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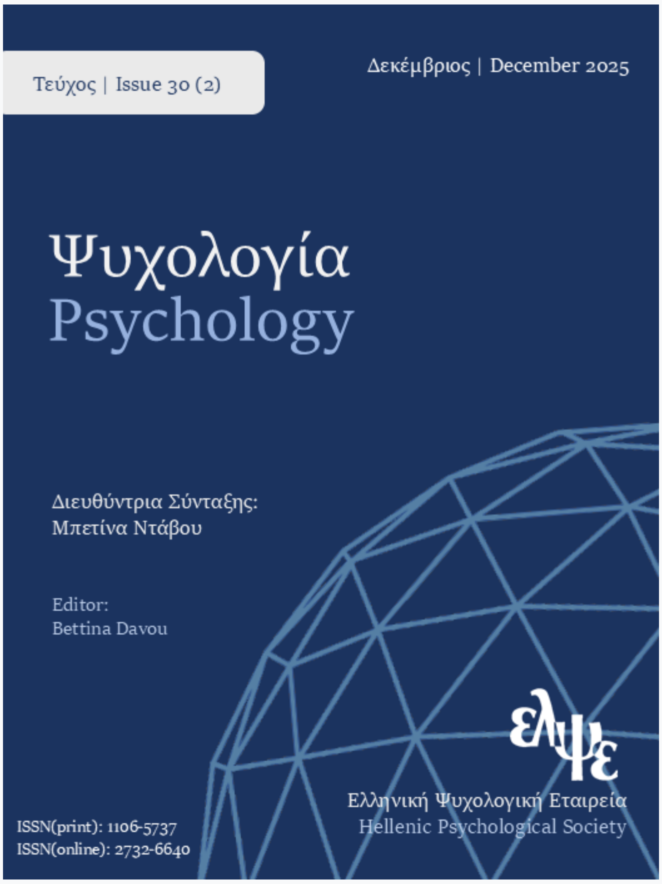

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ΕΜΠΕΙΡΙΚΗ ΕΡΓΑΣΙΑ | RESEARCH PAPER

Surviving adolescent cancer: Narratives of disruption and identity reconstruction

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KEYWORDS

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ABSTRACT

The present qualitative study adopted a narrative approach to explore the experiences of young adult survivors who had been diagnosed with cancer during adolescence. We conducted 24 narrative interviews with eight survivors aged between 18 and 25 years old - three interviews with each one of them. The participants' stories were analyzed through a thematic narrative analysis and the main thematic units that emerged are: (a) dealing with a fragile body, (b) renegotiating lost time, and (c) making meaning of illness. The participants' narratives indicate that experiencing cancer during adolescence triggers a rupture in terms of the continuity of temporality. Thus, the identity of survivors is woven around the experience of the illness and is mediated by a long course of challenges–both during the disease, as well as returning to a state of "normality". A common theme of the narratives is the approach of illness as an experience that activates inner forces and leads to the construction of a new meaning in life, along with the creation of a new identity. The findings can inform clinical practitioners highlighting the need to approach cancer not as a life event that is time-limited and ends with the completion of treatment, but as a condition leading survivors to the need for negotiation of pain, body image, relationships and the identity as a whole.

> *"In unconscious fantasy, growing up is an inherently aggressive act".* [1]

Winnicott's statement aptly reflects the severity of the changes that occur during the physical and mental development of the individual. These changes become further complicated by the appearance of a serious disease during critical developmental stages, such as adolescence. The onset of cancer induces challenges causing a disruption of the individual's biography (Hubbard & Forbat, 2012; Johnson, 2022; Le Boutillier et al., 2019), as it places the adolescent in a condition of high dependence on their parents, suspending the negotiation of autonomy-individuation processes (Mack et al., 2019; Smits-Seemann et al., 2017). Adolescents who are diagnosed with cancer face dependency, passivity and helplessness, as well as a loss of autonomy. At the same time, the invasion of physical integrity, extreme losses, and weakening produced by pain might have a traumatic character (Cook et al., 2021; Güner, 2018).

The most psychologically challenging stages are diagnosis and transition to survivorship (Hughes et al., 2024; Kim et al., 2018; Kwak et al., 2013). Despite the large increase in the number of people who survive cancer in adolescence (Keegan et al., 2024), survivors are likely to face a range of adverse late consequences as a result of the disease and the required treatment, which may affect their health-related quality of life (Cho et al., 2024; Walker et al., 2019).

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[1] Winnicott, D. W. (1971). Excerpt from the book *Playing and Reality,* p.144. Tavistock.

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Survivors typically report that the transition to survivorship is followed by a decrease in social support and the presence of unfulfilled needs (Baird et al., 2019; Wong et al., 2017). The survivors' needs are mostly focused on treatment, rehabilitation, future monitoring of their health, their ability to survive, make sense of the presence of the disease in their life, concerns linked to interpersonal relationships, social roles, body image, and sexuality (Mayer et al., 2017; Pahl et al., 2021).

In addition to physical or mental symptoms, adolescent cancer survivors report experiencing social alienation due to the disease, both during and after treatment (Sawyer et al., 2023; Walker et al., 2019; Warner et al., 2016). In fact, some patients must be isolated during important phases of treatment, such as during the transplant phase, because of the hazards to their health in case of a virus infection. Consequently, these teenagers not only lose their social ties with family and friends, but they are also forced to avoid school, play, and interaction with other hospitalized patients (Husson et al., 2017; Pennant et al., 2020).

Following the completion of treatment, survivors report a variety of social and emotional difficulties (Echo et al., 2016; Hughes et al., 2024; Jones et al., 2020). Cancer survivors confront emotional and practical challenges to their social well-being, such as returning to school, education, and employment (An & Lee, 2019; Elsbernd et al., 2018; Walker et al., 2019). In fact, some survivors indicate that upon completion of treatment, they no longer belong to the social group of "patients", but they also do not feel part of the "healthy" group (Cantrell & Conte, 2009), feeling alienated and expressing a great longing to belong somewhere. Furthermore, young adults appear to be seeking the survivors’ identity in order to be distinguished as such (Cho & Park, 2015; Steinberg et al. 2020). The desire for an identity based on survival is linked to improved adaptability and a basis for personal growth (Grinyer, 2009; Steinberg et al., 2020). Young survivors exhibit an interest in joining support groups and keeping contacts with other peer survivors (Bender et al., 2022; Walker & Lewis, 2016).

Moreover, an important issue for this population is the potential of discrimination and rejection that survivors may encounter upon return to the community after completing treatment. Cancer and its treatment can leave visible signs, such as hair loss or scars, as well as invisible signs, such as the stigma associated with cancer and its treatment (Bonanno & Esmaeli, 2012; Thomson et al., 2020). These problems can impair young survivors' capacity to engage with others, causing social adjustment issues that can persist into adulthood (Brinkman et al., 2016; Pahl et al., 2021).

Adolescent and young adult survivors are also at significant risk for developing psychological problems such as mood and anxiety disorders (De et al., 2020; Dewar et al., 2021; Osmani et al., 2023). The severity of the disease can influence future plans and how patients perceive their goals (Docherty et al., 2015; Ghazal et al., 2021). Furthermore, research has demonstrated that treatment depending on its kind, duration, and intensity, functions as a potential predictor of eventual psychological effects (Bradford, 2022; Kwak et al., 2013).

While numerous studies focus on identity disruption during therapy, few look at how identity evolves over time after treatment. There is little understanding of how survivors reconfigure their sense of self when they transition into adulthood (Morris et al. 2014; Prikken et al. 2023; Sansom-Daly & Wakefiled, 2013). Understanding these processes is crucial for providing developmentally appropriate psychosocial care to adolescents and young adults. While qualitative studies highlight the importance of meaning-making and personal narratives, there remains a lack of longitudinal and cross-cultural research on how survivors integrate illness into their life story (Quinn et al., 2015).

Aim of the Present Study

Taking into account the importance of the mental and psychological components of the developmental process during adolescence, and the gaps in previous research, the aim of the present narrative study is to illuminate the subjective processes through which survivors make sense of their illness trajectories, negotiate the discontinuities by the cancer experience, and reconfigure their sense of self and temporality in the post-treatment phase. In line with this objective, the current study aims to explore the following research questions:
(a) How do young adult survivors of adolescent cancer narrate the psychological and relational dimensions of their illness experience?
(b) In what ways does cancer during adolescence disrupt normative psychological development and perceived life continuity?
(c) How do individuals draw on personal narratives to make sense of their illness experience and reconstruct their identity in its aftermath?

Method

A narrative perspective

The present perspective is grounded in the recognition of narrative approach as a central framework for understanding how individuals symbolize, structure, and negotiate lived experience. As a method, the narrative approach is based on storytelling to investigate how people make sense of their experiences (Riessman, 2008). It acknowledges that narratives are more than reflections of experience; they are constitutive acts through which people shape their realities, construct coherence in the face of disruption, and position themselves in relation to others and cultural discourses (Frank, 2013; Murray, 2015). Given the dynamic, non-linear nature of cancer, psychological understanding is best accessed through the survivor's own unfolding life story. Rather than relying on standardized measures or structured interviews, this perspective values personal narratives as essential in capturing the complexity of disruption and the ongoing reconstruction of identity.

Participants

The sample was selected using the "snowball" method (Creswell & Creswell, 2017), which is based on social networking. Although this method does not allow control by the researcher, it is a useful approach, based on specific features that meet the purposes of the research. Prior to the main part of the interview, three pilot interviews were conducted aimed at familiarization with the process and identification of modifications that could be required.

Eight participants were selected, so that the study could analyze each narrative as a whole, but at the same time highlight the possible similarities and differences between the narratives. All participants are young adults, aged between 18-25 years old, who have survived cancer diagnosed during adolescence. The sample includes four men and four women, all living in Athens. Some basic descriptions of the participants are contained in Table 1, where pseudonyms have been used to protect the participants' anonymity.

The interviews were conducted at the Hellenic Cancer Society between May and July 2020. Three meetings were held with each participant, where each meeting was dedicated to the free narrative of life before, during and after the illness respectively. The interviews for each participant took an average of four hours. The study was approved by the Ethics Committee of the Psychology Department at the National and Kapodistrian University of Athens (May, 2020).

Table 1 *Participant demographic characteristics*

Name	Age	Diagnosis	Age of Diagnosis	Studies
Ion	19	Lymphoblastic Leukemia	11	Institute of Technology
Chrysa	25	Type-B Lymphoma	14	Institute of Technology
Manos	20	Osteosarcoma	11	Institute of Health Sciences
Maia	23	Osteosarcoma	13	Institute of Philosophy
Antonis	19	Cerebellar Myeloblastoma	11	Health Science
Agni	23	Acute Myelogenous Leukemia	14	Institute of Philosophy
Cleo	19	Ovarian Cancer	11	Institute of Philosophy
Panos	20	Acute Myelogenous Leukemia	13	School of Science

According to the principals of ethical guidelines for psychology research, all participants were given a written consent form to inform them about the purpose of the study, and their rights of anonymity, confidentiality of information and the process of storing and handling data.

While the data in this study were gathered some years ago, the ongoing nature of the phenomena under consideration assures that they remain relevant. More recent studies in the subject reveal that cancer experiences and the arisen psychological processes remain rather stable throughout time (Baudry et al., 2024; Bradford et al., 2022; Tanner et al., 2023). Furthermore, the qualitative approach used in this study yield rich, context-specific insights that are not diminished with time. This study provides data that remain crucial for understanding how the experience of cancer during adolescence is imprinted on the life course, enriching the current scientific discussions regarding this field.

Data collection and Procedure

A narrative interview design (life story / biographical narrative interview) was used (Riemann, 2003; Svašek & Domecka, 2020). The biographical narrative interview is an unstructured interview process, in which the participants are asked to narrate in a free and unplanned way their life story as a whole or for a period, recalling important experiences, events and people who are important to them. This method is ideal for investigating how people develop their identities and perceive significant life experiences like illness, trauma, or transitions (Riessman, 2015).

For the objectives of the proposed research, this method was modified to appropriately cover the three-time axes of the biographical trajectory required: (a) the period preceding the disease, (b) the illness experience, and (c) the present and future projections. As a result, each participant had three meetings, each of which focused on their life story along one of these three-time axes. The participant chose the timeline for each meeting at his or her discretion. This advice to separate the meetings, with each one devoted to a timeline of their lives, appeared to help the participants organize their narratives more effectively. However, it was noticeable from all of the stories that this direction was not completely "followed", since elements of the illness period intruded in various ways in all meetings.

More specifically, each meeting was structured based on three sub-sections. In the first part (main narrative phase), the researcher invited the participants to narrate, beginning with the phrase: "I'd like you to tell me about your life, including all events and experiences that have been meaningful to you. Each of our meetings will focus on one of the following timelines: (a) your life prior to the condition, (b) your life period from diagnosis to treatment completion, and (c) your current situation and future plans. Start from whichever period you like. Take the time you need. I will listen and not interrupt. I will only take a few notes for later". In the second part of each interview, the researcher requested additional information about the issues raised in the initial narrative, following the order in which they were described, as well as the verbatim phrases previously used by the interviewee, reintroduced by the researcher to invite clarification and deeper explanation (follow-up question phase). In the third section, participants were invited to provide assessments, evaluations, and comments on numerous subjects related to the research theme that were not stated.

To ensure methodological rigor, the study followed established quality criteria for qualitative psychological research, including transparency, reflexivity and coherence (Levitt et al., 2017; Braun & Clarke, 2021). Pilot interviews were used, while multiple interviews per participant facilitated temporal triangulation, and thematic narrative analysis was conducted collaboratively, with attention to both content and structure. Reflexive journaling and peer debriefing were also employed to enhance credibility and trustworthiness.

Data Analysis

The study adopted a narrative thematic analysis (Riessman, 2008), to preserve the sense of the history as "whole", and provide the opportunity to gain access to the common experiences and the dialogue between participants' life stories. The analysis of the interviews followed an inductive approach. The recorded material from the interviews of each participant was read several times in an attempt to approach the material as a whole. Following a re-narration process, narratives were initially developed for each participant. These accounts were subsequently subjected to comparison in order to identify overarching narrative themes.

In the final phase of the analysis process, the material was synthesized in order to allow "a meta-narrative to emerge" **(**Riessman, 1993, p.15). An attempt was made to keep the content of the results interpretively close to the authentic speech of the participants, without ignoring the significant influence of the individual context (theoretical, experiential, and professional) of the researchers on the interpretation of the material (Willig, 2013).The narratives presented are not aiming to portray representative positions for generalization, but at establishing a theoretical framework that helps to gain a deeper understanding of the complexity and importance of the life stories of adolescent cancer survivors.

Taking into consideration the extended body of collected data, it was difficult to decide which material would be finally presented and in what way. This dilemma was best framed when we accepted that whatever decision we made, the material presented will be "snapshots" and "pieces" of the participants' lives, which will always contain at the same time our own understanding and interpretive approach.

Results

The participants narrated their life stories through rich and personally reflective narratives:

The story of Solon. Solon "*the argonaut of time*", who was diagnosed with acute lymphoblastic leukemia. Solon describes himself as the overprotected family member, as well as an "adult child" who stands out from the others. For him, the disease offers an opportunity to reconsider concerns about friendships and larger family relationships. In terms of interpersonal functioning, he appears to sustain relationships but struggles to trust or believe in the concept of a 'best friend'.

The story of Chrysa. Chrysa was diagnosed at the age of 14 with type-β lymphoma. She describes that before the disease she lived in a " typical" family, where relationships were calm and children were cared for. Chrysa describes herself and other children with cancer as "*children living in a fishbowl"*, an image she used in her drawings when she was a patient to illustrate how a child in aplasia feels. Nevertheless, she remembers the disease as a "good memory" and expresses gratitude for its appearance.

The story of Manos. Manos was diagnosed with osteosarcoma in his right leg at age 11 and underwent multiple surgeries and chemotherapy treatments. He describes himself as a reactive child who frequently argued with his brother, enjoyed taekwondo, football, and the piano, was the youngest member of the family, and was known as "the child of Alexia" (his mother). He believes that his cancer experience is a vital component of his identity, a 'part' of him.

The story of Maia. Maia is a 23-year-old girl, who was diagnosed with arm osteosarcoma at the age of 13. Maia points out that her physicians and parents did not initially inform her about the disease's identity. She discusses her inclination to 'look' tough, not react, and to silently bear bodily procedures, complications, and even amputation. Although she is comfortable discussing her story, she prefers not to bring it up when engaging with new people since she does not want to be associated with it.

The story of Antonis. Antonis was diagnosed at the age of 11 with cerebellar myeloblastoma. He describes the onset of the disease, particularly the delay in diagnosis, emphasizing that he was an introverted child who did not communicate about anything and felt it was pointless. The illness was the "best time", a "pleasant break" for him, and he believes it brought about some positive adjustments in his life. It took him years to adjust to school following the treatments since he felt he had 'missed episodes' and was unable to form relationships readily. Isolation from his peers is viewed by him as the 'price' of the illness, prompting him to seek out circles of more 'delinquent' children engaged in power games, which let him feel like he 'belonged' somewhere.

The story of Agni. Agni was diagnosed with acute myelogenous leukemia at the age of 14. Agni recalls being transferred to the oncology department without being aware of her diagnosis. When she returned to school following her treatments, she struggled to adjust and realized she was on a different path than other teens. Reflecting on the disease, she emphasizes that it is a part of her life that she would not change, albeit she confesses that she wishes she had experienced "these years as normal children do".

The story of Cleo. Cleo was diagnosed when she was 11 years old with right ovarian cancer. She wasn't aware of her condition until she began losing her hair. In the beginning, she reports being withdrawn and unaffected by people’s attempts to change her mood. After completing her therapeutic cycle, she believed she had matured in a short period of time and lacked the "craziness" those other youngsters possessed. The acceptance she felt from her peers, who made her feel like a 'hero,' helped her overcome her feelings of 'badness' about herself. When the treatments were completed in the first period, she was not particularly preoccupied with thoughts about her experiences of the illness, but this came later, when she began to reflect upon what happened and what had changed.

The story of Panos. Panos was diagnosed at the age of 13 with acute myelogenous leukemia. When describing himself as a child, he mentions the "bullying" he endured because of his huge stature and the "extra weight" he constantly carried. During his childhood, he recalls having a strong attachment to the "Harry Potter story" and his magical abilities. Growing up, he naturally contrasted this series with "Game of Thrones," which he saw as a more realistic portrayal of life. At this point, he was looking for risk, claiming that "you are closer to death, you feel more alive". In the hospital, he recalls continually listening to a song with the lyrics "Don't cry, don't be afraid". When he returned to school, he had a tough time reintroducing himself to his peers. Today, he hopes to begin working as a stand-up comedian, a dream he has long held.

Conducting the above-mentioned analytical steps, the thematic analysis of the collected narrative material produced the following thematic units: (a) dealing with a fragile body, (b) renegotiating lost time and (c) making meaning of illness

Dealing with a fragile body

The first thematic unit emerges from the participants' descriptions of their hospitalization and the therapeutic treatments. It is a time span that ranges from a few months to a few years that enters an individual's life in an unexpected way, disrupting its previously linear flow. In this topic unit, participants recall and describe their hospital and treatment experiences. The narratives emphasize two aspects of the hospitalization and treatment processes: (a) the experience of the suffering body, and (b) changes in body image and how the individual perceives and processes them.

The Experience of the Suffering Body. By initiating their narration from the moment of diagnosis onwards, participants describe many scenes from the states of physical pain and the difficulties of motor functioning they experienced. An indicative experience is described by Solon, who describes a scene where he was attempting to walk while having considerable difficulty:

> I remember it because this period hurts me. They told me "you have to get up to walk," but it felt like Golgotha. When I got up, I screamed in pain, and the entire room could hear me. I recall yelling the standard "I hate you all and I want to leave" remark that every child uses.

Solon portrays a dramatic experience, highlighting how his physical frailty had left him in a situation of helplessness, which seemed to trigger aggressive sentiments. Furthermore, the difficulties of this situation are also reflected in other descriptions of Solon, where talking about the side effects of a series of vaccines he uses words associated with death, as shown in the following excerpts:

> Then I had to go through a series of immunizations that destroyed a small portion of your body in order to start over. By the end of the third week, I defecated and vomited, and by the fourth week, I was entirely dead. I believe it was a red medication dubbed "red devil" that acted. I actually had seven things, which I recall as the "7 curses of Pharaoh."

This section of his narrative concludes with a description of himself as a "corpse," accompanied by images of a violent attack ("to kill") on the body, a body that cannot cope with it; and the ambiguous "poison-medicine," which, on the one hand, enters the body to save and regenerate it while, on the other hand, appears as an invasion, causing oral reflux. This experienced attack on the body appears to elicit aggressive fantasies, as Solon refers to the drug as a "red devil" while also perceiving the side effects on his body's internal function as "Pharaoh's curses", implying an external source for the attack, but one with supernatural dimensions.

In their narrations, other participants also describe their motor difficulties, which included both immobility and feelings of pain. This state of disability, even if temporary, is a loss of physical integrity, affecting a person's self-care ability, leading to parental dependence. Chryssa's description is revealing: “I remember being unable to walk following the first round of chemotherapy. I used a stroller and was supported by my mother, as if I were a little baby. It was like learning to walk from the beginning”. Similarly, Maia points out that “after the amputation, I had to go through chemotherapy again, which was painful. I mean, after I finished again, I had to learn to walk from scratch since I couldn't move my legs correctly”.

These personal descriptions suggest that individuals had to relearn their bodies while in the hospital. The reduced physical capacity not only impairs function but is also related to a sense of losing control.

Thus, diminished functionality, a sense of loss of control, and the commonly accompanying social isolation can all lead to feelings of mental discomfort, anger, and frustration

Body Image and the Gaze of the Other. The participants elaborate on the changes in their appearance and body image, emphasizing the impact on their identity. Initially, all participants identified hair loss as one of the most significant physical issues they encountered. For example, Chryssa describes:

> Meanwhile, my first tuft was gone and my sister gazed at me, horrified. While I was looking at that first piece of tuft, I told her, "Okay, bring a ribbon," and then we decided to cut it totally, making it more masculine. I began wearing hats. I simply wore the wig to see friends at a party since I didn't want to answer any questions.

These recalled memories indicate the experienced wound of body image, which becomes more apparent in the presence of the "other". These descriptions also highlight the significance of hair loss as a physical indicator of femininity. Chryssa alludes to the "masculine" haircut she needed, yet her hair, a narcissistic weave with tufts-holes, demonstrates the disintegration of her body image and femininity. Another participant, Agni, expresses the difficulty in mirroring these changes in body image in a unique way, stating:

> Mirror? To see what? I didn't have hair, and I didn't need it; my mother could see me, but I didn't mind. It was also a moment when my clothes were generally not fitting me; buying new ones makes little sense because you will gain weight again.

Furthermore, participants stated that the physical changes they underwent made them feel exposed and vulnerable, particularly when the changes were prominent and visible to others. Some participants report their perceived "distorted" body image, which was caused by either their own opinion of themselves or the reactions of others, making it more difficult for the patients to accept their body image. Manos highlights the importance of developing a variety of abilities that will allow him to cope with others' gazes:

> The worst thing I had to deal with, was people turning around staring at me while knowing they were thinking, "What's wrong with him, why is he limping?" That was perhaps one of the most difficult experiences I've ever had. I could see, feel, know, and understand it when someone looked at me.

Overall, survivors mention their bodily changes during and after hospitalization, their difficulty in mirroring and assimilating this new body image, and their desire for acceptance by their family or other individuals with a supportive function. They recall, however, that this ambition resulted in disappointments, as they were frequently met with curiosity or rejection by others, who saw them as unusual and foreign.

Renegotiating lost time

Adolescents with cancer are absent from school for extended periods of time because of prolonged hospitalization, exhaustion, and the danger of infection. This interval can range from a few months to several years. The analysis of the participants' narratives revealed the psychological and relational processes that occurred following the patient's return after finishing therapy. Sub-themes that arose in relation to this axis were (a) changes that participants observed in themselves as well as how they were seen by their peers, and (b) how they dealt with teenage concerns.

The Self: Re-introducing Oneself. Children and adolescents with cancer miss a lot of school because of therapies, long hospital stays, and the danger of infection. The prolonged absences and hospitalizations give the impression of a separate life cycle. This distinction is recognized in connection to their peers, as well as their personal path up to that point. As a result, when patients return home after completing the main part of their therapeutic cycle, they will experience a variety of changes. For example, Manos claimed that when he went home, he was "someone else":

> My cousin told me, "When you returned, you were a completely different person". "You were not the person we knew before". Within eight months, everything had changed. I knew it, of course, but she told me so. I was more introverted and thoughtful. She stated that I was "lost in my world".

Manos describes a process of self-rupture because, after experiencing the illness, he changed and appeared more introverted and preoccupied with inner thoughts. The disease accelerated his maturation and introduced him to a more adult perspective, leading to a shift in how he perceived himself in comparison to his peers. Such difficulties are clearly represented in his description: “I was watching them doing stupid things, childish things, teenage stupid things and I was wondering: "Why would you do this?". I couldn't get along with kids my age. What I saw in the hospital made me reconsider everything.”

Other individuals, including Antonis, have described similar changes. Antonis notes that returning home and school, he found it more difficult to make friends and blend in. He relates this shyness with his protracted absence, which caused him to "lose episodes," resulting in a "gap" between his own trajectory and that of his classmates. As a result, the condition increased his shyness and made it harder for him to form relationships.

> I felt like I was still in fifth grade because I had missed a few major episodes. It appears that I had lost experiences of adolescence. I absolutely felt normal, but different in the sense that I didn't have social relationships; I still have some troubles, possibly due to the gap.

The participants report how, when they returned to school, they noticed disparities with other children their age. The return to everyday environments—such as home and school—is not a return to normalcy, but rather a transitional period in which people must rethink their social roles and personal identities. Their stories imply that surviving entails more than just physical healing; it also entails the continual psychological process of bridging the "gap" between one’s past and current identities in order to achieve a cohesive post-illness identity.

Adolescence Under Inhibition. In general, the narratives describe a "freezing" of adolescent-related concerns. Adolescent patients depart from the route of autonomy, over-investment in appearance and sexuality negotiation that is common among their age group. Participants discuss a delay in experiencing adolescence, which either occurs considerably later or is not felt by the patient even in later phases of life, according to Agni.

> Until high school, I felt like a child. Then, between the ages of 20 and 23, I expended all of my energy and longed to break out. My mother disliked it when I was coming back home in the morning, and I went through this stage as a university student, but I always used the phrase "let me go, I'm having an outburst".

The challenges being negotiated during adolescence come up after the teenager has completed therapy and a lengthy period has passed since the onset of the illness. In general, most participants express the opinion that "they did not pass through adolescence," which is significant given adolescence's role in an individual's physical and psychosexual development. Such descriptions are provided by participants, such as Manos, who states: “I don't believe I went through these adolescent experiences; instead, I believe I skipped them and moved on; that is, I overcame adolescence psychologically, which matured me much faster and caused me to take things more seriously”. Correspondingly, Panos explains: “My growth had ceased following the disease; my height was 1.88 at the time, and it is still 1.88 today. I'm not sure if leukemia contributed to my lack of beard or muscle growth because of the abrupt halt in growth during that period”.

Participants emphasize that they have not experienced adolescent challenges met by other peers. Initially, their bodies had stopped developing due to chemotherapy, which prevents the outward symptoms of puberty such as hair growth and menstruation. Furthermore, adolescent patients avoid school and outdoor activities where they would normally engage with their classmates. At the same time, they rely heavily on their parents for fundamental needs, which impedes their capacity to gradually separate themselves and become self-sufficient.

Therefore, in the present narratives, the non-linear experience of time and the negotiation of basic development processes are outlined, as time for some issues seems to freeze, suspend or even return to earlier phases, while also, it seems that time accelerates and promotes an early process of adulthood.

Making meaning of illness

A key dimension of the experience of illness concerns the way in which it is interpreted and acquires a personal meaning for the patient. In participants' narratives it appears that the perception of illness is dynamic with its meaning evolving over time. As a result, its presence is reflected in various ways from the moment it appears until the moment when the survivors engage in discourse about it. The narratives reveal (a) the participants' meaning-making processes in regard to how their medical condition was generated, (b) their perception of illness as an empowering experience, and (c) identity concerns associated with illness.

Answers about the Underlying Causes of the Disease. The onset of illness necessitates the need to make sense of its origin, which may serve as a function of control, rationality, and purpose. Thus, participants describe how they perceive the disease to have occurred, and outline how the illness is inscribed in the subject's biography, with components of life before cancer - personal, familial, or intergenerational - appearing to play an important role. For example, Cleo explains that the tumor in her ovary was her 'twin sibling', which she had absorbed during her mother's pregnancy, and so emerges in her adulthood as a 'tumor in her own ovary':

> I had no idea that youngsters got such issues, and I was used to it with the older ones, so I was like, "Why would I get it now?" Have I done anything in my life? That was how I took it at first, but then I stopped wondering and decided that since it happened, I'd deal with it. My mother was always carrying twins with me, and at some time I absorbed the other one, which is how the tumor formed. And it was to be. It expanded and became visible over time.

The body in the participant's case is described as bisected, since its twin half has been removed along with the cancer. In this way, the patient is fighting against the threat of fragmentation. At the same time, another participant, Sotiris, blames the emergence of the illness on his parents, the habits in the family and a poorly understood (according to him) over-protectiveness of the parents, which eventually brought about the opposite outcome and "made their child sick":

> I blame them entirely for this; if you see your child's weight deteriorating and you have essentially caused him a health problem as a result, and he tells you, he asks you to exercise somewhere, why don't you let him do so? With their overprotectiveness, they almost lost their child for me.

The participants' attempts to explain the causes of their illness reveal a deeper psychological urge to give meaning, coherence and personal agency to an otherwise unpredictable and terrifying situation. For some, like Cleo, meaning-making is embodied and mythologized, blending personal and ancestral narratives, while for others, like Sotiris, casual attributions are emotionally and relationally shaped, serving, in both cases, a way to navigate blame, vulnerability, and responsibility. This theme emphasizes how young survivors draw on personal, intergenerational, and psychological information to place the illness inside a meaningful framework, underlining the importance of narrative in transforming pain into a story that can be shared, comprehended and emotionally contained.

Illness as a Battle and a Source of Empowerment

Participants who have lived through the illness report how they now view it, how they make meaning of it as an experience, and where it fits into their broader biographical trajectory. These descriptions depict a process of reframing the experience, acknowledging the major issues it presented while also emphasizing its role as a source of personal empowerment and a defining experience for the subject's life and identity.

The illness at some points appears in a "warlike" context, in which the patient faces a real life battle, where he or she is not placed in a passive position, but demonstrates an active - combative attitude towards the illness, as Manos points out: “It's a battle for life, everyone fights for his life I think; some harder, others weaker, we all fight. You have to be combative too, to accept, to listen, to be patient. It's a struggle even to smile”.

So, at this point, Manos depicts the disease as a problem that calls for active combat, referring to something idealized that reminds us of mythical heroes who triumph in continual conflicts. These are allusions that alternately represent fundamental aspects of teenage difficulties, such as the need to identify with idealized others. The heroic victory is not confined to a war that demands physical power (although the "battle" in the event of illness is also waged with the body), but also includes a battle that requires the activation of inner vitality.

On the other hand, most participants emphasize the general appreciation of disease as an occurrence that contributed positively to the path of life, as evidenced in the Cleo’s account: “I admire me for that. In the back of my mind I have an admiration for my little self... How I made it through that. ... for my little big self”, or Antonis, when he refers: “I believe it had a great impact on my life. All of that. It characterized my life. It's not necessarily a good thing, but this is my life” Accordingly, Manos gives a similar description:

> "Sometimes I miss them. I'm not sure what I miss. I surely do not miss chemotherapy. I'm not sure, but I remember them not with fear or hatred, but with joy and love, and when I think about them, I say, "Look what I went through back then; I can do even better."

Participants tell their experience, incorporating elements of triumph and victory in a challenging life journey from which they emerged victorious and ready to face any future challenges. The participants rely on metaphorical language, emphasizing the notion of illness as a conflict, and then juxtapose the old with the new, what existed prior to the illness and what was recreated afterwards. Participants' discourse emphasizes the supportive role of disease in the pursuit of an 'ideal' and 'empowered' self. Illness, thus, appears to operate as a milestone for identity reshaping, with components of greater maturity, mental resilience, willingness to face obstacles, and an identity more solid, more mature, possibly in early adulthood, coming from the difficulties of this experience.

Identity within and beyond cancer. A significant part of the narratives focusses on how participants positioned themselves in the context of their disease, building or reconstructing their identity. By emphasizing the reflexive but also 'regenerative' dynamics of illness, as documented in the previous section, this thematic section focuses on the processes of making sense of the illness emergence in order to synthesize present identity. Thus, what is stressed in the narratives is not whether changes in regard to the prior personality are positive or negative, but rather that the new identity fully incorporates the illness into the individual's life while also moving beyond it.

Manos points out how he marks the experience of illness as part of his life and the place of this experience in his present life, emphasizing that it continues to have a central imprint in his life:

> I don't view cancer as a problem, and I'm not going to run away from it because I had it and it harmed me, but I survived, and I'm going to battle it more directly. No, I regard it as a part of my identity; I am who I am, the person I am now, and I can't get away from it.

Maia talks about how she currently perceives herself and the illness as an experience inscribed in her overall biographical trajectory. First, she emphasizes her urge to highlight and re-constitute herself through components of her personality that transcend the restricted bounds set by the cancer patient's identity. Survivors do not misrecognize or forget their experience, but instead seek to portray and define themselves through components other than their illness experience:

> Some years ago, I would introduce myself to someone and say directly, "Hi, my name is Maia, and once we started talking about ourselves a little bit, I would mention that I had cancer and so on." Now, if you ask me what caused your arm loss, I may address it, but if I start talking about myself, that will not be one of the first things I say. I have much more to say about myself than saying, "My name is Maia, and I had cancer," since it does not define me.

The experience of disease is described as a 'rupture' that allows the patient to reconstruct a new identity, with the experience of illness playing a significant role. However, survivors are not pleased with this. The condition of rupture they are experiencing triggers meaning-seeking processes in which they reconsider their entire life, their perceptions of themselves, and their relationships with others. In this ongoing introspection, people end up wanting to identify themselves as ''carrying the experience of disease'' while also ''carrying many other components and experiences'' that characterize them. Meanwhile, they highlight illness's auxiliary function in the search for a 'ideal' and 'empowered' self.

Discussion

The present study provides insight into how young survivors reconstruct their adolescent cancer experience through narratives. The participants' life experiences were constructed with a central focus on illness, which is positioned as a period of rupture as well as restructuring and restoration at the intrapsychic and intersubjective levels.

The use of life-story interviews in this study provided considerable methodological and conceptual benefits. Given the study's emphasis on identity disruption and reconstruction, the life narrative style allowed participants to recount their experiences in the context of their lives – before, during and after the illness – shedding light on how cancer incorporated into their developing sense of self. The open and temporally broad structure of the life story interview encouraged depth, emotional richness, and thought, allowing complex processes like blaming, myth making and biographical re-anchoring to emerge. It also gave participants choice over how their story was delivered, which bolstered the study's narrative approach and highlighted the active role of the self in meaning-making. In this setting, the life story interview emerged as a particularly valuable tool for capturing the lengthy, multifaceted and frequently conflicted psychological effects of surviving adolescent cancer.

Findings indicate that the disease diagnosis, symptoms, pain, changes in appearance, and side effects of treatments are perceived as a physical and psychological crisis during which time expands and appears to occupy a magnified part of the subject's biographical course. These descriptions are better understood taking into account the central importance of the acceptance of the body image for the process of identity formation. These narratives are consistent with studies showing that children and adolescents with cancer perceive their appearance as abnormal, ugly, weak, and unattractive, comparing their body's condition to how it used to be or to the bodies of their peers (Brierley, 2019; Zucchetti et al., 2017). This sense of difference stems not only from the attitude of others, but also from an inner perception of difference and the inability of the adolescents to find people with whom they can identify (Fern & Whelan, 2013).

The loss of physical integrity acts as a narcissistic wound, and the subject's reaction appears to be shaped by the presence of the 'other': The 'other' is sometimes portrayed as capable of creating a supportive environment for the adolescent, while other times he/she appears as a witness to the loss process. The disease brings the patients face to face with many losses, which causes a withdrawal or an attempt to "hold" from someone. The patients search for a relationship, an experience of being recognized or mirrored. This importance of the family and peer support is indicated in similar studies, regarding the need of satisfaction of practical and emotional needs (McDonnell et al., 2020).

Furthermore, participants' narratives show that the cancer experience is complex in terms of the sense of temporality in patients' lives, which is consistent with findings from corresponding research (Andersen, 2022; Tindle et al., 2018). This component of the returning home is crucial since it impacts the individual's perception of normalcy (Belpame & Verhaeghe, 2019). Patients recognize that a gap has been created between themselves and their classmates, as they sometimes believe that the demands of their experiences have forced them to mature and that they can no longer operate in a more childish / adolescent manner. In other circumstances, they believe they have stagnated, which makes it difficult for them to rejoin their peer group.

The condition seems to have an impact on the position, quality, and perception of relationships, as well as serving as a marker for re-evaluating earlier relationships (Kent et al., 2012). Thus, the participants underline that after their illness, they reassessed the significance and position of their parents, siblings, and friends in their life. Furthermore, the participants' reports of a diverging life course from the rest of their peers, reflect their sense that they did not experience adolescence, as the separation processes are delayed and experienced later, during the first years of adulthood. Finally, narratives are used as a process that makes it easier to distance oneself from the lived experiences, to better understand, to be introduced to a process of meaning-making and to reduce emotional distress.

Under these conditions, the identity of the survivors and their later life is woven around their experience of the disease, based on which they may be presented as winners, a goal in the end of a “bumpy” challenging road. The discontinuity, caused by the event's traumatic nature, creates a temporal crisis that might "block" present and future projections. Studies on survivor transition experiences reveal similar difficulties encountered when returning and attempting to reclaim one's old identity (Darabos & Ford, 2020). Cancer as a disease is not an event that occurs in a definite or short period of time, but a disease that continues to be present, even when treatment is completed, as it can bring about physical and mental changes that continue to exist for a long time, after the treatment.

The findings of the present study can inform and enrich clinical practice, highlight the need to approach childhood and adolescent cancer not as a life event that is limited in time, as the bodily trauma leads to the need for negotiating pain, body image, relationships and the identity as a whole. Using stories as a helpful resource for counselors, therapists, and doctors, it is clear that we must enable the building of a new narrative meaning that fits the traumatic event into a broader life narrative, with a focus on processing "towards" a new meaning. At the same time, support groups -through the process of meaningfully restructuring terms as "normality" and "health"- can provide a framework for searching and addressing issues concerning both their interpersonal relationships and future plans.

However, this research contains some limitations that are worth noting. Specifically, the sample does not provide the basis for broader generalizations. Narrative research is a type of research based on individual cases. Of course, in accordance with Bryman, case studies include “generalizations in theoretical propositions” (Radley & Chamberlain, 2001, p. 324), which are to some extent transferable and can be reduced to broader concepts of social processes. At the same time, the present study was conducted by taking three interviews with each participant, where all interviews were conducted at the same period of time. It would also be helpful to conduct a longitudinal study that could analyze the evolution of meaning-making and identity negotiation processes, when survivors proceed to later stages of their lives. The limitations of the present work do not deprive it of its value, but functions as an open field that invites new approaches, changes, modifications and compositions.

The advent of cancer, as evidenced in the participants' narratives, breaks the smooth trajectory of life and the sense of self-continuity, triggering a variety of identity-formation processes. The current accounts retrospectively conveyed cases of biographical rupture, as well as their introduction to meaning-making processes, which highlight characteristics of biographical reconstruction. Indeed, the narration of lived experience supports this process, which in this case, by incorporating the period before and after the disease, allows for the connection of various life experiences and the understanding of how they are inscribed in the subject's present life.

Overall, it appears that by focusing on the narrative of experiences and acknowledging them within a context of empathic understanding-in which experience is re-temporalized-survivors were introduced to a process that improves the meaning-making of their experiences as well as reflective processes of psychic processing. Thus, a meaning is formed that connects the past, present, and future. The participants' life stories were built around the central axis of disease, which is positioned as a moment of rupture, as well as rearrangement and reconstruction on an intrapsychic and intersubjective level. The emergence of components of the participants' overall life stories calls for an approach to cancer disease that is not only traumatic, but also one in which themes of previous psychological trauma are transferred, translated, and revisited.

Competing Interests

The authors have declared that no competing interests exist.

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ΕΜΠΕΙΡΙΚΗ ΕΡΓΑΣΙΑ | RESEARCH PAPER

Εμπειρίες επιβίωσης από καρκίνο στην εφηβεία: Αφηγήσεις ρήξης και ανασυγκρότησης ταυτότητας

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ABSTRACT IN GREEK

Η παρούσα ποιοτική μελέτη υιοθέτησε μια αφηγηματική προσέγγιση για να διερευνήσει τις εμπειρίες νεαρών ενηλίκων επιβιωσάντων που είχαν διαγνωστεί με καρκίνο κατά την εφηβεία. Κατά τη μελέτη πραγματοποιήθηκαν 24 αφηγηματικές συνεντεύξεις με οκτώ επιβιώσαντες ηλικίας μεταξύ 18 και 25 ετών - τρεις συνεντεύξεις με τον καθένα από αυτούς. Οι ιστορίες των συμμετεχόντων αναλύθηκαν μέσω μιας θεματικής αφηγηματικής ανάλυσης και οι κύριες θεματικές ενότητες που προέκυψαν είναι οι εξής (α) όταν το σώμα ευθραστοποιείται: σωματικές, ψυχικές και σχεσιακές συνιστώσες της νοσηλείας, (β) επαναδιαπραγμάτευση του «χαμένου χρόνου» και (γ) διαδικασίες νοηματοδότησης και διαπραγμάτευσης της ταυτότητας σχετικά με την ασθένεια. Οι αφηγήσεις των συμμετεχόντων υποδεικνύουν ότι η εμπειρία του καρκίνου κατά την εφηβεία προκαλεί μια ρήξη όσον αφορά τη συνέχεια της χρονικότητας. Έτσι, η ταυτότητα των επιβιωσάντων υφαίνεται γύρω από την εμπειρία της ασθένειας και διαμεσολαβείται από μια μακρά πορεία προκλήσεων - τόσο κατά τη διάρκεια της ασθένειας όσο και κατά την επιστροφή σε μια κατάσταση «κανονικότητας». Κοινό θέμα των αφηγήσεων είναι η προσέγγιση της ασθένειας ως εμπειρίας που ενεργοποιεί εσωτερικές δυνάμεις και οδηγεί στην οικοδόμηση ενός νέου νοήματος στη ζωή, μαζί με την ανασύσταση μιας νέας ταυτότητας. Τα ευρήματα της παρούσας μελέτης μπορούν να αξιοποιηθούν σε κλινικό επίπεδο, αναδεικνύοντας την ανάγκη προσέγγισης του καρκίνου όχι ως ένα γεγονός ζωής που είναι χρονικά προσδιορισμένο και τελειώνει με την ολοκλήρωση της θεραπείας, αλλά ως μια κατάσταση που οδηγεί τους επιβιώσαντες στην ανάγκη διαπραγμάτευσης του πόνου, της εικόνας του σώματος, των σχέσεων και της ταυτότητας στο σύνολό της.

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