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The Palliative Function of Narrative for Children with End-Stage Cancer and the Psychopoetics of Resilience.

Aliki Chiotaki³⁶

Summary

The present study focuses on the multiple palliative function of narrative in the frame of the palliative care for children with end-stage cancer. Narrative of today can be a useful tool in the psychologist's hands to meet children's psychological and spiritual needs, to appease fears and to give clear and honest answers to their anxious questions facing death and illness. Narrative is helpful for the support of the whole family and of the caregivers, volunteers and health professionals and a way to encourage the activation of resilience in all these people. With the basic criteria of the intercultural quality and of the credibility and preciseness we have chosen four stories written by authors who as parents have a personal experience of the loss and illness or have performed a thorough investigation of the subject. These stories serve as a model to explain the possibilities of the narrative for the support of the little patients and of their parents and caregivers. For the general public, these narratives can serve as a source of information and familiarization with an innovate interactive biopsychosocial model of care, based on participatory type and useful for all people, patients and caregivers, children and adults alike.

Keywords: Children with end-stage cancer, Narrative in children's care, Resilience, Models of medical care, Palliative care.

A. Objection of the Study

The main propose of the study that follows is to examine and determine the importance and multiple supportive and beneficial functions of narrative in the frame of palliative care provided to children with end-stage cancer. Specifically examined are the benefits the use of storytelling can provide to young cancer patients, their family members, and especially to their siblings, but also to caregivers, be they professionals

³⁶ Psychologist, Tailor Ed Foundation, 11 Maritime Street, Leith, Edinburgh, EH6 6SB, UK
Tailoredfoundation.co.uk
Tel: 031 6248970 / 0044 7446727058, 0044 6937236752, e-mail: alkchiotk11@gmail.com

or volunteers. Finally, the study examines whether a literary narrative that has its main character a young patient with end-stage cancer, or one that refers in a different way to the subject of pediatric cancer, may be useful to the general public.

B. Terms and Questions

In an old French film entitled, *Le petit Prince a dit* (*The little Prince said*), by director Christine Pascal (1992), the ten-year-old heroine, Violette, a patient with end-stage cancer, invents an image to describe her imminent death. She recounts her dream to her father: a butterfly leaves from her head (the little girl suffers from brain cancer) and flies with her to a country landscape. Her father, who is a physician-researcher, lying to her, refutes the imminence of her death. To explain what is happening to her, he uses medical terminology and tries to draw a rough sketch of the destruction of brain cells. The father here appears to represent the so-called “biomedical model” in medical education - as opposed to the holistic “biopsychosocial model” (Christakis, 2008; Engel, 1997; Frankel et al., 2003; Papadatou, 2009) - which here seems not enough to meet the psychological needs of the little girl (Mc Sherry et al., 2007). Violette isn’t seeking for false hopes, and she is not especially interested in the biological side of death, as she is in the psychological, and even the spiritual. The agonizing questions that concern her are, “How is it when you die?” “What do you feel when you die?” “Where do you go after you die?” Similar questions are posed in children’s narratives presenting heroes who are children with end-stage cancer. Even in real life children with end-stage cancer often ask similar questions (Mc Sherry et al., 2007; Papadatou, 1991; Wass, 1991).

As relevant research has shown, even the youngest children when reaching the end of their lives show an awareness of the situation, and it is useless for health professionals and family members to try to conceal it from them (Hatira, Lioffi, & Kostopoulou, 2012; O’Halloran, & Altamier 1996; Spinetta, 1982). However, implacable questions arise: What answers can we give to a child concerning such a heavy and loaded subject, as is his soon imminent death (Papadatou, 1991)? How can we offer psychological support to the child’s family circle, to the parents and siblings? How can we help the caregivers, professionals or volunteers? How can we encourage the activation of resilience in all these people (McCubbin et al., 2002)?

Here we must define resilience as a dynamic and multidimensional concept (Pooley & Cohen, 2010; Rutter, 2012), which is activated in a positive manner in the duration of and after exceptionally stressful and painful situations, such as disease and death, and it allows the efficient management of the difficulties and trauma undergone, preventing psychopathological conditions. Children's resilience can be constructed and cultivated by psychological interventions in different environments (Froelich-Gildhoff & Roennau-Boese, 2015; Ungar, 2012). Resilience depends on a number of psychosocial factors, and therefore is defined in an interdisciplinary way (Chiotaki, 2013; Fletcher, & Sarkar, 2013).

Narratives on the death of a child with cancer can be used as a useful tool in the hands of a psychologist in order to provide support and even to help activate resilience. Readers of books with relative subject, or listeners, mainly in the case of preschool-aged children, can be the little patients to whom palliative care is provided. The present study aims to highlight the palliative quality of the narrative and the value of the story to the psychological support of sick children. However, the whole family, parents and siblings, even health professionals, and even volunteers involved in palliative care can receive psychological support through contact with the literary narrative for children. The underlying goal is the activation of resilience in all these people.

In general terms, the specialized children's narrative offers psychological preparation for real life (Heath et al., 2005; Sridhar, & Vaugh, 2000; Wass, 1991) especially when it successfully reproduces reality with precision and penetration, and particularly in cases where the authors have a personal experience (Loedec, 2006; Sinis, 2015) and employ "the human capacity to organize and transmit this experience in a narrative form" (Bruner, 2003) or have performed a thorough investigation of the subject (Nicholls, 2008). Furthermore, narratives for children, written in children's books, due to their ability to be accessible to all, have the advantage of not discouraging even an unskilled reader, regardless of his age.

The term "Psychopoetics", conceived of in the past by Narratology, to bring forth an interdisciplinary approach to Literature, upon which the psychoanalytic side was favored (Bal, 1984), here is used to declare the conception of children's narratives not only as literary work, but mainly as a psychological tool. For this reason the four books with which we are mainly dealing, the texts of the writers Catherine Loedec

(*Falikou*, 2006), Christos Sinis (*The cancer dragon*, 2015), Erich- Emmanuel Schmitt (*Oscar and the lady in pink*, 2005) and Sully Nicholls (*Ways to live forever*, 2008), were chosen with the basic criteria of how supportive they may be in the transmission of emotions (Heath et al., 2005) and even as regards the enhancement of the resilience of the readers. Another criterion is the intercultural quality of the narrative, that is to say the possibility to be clear and useful to many people with different cultures and mentalities. Readers as young patients, siblings, parents or care-givers can easily identify with the corresponding characters (Heath et al., 2005)

C. The Narrative as modelization of a difficult reality

The experience of accompanying dying children in the journey through life and death is described with affecting precision by psychologists (Hatira, 2000; Hatira, Lioffi, & Kostopoulou, 2012; Papadatou, 1991). The need for psychological support, but also the difficulties that exist in terms of preparing a young child to face death, are underlined by Anne Auvrignon, oncologist-pediatrician at the Parisian hospital, Armand Trousseau, while wondering if a narrative could provide relief and answers to a preschool-age child (Auvrignon, Leverger, & Lasfargues, 2008). In this context, the mother of her young patient, in the last 48 hours before his death, devised and recounted a story to accompany and reassure the child in his last moments. Later this story was recorded and it was illustrated with great success. Thus, it was born the book *Falikou*, written by Catherine Loedec and illustrated by Jorg (2006). It is a poetic narrative based on metaphor and allegory, since the mother had decided from the beginning not to mention the name of the disease nor the word “death”, an attitude common even in adults’ narratives about this subject (Sontag, 1977; Teucher, 2003). However, on the back cover of the book, the hospital’s doctor informs the reader as to when and how the book was created.



Picture A



Picture B

The colorful scene of the narrative is an exotic village in nature, where in an idyllic cottage lived a loving and happy large family. The illustrator presents the time of the evening meal, a happy hour, says the text, when each member tells of how he spent the day, which symbolically displays and documents the emotional ambience as being a warm one, and shows the family bonds (see *picture A*). But one day, the little Falikou, the third son of the family, feels an irresistible force that pushes him to definitely leave the village, and he asks how that will happen. Then the mother tells the little boy about the long road that often very old people take to leave. The parents accompany the child in the beginning of that road, they say goodbye to him with affection (see *picture B*), and the mother assures his son that in her mind she will be saying goodnight to him every night as she gave each of his siblings a kiss in turn, one by one. The parents then explain why they have to stay behind to keep alive the memory of the child in the village and to care for the rest of the family.

The similarities between the story and reality are easily recognizable: The village corresponds to life and the journey to death. Here the metaphor attempts to operate more as a “modelization of reality” and not as an exaggerated and unconvincing beautification of it (Sparkes & Smith, 2011). The narrative avoids the use of medical terms scaring the little child, but it honestly states that it is impossible to cancel or to postpone this journey. The narrative avoids the use of medical terms scaring the little child, but it honestly states that it is impossible to cancel or to postpone this journey. Moreover, as research has shown, in similar situations even very young children are aware of the definitive and irrevocable nature of death (O’Halloran, & Altamier, 1996). The narrative also explains how it is impossible for the parents to accompany their son, no matter how much they love him. However, the assurance that his loved ones will

remember him acts, as much as possible, in a reassuring way for the little patient–listener. The book was used by the department of Pediatric Hematology and Oncology Hospital Armand Trousseau for reading to patients, as well as a starting point for oral narrative, and it operated as a supportive tool for thirteen cases of dying children to provide psychological support to them and their families (Auvrignon et al., 2006).

This narrative can be used to offer support primarily for the siblings of the little patient. The story can work relatively reassuringly even for them. It indirectly reassures the younger readers that the family will continue to remember with affection the little sibling who has left and that, after his death, the parents, despite their grief, will not fail or be absent, rather they will continue to live and will be able to care for their other children with affection and devotion (Bonanno, 2004). The siblings therefore will not be left alone to feel neglected (Wilkins, & Woodgate, 2005). Here let us remind one how often in families that have been put through the difficult trial of pediatric cancer, parents are forced to devote their energy to the care of the sick child, so often the siblings exhibit negative reactions as emotional instability, rivalry, or rejection (Bluebond-Langner, 1996; Kübler-Ross, 1997; Karambela, Hatira & Damigos, 2011; Wilkins & Woodgate, 2005).

Indeed, the mother says she will continue to say goodnight to her children in the same order every night, first to the older and then to the younger, and she repeats each of the children's names. She repeats also all the scenes that the third-person narrative has already outlined to present life in the village before Falikou was hospitalized and assures that some things will keep going on as always: The friends of Falikou will still play, his father will still every day go to hunt with his eldest son and bring home food.

With repetition, the necessary return to regularity is declared to provide the children a sense of security. After the departure of the little brother, life will continue as it did before for the family. This maintenance of the routine in the family life is a crucial component to resilience and helps the members to bind together with regular contact and order. The continuation on everyday life and occupations and the connection with friends and family is an important support for children struggling with the loss of the sibling (Heath & Cole, 2012). In this context, it is not unreasonable to expect that the experience of loss as a shared tribulation and the joint preservation of the memory of the deceased child will further strengthen bonds between family members.

Family cohesiveness is an important factor to promote resilience (Patterson, 2002; Walsh, 2006). After this trial, probably family will be more coherent and stronger (Patterson, Holus, & Gurney, 2004; Walsh 2006).

When the mother says goodbye to her little boy, she tells him “Go to discover what there is on that road.” Death is presented therefore as something unknown that the small child should “explore” on his own, but not something that is necessarily dreadful and frightening. This very simplified Platonic starting point is met in other excellent children’s narratives with related subject matter. Although the Falikou affair unfolds in a paradisiacal environment, amidst unspoiled nature, with rich vegetation and many animals, as the illustrations show, there is no reference whatsoever to Biblical narrative about the afterlife or about a particular type of religious paradise. For this reason, this story can be useful for many people with different cultural backgrounds and origin and completely different worldviews (Waller, 2001).

A similar most painful experience from the parent’s side is documented in a Greek picture book. The author, Christos Sinis, a father-doctor whose young daughter lost her battle with death, has written the story, *The Cancer Dragon* (2015) to narrate what exactly happened. The Cancer Dragon grabs the little girl, Neni, and unfortunately nobody manages to prevent her abduction, neither with the love of her siblings nor with the care of her parents. Here the author uses metaphor and allegory, not only to allow the delicate development of such a difficult subject, but also to serve again as a “modelization” of reality. The folktale element neither precludes the name of the disease in any way, which is there already in the title of the book, nor the representation of it, which is relatively realistic, as the family observes the little girl “*struggling, resisting with all her strength and courage, changing day-by-day, becoming thinner and weaker losing her beautiful hair.*” Moreover, it is clearly stated that, “*this fairytale had a different type of ending than the usual fairytales do, and the Cancer Dragon gets the valiant knight.*”

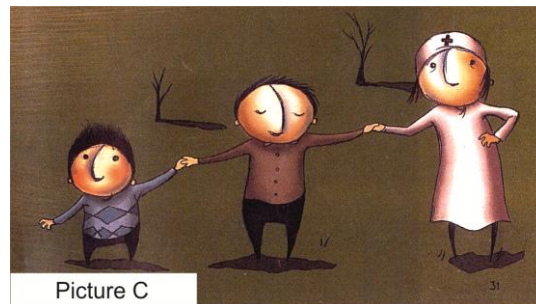
The book, dedicated to Neni’s mother and to all mothers who have found themselves in a similar position, is aimed primarily at families who have already experienced the loss, and even to health professionals who give palliative care to children with cancer. The narrative could offer support to these people. Although the story is of course sad and the illustration of Nikos Giannopoulos uses mainly cold and

dark tones, the sensation one is left with from the narrative is relatively optimistic as a kind of catharsis (Sridhar & Vaughn, 2002). Little Neni has gone, but her family continues to struggle, united and loving, and in cooperation with other people, parents, friends and healthcare professionals, often with positive results. The book reassures those who are fighting for the care of children with cancer “...*have seen sometimes—or many times, rather—the dragon be defeated and to flee far away.*”

The narrative promotes in a successful way the concept of resilience, which here is manifested as a tireless energy, inner strength, and fervent motivation, in terms of what is offered by people who are involved in the care of child cancer patients. A practical example is the author himself, who is struggling with many ways to improve the treatment and living conditions of children with cancer and their families, as stated on the biographical note in the last pages. In his story, indicated in an indirect way, the concept of resilience emerges from an eco-systemic perspective in multiple dimensions (Kourkoutas, 2008; Ungar, Chazinour, & Richter, 2013), as something that is cultivated in various interactive environments: on the level of the emotionally connected family, on the level of the hospital, where everyone struggles for the same purpose, and finally on the level of the greater whole of the community, which here has the name “Flame” and is the “Association of parents of children with neoplastic disease” in Greece (Prince-Embury, 2011; Ungar, Chazinour, & Richter 2013; Waller, 2001).

This narrative makes use of and ingeniously transforms the ancient Greek myth of Atlas, the giant who held the entire sky on his shoulders. As the story tells, “*The Atlantians big and small fought with all their might. Together with the Atlantian doctors and the Atlantian nurses, and with a few good Atlantian companions who were willing and able to undergo the terrible battle.*” Here metaphor acts as a “modelization of reality” to declare the titanic effort that is required when facing a serious pediatric illness (Bonanno, 2004). The fact that there are so many adults–Atlantians and many children–Atlantians, as the story tells us, suggests that the concept of resilience can be activated and manifested in everyday usual people, when there are strong emotional foundations and most powerful family ties, as well as broader support from the social environment (Bonanno, & Mancini, 2008; Walsh, 2012). “*This love strengthened to the point that it flowed over...*” assures Ch. Sinis, whereas N. Giannopoulos illustrates these emotional bonds, presenting a child, an adult, and a health professional holding hands

(see *picture C*). Here again resilience is manifested in an obvious and assertive realization of what it has to offer to children with cancer and their families who have undergone this so difficult trial.



D. Representations of Caregivers, Spiritual needs and Humor

It is a fact that caregivers, not only the relatives of the little cancer patients, but also health professionals themselves, need psychological support. As many relevant studies have shown, doctors and nurses who care for dying children very often feel grief and disappointment (Hatira, 2000; Papadatou et al., 2002) and sometimes exhibit the syndrome of professional exhaustion (Haritou-Fatourou, & Papathanasiou 2008; Papadatou et al., 1994). In the well-known narrative of E.E. Schmitt, *Oscar et la dame Rose* (*Oscar and the lady in Pink*), Dr. Dusseldorf, who operated on little Oscar unsuccessfully, feels very bad when he has to announce to the parents the terrible news on the negative development of the health of their son, and he awkwardly repeats the phrase, “*We’ve tried everything, please believe me...*” in front of the mother, who is sobbing. Even in front of the little sick boy, as Oscar says himself, he always looks “*miserable,*” and “*he looks so sad, like Father Christmas who’s got no more presents left in his sack.*”

In an impressive inversion of roles, the charismatic boy is shown as advising and comforting his doctor, saying “*...It’s not your fault if you have to give people bad news... You need to relax. You are not God the Father. You don’t give orders to nature. You are just the repairman. You need to slow down...ease off the pressure and do not take so much responsibility yourself, or you won’t be able to keep this job for long...*” It is easily understandable that the reading of this book can prove supportive to a health professional: the reader’s identification (Sridhar, & Vaughn, 2002) with Dr.

Dusseldorf is reasonable. Also, we can easily understand why this book was praised and awarded by professional doctors' and nurses' associations. This narrative can provide a contribution to the activation of resilience of health professionals (Jardine, 2005).

The narrative gives a very important role to the elderly volunteer Granny Rose, who stands by Oscar admirably, and helps him live well in the last days of his life. As research shows it is very important to combine palliative care and quality of life (Mc Sherry et al., 2007). Granny Rose helps the little boy to restore his relationship with his parents; this relationship, as expected, has been disrupted by the intense stress of the illness (Barakat, & Alderfer, 2011). After the death of the child, Granny Rose declares that despite her age, she will continue to offer her services as a lady in pink (volunteer) and confesses that "*she is full of love*" and she feels empowered because Oscar gave her "*so much love that she's got enough for all the years to come.*" This phrase serves as a confirmation of the concept of resilience as interactive and dependent especially upon emotional bonds.

In the face of Granny Rose, anonymous volunteers, whose contribution is invaluable and whose difficult work is not always performed under ideal conditions, are honored and strengthened. We can say that through her presence, volunteering itself is praised and recognized in its entirety and throughout history. As may already be known, the French association "Blouses Roses," to which Granny Rose belongs to, was created in 1944 in Grenoble in order to help young TB-sufferers and operates until today.

Although the subject of end-stage pediatric cancer is obviously a particularly charged one, the children's books that deal with the subject are most of the time drafted with humor and often make the reader smile. In this context, Granny Rose encourages Oscar to live each of the ten or twelve days he has remaining as if each were a decade, and to imagine that he reaches adulthood, maturity, and even deep old age. She urges him to record this hypothetical life and the relative experiences in twelve letters. The letters that the boy writes make up the parody of a whole autobiography in miniature, where one can distinguish the adaptation of different stages of a person's life (Erikson, 1963). The reader smiles, when the eleven-year-old child refers to the positive elements of married life, when he talks about his parents in-law, when he supposedly is living

through a midlife crisis and he is not loyal to his beloved, when he makes up with her, when he portrays the experienced and wise old man ... As is well-known, humor is one of the most important defense mechanisms (Gleser, & Ihilevitch, 1969).

“*There are many ways to tell a story and I chose the funny side,*” says the sixteen-year-old Hazel, patient with end-stage cancer, central heroine and narrator of John Green’s bestseller *The Fault in our Stars*, one of the many books in the so-called “Sick Lit” of the last years that is aimed mainly at young adults. For children’s books, this style of the “funny side” is the norm. When a narrative tells of illness and death, and doesn’t use metaphor and allegory, it chooses humor. In the popular children’s book, *Ways to Live Forever* (2008) by Sally Nicholls, it seems that the whole medical treatment of children with cancer is based on this type of defense mechanism, in an apparent attempt to achieve as adequately as possible a management of the anxiety of young patients and their families.

Thus, the pediatric oncologist wears a red headscarf with white dots, to look like a pirate in a children’s book illustration, and so that the young patients who have lost their hair to chemotherapy won’t feel bad. Annie, the nurse who goes to the homes of the children to take blood is characterized as “crazy” by the heavily ill little protagonist Sam, because she goes around with a pink scooter and calls herself “Dracula,” while on the medical catheter, which he has permanently attached to his body, there are vampire stickers, well-known from children’s cartoons. Based on this defense mechanism, entertaining adventures unfold, starring two mischievous boys, Sam and his friend Felix. They understand, as did the hero in Schmitt’s novel, that their illness gives them the opportunity to become as manipulative as they want and to enjoy what is forbidden to minors, since we all well know that presumably no one denies anything to a severely ill child (Kübler-Ross, 1997).

It is true that religious beliefs about death, irrespective of any particular dogma, can help develop the resilience of adults (Walsh, 2008). In children, metaphysical concerns very often are summarized with specific questions such as, “Why does God allow children to die?” to which they sometimes seek their own answers. In one tragicomic scene, Sam tries to comfort his mother who is crying, and he tells her that after his death he will meet God and he will tell him how he makes mistakes, as in his case, which he should correct. In Schmitt’s novel, Oscar addresses his letters to God.

Because initially he doesn't believe in his existence, Granny Rose tells him, characteristically, "*Make God exist yourself.*" Oscar communicates with a God who is very familiar and ailing, with a body that is tormented as is his own, thus projecting his own situation to him. He asks if God were bedridden and he remarks that the statue of God on the cross reminded to him his own illness.

These personal representations of God from the side of the little heroes provoke reader's smile and they meet with their anxiety in facing death. It would be really difficult to fully associate them with a particular religious dogma. Sometimes spiritual needs of children and adolescents meet real cares and inquietude for the life of parents and siblings (Wass, 1991). In the young adult novel *Before I die* (Downham, 2007), the dying young heroin, Tessa, writes a letter with "instructions" for her mother who has left the family some years before to live with a boy-friend. The reader of these lines could smile and shed tears in the same moment: "*Don't give up on (my brother) Cal. Don't you ever slide away from him, ...think that any man is more important. I'll haunt you if you do. I'll move your furniture around, throw things at you and scare you stupid. Be kind to Dad. Serious. I am watching you.*" Humor can really serve as a narrative way, as a defense mechanism (Gleser, & Ihilevitch, 1969) and also as a protective factor to activate resilience (Cameron et al., 2010; Jourdan-Ionescu, 2010; Kuiper, 2014)

E. Narrative Serving Psychology

Sometimes, the anxiety of children facing death is manifested with the expression of individual fears associated with the purely medical and biological aspect of death (Wass, 1991). For example, they worry about the possibility of being buried alive, as in the case of a medical error where someone is pronounced dead and his body is delivered for burial although he has not died yet. Experts who are involved in the palliative care of children have documented such questions (Wass, 1991). Nicholls' narrative undertakes dealing with these issues. It shows the little protagonist asking related questions of the nurse in charge of his home care, and the nurse answers reassuringly, explaining the exact methods doctors use to verify and certify the death of a patient.

Here it is worth noting that the author, as she states in her narrative, has carefully studied the collective volume *Children and Death* (edited by D. Papadatou and C.

Papadatos in 1991). From this book, the author borrows *real* questions asked by children, just as the experts have recorded them. These questions are put in the mouth of her hero. In this way, the narrative is close to reality, and can be seen in practice as very useful in the education and preparation of volunteer caregivers and professionals (Papadatou, 2009).

In this context, Nicholls' narrative systematically deals with the two most common childhood questions, "*What is it like when you die?*" and "*Does it hurt to die?*" She attempts to answer those questions mainly in two ways. Instructing through the character of the nurse, she explains to the little protagonist, but also to the readers, in a simple and precise manner, the medical and biological aspects of death. Meanwhile, in the preceding pages, in a quite courageous way for a children's narrative, she presents in detail the scene of Felix's death. Little Felix breathes his last breath on the hospital bed, in front of the eyes of his friend Sam, who at that moment is the only visitor in the room. The scene is a significant answer to Sam's questions and simultaneously a preparation for his own imminent death. It is a scene more tender than gloomy, as it shows Felix coming out of his deep coma for a minute, and seeming pleased, he gives a big "*wide face-splitting grin*" to his friend, who smiles back at him spontaneously. The narrative makes the frightening matters that scare children but also adults, which were in the past taboo and remained without answers, a little less scary (Wass, 1991).

In general terms, children's books reveal the supporting and therapeutic value of narrative, written or oral. Firstly, this quality of narrative works for the authors themselves (Smyth, True & Sato, 2001). The books *Falikou* and *The Cancer Dragon* were written, as we saw, by parents who have experienced the pain of loss, and their creation possibly worked for them as a type of scriptotherapy (Smyth, & Greenberg, 2001) and then as an aid for the activation of resilience. These accounts can in turn prove to be, as we have seen, useful for the readers who have experienced loss.

In some pages of the novel, *Ways to Live Forever*, the appearance of the printed book imitates the children's (handwritten) manuscript. Sam is presented as the author-narrator of the last months of his life, and at the same time, with the encouragement of his teacher, he writes a "research paper" on the subject of death. In Smith's text, when Granny Rose proposes to Oscar to write letters for God and the boy asks why, she gives him the answer: "*Let him know what you are thinking. The things you don't say—*

they're things that weigh on you, they take a hold, wear you down, paralyse you.... You're going to become a dump for old ideas and you start smelling if you don't talk." With this realistic version of his heroine, the author summarizes the palliative function of the written narrative for the narrator himself. Generally, Schmitt's narrative, and to a lesser extent Nicholls' narrative, encourage the reader to express and manifest himself in any way and in any position he may find himself in, be it that of the patient, or belonging to the family environment, or being a healthcare professional, or a volunteer care provider.

Oscar records what happens in the hospital, while Granny Rose tells him of fight scenes in which she supposedly took part of as the champion-wrestler when she was young. The young internal listener identifies with her, and there is presented a correlation between the life of Oscar and the facts that the volunteer tells of, as it is well-known that in literature cancer is often likened to either a sports or warlike event (Dafermos, 2011; Sontag, 1977; Teucher, 2003). In Schmitt's text, there are documents that disclose the triple function of the narrative, written or oral, which can be palliative, supportive, and helpful in the activation of resilience. As a documentation of events that take place at the hospital, the story relieves the little sick boy. As a listening process, it strengthens him. Finally, the act of reading can work as an enhancement for the reader.

For the general public, the narrative becomes a source of information, awareness, and familiarity with innovative perceptions and attitudes in the health sector. When for example the narrative presents the young patients deciding in cooperation with the treating physicians on what treatment they will follow by choosing among different possibilities (Green, 2012; Nicholls, 2008) this indicates the good communication between patient and physician (Paschali & al., 2015) and promotes a more sophisticated and personalized model of medical care, which is interactive and relationship-centered (Papadatou, 2007) and based on a participatory type (Christakis, 2008).

In one of the final scenes of Schmitt's book, Oscar and Peggy Blue, his little friend who was operated upon successfully, browse a Medical Dictionary. Oscar seeks in vain the words that interest him: "*Life*," "*Death*," "*Faith*," "*God*." He believes that such a "serious book" should contain these words. In this way, the little protagonist

symbolically reveals and documents the spiritual and psychological needs of children and adults in the face of illness and death (Mc Sherry et al., 2007). In an indirect way he shows the necessity of a holistic biopsychosocial approach to medical care and the education of health professionals (Frankel, Quill, & McDaniel, 2003; Papadatou, 2009). Despite the simplicity in appearance, the narratives with which we have dealt are inspired and important, and they can prove effective. Their reading or listening can contribute positively in the psychological support of patients and caregivers, of health's professionals and volunteers and of children and adults alike.

F. Conclusion

In the context of palliative care for children with end-stage cancer, the use of a properly selected narrative is of great importance and proves to be a precious tool in the hands of a psychologist. The use of narrative can play an essential role in the support of young patients and mainly satisfy their psychological needs. It can appease their fears and concerns, with the ability to offer adequate honest and clear answers on the medical and biological aspects of death, crafted with precision and simplicity. But the most important function of the narrative and the eminently palliative quality it has is that it can meet the spiritual and metaphysical needs of the sick child, because it helps to handle the spiritual side of death. This can be achieved regardless of the personal beliefs, culture or religion of the child and its family. The ability to activate a key defense mechanism remains, which is the humor to be found in all readers and listeners.

The narrative can also serve to support and prepare the siblings of a sick child to cope as effectively as possible to the painful experience of illness and loss, working to encourage strength and to reassure by showing that life for the family continues. It may even contribute to the activation of resilience for all family members.

For caregivers, be they professionals or volunteers, the identification with the heroes of the story (especially those shown as having their same role) contributes to psychological support, activation of humor, and in the long term even to the activation of resilience. The narrative close to reality can be seen in practice useful in the education and preparation of caregivers.

Finally, for the general public a narrative that relates to children with end-stage cancer can serve as a source of information and familiarization with an innovative interactive biopsychosocial model of healthcare, based on participatory type and more functional and useful for all people, patients and caregivers, adults and children alike.

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***Η Παρηγορητική Λειτουργία της Αφήγησης για Παιδιά με
Καρκίνο Τελικού Σταδίου και η Ψυχοποιητική της
Ανθεκτικότητα***

Αλίκη Χιωτάκη³⁷

Περίληψη

Η μελέτη αυτή εστιάζει το ενδιαφέρον της στην πολλαπλή παρηγορητική λειτουργία της αφήγησης στο πλαίσιο της φροντίδας που παρέχεται σε παιδιά με καρκίνο τελικού σταδίου. Η σύγχρονη αφήγηση αντιμετωπίζεται ως ένα χρήσιμο εργαλείο στα χέρια του ψυχολόγου, γιατί μπορεί να προσφέρει βοήθεια στην κάλυψη των ψυχολογικών και πνευματικών αναγκών των μικρών παιδιών, να έχει καθησυχαστική επίδραση στους φόβους τους και να δώσει ειλικρινείς και ικανοποιητικές απαντήσεις στα εναγώνια ερωτήματά τους. Μπορεί επίσης να αποβεί βοηθητική για όλη την οικογένεια και να επιδράσει θετικά στην ενεργοποίηση της ανθεκτικότητας των μελών της. Ανάλογο ρόλο μπορεί να διαδραματίσει και ως προς την στήριξη των ανθρώπων που φροντίζουν τον μικρό άρρωστο, είτε αυτοί είναι εθελοντές, είτε επαγγελματίες της υγείας.

Με βασικό κριτήριο την καταλληλότητα για ανθρώπους διαφορετικής εθνικότητας και κοσμοθεωρίας, αλλά και την ακρίβεια των πληροφοριών που περιέχουν, επιλέγονται τέσσερες σύγχρονες αφηγήσεις από ισάριθμα παιδικά βιβλία, δημιουργημένες από συγγραφείς που είτε έχουν οι ίδιοι, ως γονείς, βιώσει την ασθένεια και την απώλεια, είτε έχουν πραγματοποιήσει ενδελεχή έρευνα και μελέτη για το θέμα αυτό. Οι αφηγήσεις αυτές εξετάζονται ως συγκεκριμένα παραδείγματα που μπορούν να αξιοποιηθούν στο πλαίσιο της ψυχολογικής βοήθειας που προσφέρεται στους ίδιους τους μικρούς ασθενείς, αλλά και στα πρόσωπα που τους περιβάλλουν και τους φροντίζουν. Για το ευρύτερο κοινό οι αφηγήσεις αυτές μπορεί να βοηθήσουν σε μια προσπάθεια γενικότερης ενημέρωσης και ευαισθητοποίησης, γιατί προβάλλουν ένα σύγχρονο βιοψυχοκοινωνικό και περισσότερο συμμετοχικό μοντέλο ιατρικής φροντίδας που συνυπολογίζει τις ψυχολογικές και πνευματικές συνιστώσες, ένα μοντέλο περισσότερο βοηθητικό για ενηλίκους και παιδιά, θεραπευτές και θεραπευομένους.

³⁷ Ψυχολόγος, Tailor Ed Foundation, 11 Maritime Street, Leith, Edinburgh, EH6 6SB, UK
Tailoredfoundation.co.uk
Tel: 031 6248970 / 0044 7446727058, 0044 6937236752, e-mail: alkchiotk11@gmail.com

Λέξεις κλειδιά: Παιδιά στο τελικό στάδιο του καρκίνου, Αφήγηση και περίθαλψη παιδιών, Ανθεκτικότητα, Μοντέλα ιατρικής φροντίδας, Παρηγορητική φροντίδα.