of selected items from other questionnaires.

Model of resilience in paediatric cancer

As a result of all the information from the section above, it can be concluded that there is not a single operating model for the study of resilience, and a lot less in the field of paediatric psycho-oncology (Haase, 2004; Noeker, 2012). However, a number of variables that have demonstrated to be linked to some extent with overcoming adverse events and health-related quality of life can be identified (Phipps, 2007; Teall, Barrera, Barr, Silva & Greenberg, 2012). These variables can come from either the paradigm of resilience or other approaches essentially based in cognitive-behavioral principles (e.g. positive psychology).

Assuming all of this, the current model of resilience in childhood cancer survivors will be based on the interaction of different variables that correspond to various individual and social characteristics that are attributed to people with resilient trajectories. In other words, features attributed to people showing adaptive patterns in front of significantly adverse situations will be considered. Hence, we propose to study resilience as a process that has specific characteristics, which from the experience of a threatening situation, univocally lead to a concrete result. That process or trajectory is incompatible with other two processes that depending on a different interaction of the variables considered, will lead to other results as indicated in Figure 1.

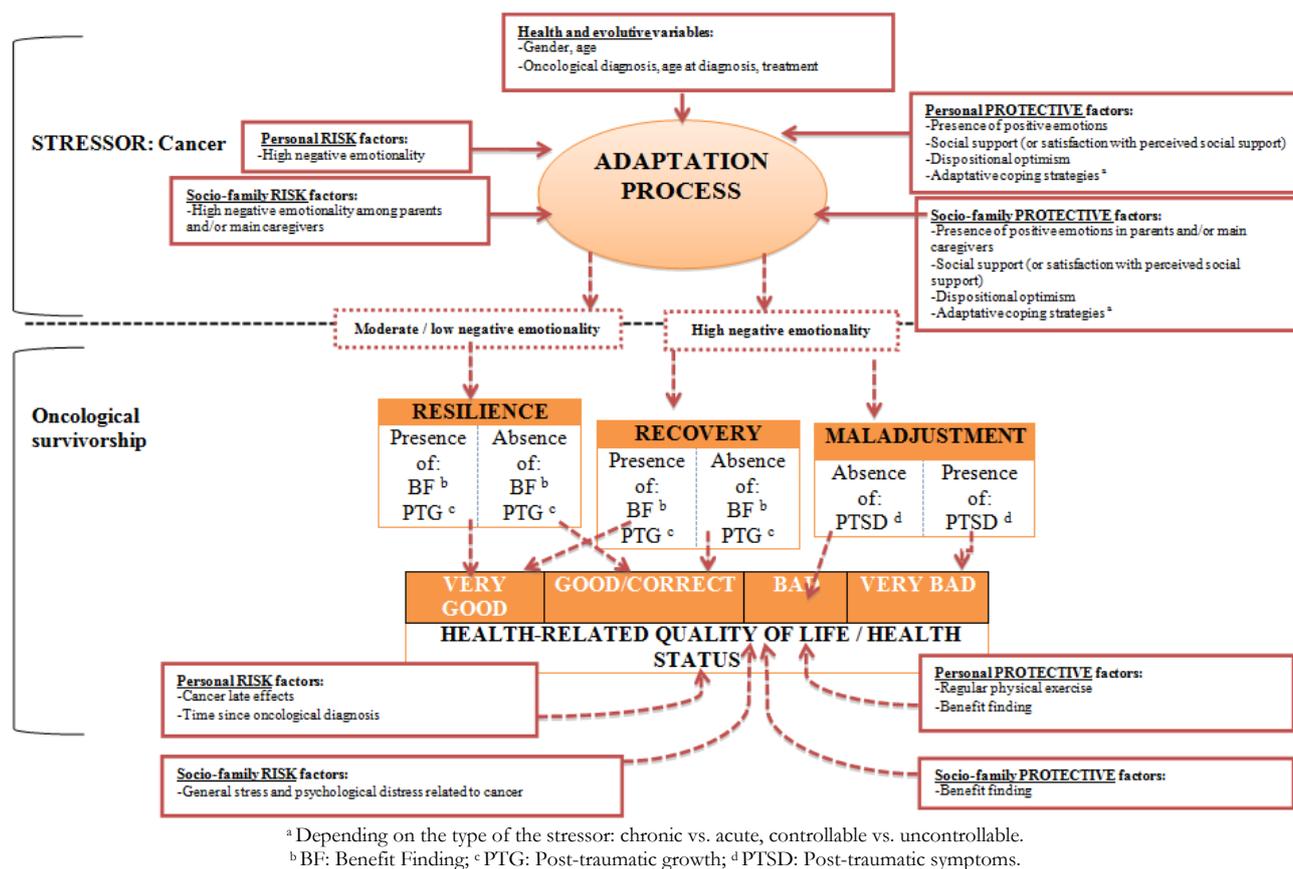


Figure 1. Resilience model in childhood cancer.

This model of resilience to the adverse event – the oncologic disease and its implications – classifies the assessed variables into risk factors and protective factors, both personal and socio-familial. The presence of these factors is divided in two stages: 1) during the illness (specifically focusing on the worst moment experienced) and 2) in the period of survival. As a result of the interaction between these factors, a different prototypical pattern of response is proposed, taking into account the interference level of the event in the daily life of the individual over time. These paths are the following: 1) Recovery, 2) Resilience, and 3) Maladjustment. Below, we will briefly describe each of these paths:

In a **recovery** path, the individual shows high negative emotionality in different critical moments of the oncological disease (e.g. at the time of receiving the diagnosis, when a relapse occurs). The individual could also suffer some dysfunction in different areas. However, once the stressor finishes or its intensity decreases, the individual is able to gradually recover his/her regular functionality. In the case that it happens during the hospitalization, a high negative emotionality could hamper, for instance, adherence to treatments, or even interfere with the relationship with his/her family and/or the health provider. On the other hand, if this high negative emotionality moment occurs at discharge – once

the adolescent is at home – this could interfere too with his/her daily functioning; for example, hampering the proper functioning of academic tasks, health guidelines or even interfering with social and family relationships.

In this path, is very common that across time the symptoms vanish and the person continues with the regular vital course, leading to a natural recovery process and not developing any disorder. According to some authors (Bonanno, 2004; Vazquez, 2005), the gradual recovery among the population that has been subjected to significant adverse situations is one of most common patterns (> 70%).

In the **resilience** path, the individual facing a potential traumatic event does not experience high negative emotionality at any time. That is, unlike the "non-resilient" (category in which individuals following a regular recovery pattern or in worst case scenario, a maladjustment path, will be included), resilient individuals could experience negative emotional states but their intensity will be moderate to low; managing to maintain relatively stable balance without affecting their performance and their daily lives (Vera, Carbelo & Vecina, 2006). In stark contrast to those who recovered gradually after a period of dysfunction, resilient individuals do not go through this period and its subsequent gradual recovery, but remain at suitable levels of functionality despite the traumat-

ic experience. Resilience is a widely observed phenomenon (e.g. in the study of life trajectories) but little systematic research has been conducted. Moreover, this research has been, in many cases, methodologically and conceptually inadequate (Held, 2004; Lazarus, 2003; Masten, 2001). Hence, although it seems it is a common phenomenon (> 50%) among people facing adversity (Bonanno, 2004), there is no reliable data on its accurate prevalence.

Finally, if the result is **maladjustment**, we will observe the case of an individual who has not been able to cope with the demands that the stressor has imposed. This situation will imply a high and persistent negative emotionality that would have a strong impact on their functionality, and which is plausible to endure even when the stressor is not present. This will prevent, in turn, the gradual recovery of its previous performance levels (e.g. that would be the case of an individual with post-traumatic symptoms). Epidemiological data indicate that less than 2% of individuals undergoing significant adverse situations end up having maladjustment (Miguel-Tobal, González-Ordi & Lopez-Ortega, 2002; Vázquez 2005; Vázquez, Pérez-Sales & Matt, 2006).

The possibility of perceiving certain benefits (*benefit finding*) after cancer experience has been described. Individuals recovering gradually and those following a resilient trajectory can show benefits. In this sense, that would be a concrete type of PTG.

In general, people following a resilient trajectory and/or of recovery, show satisfactory health-related quality of life and perceived health status outcomes; unlike what happens with those who show a maladjustment trajectory (Luthar & Cicchetti, 2000). In the last years, there is a growing body of empirical evidence in this field, as a result of an increasing number of studies on BF and PTG. It suggests that, among those subjects who report certain benefits and personal growth following the struggle against adversity, health-related quality of life results and/or health perceptions are more satisfactory than those who did not perceived any benefit (Lechner et al., 2006; Mattsson et al., 2007; Sundberg et al., 2009). However, results are not conclusive yet. In this model, BF and PTG have been considered as promoting factors for quality of life and adjustment after the oncological experience.

Similarly, it is also proposed that keeping healthy lifestyles, in particular, regular physical exercise (such as personal protective factor in survival) can counteract the possible side effects of cancer and its treatments (personal risk factor in survivorship), which, consequently, will promote health-related quality of life (Castellano et al., 2013).

Furthermore, because relevant scientific literature in this field documents a persistence of parental distress even when their children are in survivorship (Bruce, 2006), the model has also considered these variables as a socio-familial risk factor.

Discussion

Currently, several theoretical models to the study of resilience exist. However, most of these models do not have enough empirical evidence to support them. Consequently, it is not possible to establish which model or approach is presumably more valid. Additionally, some of them overlap or merge with other alternative models of traumatic experiences such as the PTG approach and the perceived benefits.

This little consensus among the different theoretical approaches regarding what are the core features of resilience and what are the processes operating to its existence, hinders its operationalization and assessment. Thus, it makes difficult to design research to explore the applicability of the term in different areas. However, for most of the researchers, the trend is to conceptualize resilience as the sum and synergy of individual, family and social protective and risk factors (internal, external and interpersonal resources); (Luthar et al., 2000; Masten & Powell, 2003; Masten & Wright, 2009; Vinaccia, Quinceno & Remor, 2012). From this perspective, it could be argued that, to effectively study resilience, it is essential to begin from operating, systematic and replicable models.

To date, we have no knowledge of childhood cancer survivors' resilience models developed that take into account all these considerations or that have been applied consistently and given sufficient empirical validation. The present research has provided a proposed integrative model of the concept of resilience in child and adolescent cancer, suggesting its heuristic potential to the rest of the scientific community. This model has already been subjected to various empirical analyses (Castellano et al., 2010; Castellano et al., 2011; Castellano et al., 2013) and the results support the major relationships postulated in it. Thus, several roles have been demonstrated. Firstly, coping strategies both personal and socio-family; secondly, social support; thirdly, healthy lifestyles, specifically physical exercise; and finally, BF after cancer experience with more resilient paths and better health-related quality of life in adolescent survivors of childhood cancer. It remains unclear whether or not more dispositional factors such as optimism (personal or family), post-traumatic growth (PTG), or the intensity of negative emotionality (personal and family) determine in some degree these trajectories. So there are still some aspects of the model that should be studied more thoroughly and subjected to empirical testing. Consequently, more research is needed with larger samples, in order to clarify the role of each of the variables included in the model, and their relationship to health-related quality of life and subsequent adaptation of the adolescent in survivorship.

Therefore a synergy is required among all researchers in the field, in order to establish what are the core elements of resilience in childhood cancer and what are the rest of complementary factors depending on the specific oncological

population studied (e.g. population of children, adolescents, patients in treatment, survivors, palliative patients, etc.).

In addition, if evidences regarding variables and processes that could lead to a positive adaptation in individuals with different problems are identified, more emphasis could be placed on them, thereby reducing disturbances that may arise from the experience of adversity, or even providing population with a number of tools and useful information to overcome or cope with adversity in a more adaptive manner.

In summary, the study of resilience, although relatively recent, lacks of a theoretical and empirical basis (Luthar et al., 2000; Vinaccia, Quinceno & Remor, 2012) and, as sug-

gested by the American Psychological Association (APA) through its "campaign of 10 steps" to promote resilience, it is very important for health and social sciences' professionals to believe in its existence and usefulness (for more details, please see the following link: <http://www.apa.org/helpcenter/road-resilience.aspx>).

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