

Weaving meaningful pathways through the end of a child's life

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Received and accepted on December 22nd 2020

Summary. Weaving is a process through which we assemble and interlace different threads into a fabric. The color and quality of the threads, and the process by which they are inter-woven, affect the unique tapestry that emerges among endless possible options. In pediatric palliative care, our role is to help children and families to weave a meaningful pathway to the border of life, by embracing both their suffering and vitality at distinct turning points in their trajectory: at diagnosis, when the illness is under control and families seek to establish of a new sense of normalcy, when the illness deteriorates, and finally when the child is dying. Weaving a pathway through each of these turning points requires a deep understanding of the challenges involved. The purpose of this article is to describe the challenges that families experience at two critical periods: (a) the period of "liminality" when the child is neither well-enough nor dying, and (b) the period of "separation" when the child's death is impending. Examples are offered to illustrate how children and parents communicate their experiences, concerns, and decisions when death becomes probable or certain. Special emphasis is given to our role as "companions" and to those abilities we need to develop in order to ensure meaningful and fulfilling encounters in the face of death.

Key words. Pediatric palliative care, child, family, professional role, decision making, end-of-life.

Tessere i percorsi verso il fine vita di un bambino.

Riassunto. La tessitura è un processo attraverso il quale assembliamo e intrecciamo fili diversi in un tessuto. Il colore e la qualità dei fili e il processo con cui sono intrecciati influenzano l'arazzo unico che emerge tra le infinite opzioni possibili. Nelle cure palliative pediatriche, il nostro ruolo è aiutare i bambini e le famiglie a tessere un percorso significativo al confine della vita, abbracciando sia la loro sofferenza che la vitalità in punti di svolta distinti del loro percorso: alla diagnosi, quando la malattia è sotto controllo e le famiglie cercano di stabilire un nuovo senso di normalità, quando la malattia peggiora e, infine, quando il bambino sta morendo. Tessere un percorso attraverso ciascuno di questi punti di svolta richiede una profonda comprensione delle sfide coinvolte. Lo scopo di questo articolo è descrivere le sfide che le famiglie affrontano in due periodi critici: (a) il periodo di "liminalità" quando il bambino non sta abbastanza bene né sta morendo, e (b) il periodo di "separazione" quando la morte del bambino è imminente. Vengono offerti esempi per illustrare come bambini e genitori comunicano le loro esperienze, preoccupazioni e decisioni quando la morte diventa probabile o certa. Particolare enfasi viene data al nostro ruolo di "compagni" e a quelle capacità che dobbiamo sviluppare per garantire incontri significativi e appaganti di fronte alla morte.

Parole chiave. Cure palliative pediatriche, bambino, famiglia, ruolo professionale, decision making, fine vita.

Introduction

Haralambos was a 14 years old boy with kidney failure who needed hemodialysis three times per week while awaiting a kidney transplant. He had made the pediatric hospital into his "home away from home" since his family lived on a remote Greek island. His world revolved around the personnel, children and their families on the dialysis unit, who had become surrogate parents and siblings. Following the death of Maria, a 7-year-old patient on the unit, the team told him that she had gone to the United States to receive a kidney transplant. At the time, I was a young psychologist on that unit and had developed trusted relationships with all the children. Haralambos came up to me and asked directly, "Did Maria die?". I hesitated for a moment, and then replied: "I am very sad to say that, indeed, Maria has died." "I knew it!" he shouted with elation, a reaction which caught me by surprise. He admitted that he had looked up her phone num-

ber in her medical file, called, and when he asked for Maria, her mother began to sob.

Once Haralambos was assured that I was willing to talk about Maria's death, he shared his anger that the staff had not informed him honestly. Then suddenly, he stopped talking, looked straight into my eyes, and in deep sadness asked: "Why do children die?". I experienced an extreme sense of helplessness. How should I respond? Should I turn the question back to him? Should I suggest that it was God's will? Should I change the topic of conversation? After a long pause I replied: "I do not know.... I really do not know." By admitting my utter helplessness to make sense of a harsh reality, I joined him in his existential quest. For a while we stood in silence and experienced an unparalleled sense of solidarity and connection.

A while later Haralambos shared his thoughts and feelings about the unknown of death, the uncertainty of life, and his hopes for the future. He was the most expressive I had ever known him. We both parted that day with a deep sense of fulfillment for having con-

nected in such an intimate way. “I’ll see you tomorrow” he said with anticipation as he accompanied me to the hospital’s main entrance. But there was no tomorrow; Haralambos died that night, leaving me with an utter sense of loss and grief.

This was my first encounter, 45 years ago, with a child’s death. It was a profound experience that taught me four things:

- to acknowledge with the utmost respect children’s preoccupations with life and death issues,
- to create a safe space for them to freely express themselves,
- to come to terms with our own vulnerability, and
- to cultivate intimate and authentic relationships which transform, and render more bearable, suffering in the face of death.

I learned that day that intimacy can develop within seconds, when we least expect it. It requires an openness to the moment-by-moment flow of experiences; a willingness to *truly connect* with a seriously ill child, sibling or parent-first as a human being and then in our professional role; and accepting that we may be transformed in our relationship and confrontation with death.

Weaving a pathway through a life-threatening or life-limiting illness

Weaving is a process through which we assemble and interlace different threads into a fabric. The color and quality of the threads, and the process by which they are inter-woven, affect the unique tapestry that emerges among endless possible options. In pediatric palliative care, we help children and families to weave a meaningful pathway to the border of life that “contains” both their suffering and their vitality. We become active participants at various turning points which trigger the re-organization of personal, interpersonal, and social processes in their lives. These turning points involve the diagnosis, the rebuilding of a new sense of normalcy, the worsening of the illness, and the dying of a child. Weaving a pathway through each of these turning points requires a deep understanding of the challenges involved.

- *A pathway through major disruptions.* These disruptions are associated with the traumatic impact of the diagnosis of an illness that is life-threatening or life-limiting. The family’s story is split into “life before” and “life after” the diagnosis of the disease – their “irreversibly altered reality”¹ – while the child is exposed to what are referred to as “unthinkable anxieties”².
- *A pathway into a “new normal.”* The illness throws the family into a re-organization of its dynamics, as members learn to *live with* an illness and its treatment. As new routines are gradually established, the disease takes a secondary place in the life of a child who becomes more preoccupied with living life and fitting in at school and among peers.

- *A pathway in liminality.* This pathway emerges with the child’s slow or rapid deterioration in health and with the new limitations imposed by the illness. The family stands at the threshold of two worlds: life and death, given that the child is “not well enough” to lead an ordinary life, but not “dying” either.

- *A pathway through separation.* Anticipatory grieving triggers a process of coming to terms with the awareness that death is inevitable. Focus is placed on the present moment, and both the child and family members are faced with relational challenges, profound exchanges and, to the extent that such planning is possible, decisions about the place of end-of-life care and death.

After the death of the child, the family has to weave another pathway through a long-lasting grieving process, which involves adjusting to the child’s physical absence while maintaining an internalized, ongoing and comforting bond with him or her.

This article focuses only on the challenges that children and families experience when faced with liminality and separation and describes our professional role as companions in carving a pathway when death is unavoidable and impending.

Living “in limbo”

Both the child and family members have to come to terms with the challenges of living in a liminal space and time. The word “liminal” has its roots in the Latin word “limen” which means “threshold”. Children stand *at the threshold*, “betwixt and between” different worlds. During this liminal season, family members are faced with “*ambiguous loss*”³. Parents and siblings may feel that they have “lost” the child as a result of physical and emotional changes. Given that his or her health condition is not terminal, they are faced with the extraordinary challenge of living concurrently with both hope and grief. Discussions about the goals of care, decisions about treatment options and aspects of end-of-life care are raised and reconsidered. The practice of “Advanced Care Planning” integrates the parents’ and child’s wishes in prolonging and ensuring quality of life and involves conversations for the development of a plan about the nature and place of care which is regularly revised. According to recent research, many families who become involved in such discussions refuse to engage in definitive plans about end-of-life care, but prefer to keep all options open⁴. Parents are in need of support about challenging issues such as *how* to address “difficult” topics, *what* to disclose, and *when* to engage in discussions with the ill child and the well siblings. Given that nobody can absolutely predict how long the child will live, parents may experience a sense of uncertainty that is both daunting and comforting. Seriously ill children experience a similar ambiguity and fluctuate between hope and despair.

“My victory” – Lito’s account of a drawing.

Lito was diagnosed at the age of 9 with rhabdomyosarcoma. Thanks to the support of her family and our team, she had developed into a very mature adolescent who, at the age of 14, was effectively coping with the challenges of repeated relapses and remissions of her illness. One day I found her in total despair. She openly expressed a desire to stop treatment, because she was too tired and fed up to continue. I invited her to paint her feelings, and a day later, she came back with a drawing that was entitled “My victory.” In the middle of the drawing she painted a big fire with flames around, representing her cancer and its metastasis. Then around this fire she depicted the four resources that she believed were helping her to fight her cancer: a) an *oasis*, which according to her symbolized the chemotherapy drugs; b) a *fist* that represented her determination to fight her disease, with the support of people who treated her as a normal rather than a sick or handicapped teenager; c) a *heart with teeth in the middle* which represented both her love and hate for her cancer experience: love because it enabled her to revise her values and priorities and enjoy life rather than worry about failing school exams, and hate for the suffering it was causing her family; and d) a *candle*, that she described as her faith in God and faith in her desire to live and survive her disease.

Children, like Lito, move back and forth between desperation and hope. While they should not be deprived of hope, neither should they be bombarded by false reassurance. Our role in liminality is to create a space which embraces uncertainty along with hope, anxiety, sadness or despair. Through this process, children redefine their self-concept and relationships to others.

Death at the family’s threshold

Rather than being probable, death is now certain. Manifestations of anticipatory grief are both healthy and adaptive as the child and family psychologically prepare for the upcoming separation through death. Some children withdraw into themselves, talk very little, retreat from activities, and may even avoid physical contact. Although such withdrawal is not universal, a certain degree of quietness and silence is almost always present⁵. While they may limit their encounters with many people, they simultaneously need to feel that they still belong and will not be abandoned or forgotten. Many children refer to their dying directly or symbolically. Some share their awareness and desire to be held, others convey their farewells, and some adolescents seek to “put things” in order.

Quite often, parents and clinicians disregard these messages and signals. They refuse to address the con-

cerns that the child may have about impending death, both out of their own pain and the fear that he or she will ‘give up’ or ‘lose hope’. While perceiving their role as protectors of the child, they concurrently seek, consciously or unconsciously, to protect themselves as well. Some may provide false optimism or vague explanations. The child who is aware of his or her own dying often feels lonely and fearful in the face of a reality that is experienced as daunting or overwhelming. Role reversal is not uncommon, when children protect their parents by avoiding questions and conversations that cause them distress, or by preparing them for the upcoming separation.

Lito’s awareness of dying.

When Lito came to the awareness that she was dying, she invited me one day to talk about her death: “*I am not afraid of death...*” she reassured me, “*I know I will be okay when the time comes. I’m only concerned about my parents, and how they will manage after I am gone. So, I want you to promise me that you will help them work out their conflicts and support them through their grief*”. I reassured her that I would look after them, and then, invited her to tell me more about what it was like to be aware that her life was coming to an end. She said she felt in peace given that she believed that both her grandmother and a girlfriend who had also died of cancer, would be waiting for her: “*I am not afraid about what lies beyond this life*,” she said, “*but what makes me sad is that I will never have the opportunity to fall in love, get married and have children*”. Her eyes filled up with tears; mine too; we embraced without words. At that very moment, this young adolescent was grieving the loss of her own “self” as projected into the future: Lito the lover, the spouse and the mother she would never become. Shortly after this encounter, she returned home for the summer, with no further disease-related treatment and with instructions about managing any distressing symptoms. When she returned to the outpatient clinic two months later, she was beaming with joy and confided in me that she had met a young man and that they had fallen in love. That day, we both celebrated the beauty of *being in love*!

Like Lito, many children who come to terms with the suffering caused by the awareness of their dying, experience an intensified desire to live as fully as possible. They struggle with questions such as *Who am I now?* (present) as I encounter increasing losses, limitations, changes in physical appearance and in relationships with loved ones and peers. Their self-concept is compared and contrasted with *Who was I?* (past) and *Who had I hoped to become and will never be?* (future)⁶. Existential questions, such as *Where am I going?*, often preoccupy children regardless of age.

“The stairs”: a farewell from 5-year-old Eva (figure 1).

Danai: Tell me about your drawing
 Eva: These are stairs leading up into the sky
 Danai: Who is going up into the sky?
 Eva: People... Me.
 Danai: What is up there?
 Eva: The sun, the clouds, the moon
 Danai: And what are you going to do up there?
 Eva: I will be watching you
 Danai: Will I be able to see you?
 Eva: No. You will be able to see me only in your heart

Our clinical experience and research evidence suggest that, regardless of age and cultural background, children know when they are dying, and have multiple ways to communicate their awareness^{5,7-9}. Quite often this awareness is associated with a desire to live on in the memory of their loved ones. As a result, ordinary activities and ordinary relationships are invested in such a way, that they are experienced as extraordinary and lived with an acute vitality. This process offers a renewed sense of existence in the world. Children *re-appear* into the world, so as to leave their imprint and express their love and affection, before they *disappear*. The challenge for both families and health care professionals is to be able to acknowledge their message and respond in ways that bring comfort.

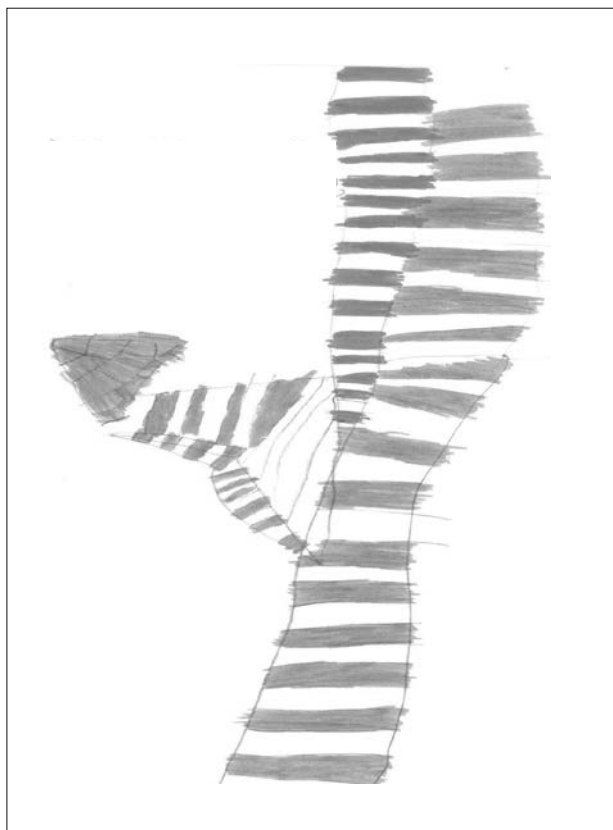


Figure 1. “The stairs”: a farewell from 5-year-old Eva.

The challenges of decision-making at the end-of-life

Critical challenges in weaving a pathway include engaging in decisions about the nature of expected care and the place of dying and death. Most commonly the key participants in decision-making are the parents, members of the care team, and the dying child who conveys directly or indirectly his or her desires. Decisions, however, are also affected by the sibling(s), the grandparents, the family's religious healer, and key community members whose needs, beliefs, and involvement with the family varies at the end of life.

In a qualitative study¹⁰, conducted with a sample of 36 bereaved Greek parents, decisions among parents and professionals about the place of end-of-life care and death, were reached through four distinct processes:

- *by consensus* among parents and professionals
- *by accommodation* of parents to a proposed option offered by clinicians or by accommodation of clinicians to the parents' desires
- *by acceding to clinicians' decisions*, when parents are not offered an option, and
- *by excluding clinicians from the decision-making process*, when parents' desires are not respected.

These processes are affected in distinct ways, by the nature of the partnership between parents and professionals which is re-defined, strengthened or distanced at the end of a child's life. The researchers described an explanatory model of 6 interrelated factors that affect parents' decisions about whether their child will be cared for and die at home or in the hospital. These factors include: 1) the parents' *awareness* that their child is dying, 2) their *perceptions of the competence and trustworthiness of professionals* to assume the child's care at home or at the hospital, 3) the *timing* they are presented with the decision to care for their child at home or hospital, 4) their *perceptions* of whether they are *competent enough* to assume the child's care at home, 5) their views of *symptom management*, and 6) their *beliefs of how a “good parent” should act* at the end of his or her child's life. Findings highlight that the home or hospital setting may be preferable to different families, for different reasons, at different times. Clinicians can help parents with this decision by providing honest information, by presenting them with options in a timely manner, and by supporting them to develop the necessary competence to deliver care at home, should they choose to do so, always reassuring them that they can return to the hospital for whatever reason. To help them weave a pathway that is meaningful requires a capacity of accompanying the child and family to the borders of life.

Accompanying the child and family through dying

The word “companion” stems from the Latin roots *com*, which means “with,” and *pan*, which means

"bread." A companion "breaks bread with" a person while listening to their stories. As companions, we do more than listening to stories which have been disrupted by the diagnosis of a life-threatening illness, by the progressive decline in a child's condition and the imminence of death. We assume different roles. Sometimes we become *the container* of the child's or family's suffering by creating a space in which they feel safe enough to experience, explore and share whatever feels threatening. Other times we become *encouragers* by helping them to cope with daily challenges, practical or existential concerns, and interpersonal and family communication issues. But almost invariably we assume a role as *facilitators of transformations* by enhancing both inter-connectedness and letting go in the face of impending death⁸. As companions to children and families through liminality and dying, we cultivate at least four abilities in ourselves: 1) the ability to be fully present, 2) the ability to become a "container" of their experiences, 3) the ability to facilitate explorative pursuits and meaningful exchanges, and 4) the ability to come to terms with our personal vulnerability in the face of death.

THE ABILITY TO BE FULLY PRESENT

Being "fully present" calls for an involvement with all aspects of ourselves (physical, emotional, cognitive and spiritual). This lowers the risk of fragmentation, the "turning off" of specific aspects of our experience. It also requires availability, openness, commitment and a promise conveyed (verbally or not) that "I will not abandon you." Sometimes, we are "physically present" by staying calmly at the bedside of a child, without necessarily having to say, fix, or do something. We are aware of what non-verbal communication transpires in the relationship. We are in touch with our own bodily sensations (e.g. blushing, muscular tension, calmness, tears) and do not pretend that our bodies are neutral. "*Embodied encounters*" allow us to better understand ourselves, the child or parent, and our relationships with them.

Other times we are "psychologically present" by inviting family members to share worries, hopes and personal stories, by raising or answering questions, by encouraging the expression of feelings and concerns through creative activities, and by facilitating family communication^{11,12}. This process requires an ability to bear witness to the family's unavoidable suffering, without rushing to offer solutions. Instead, we remain open to the unpredictable and the unknown and listen with genuine interest and empathy without trying to confirm our theories or whatever is already known. Scharmer and Kaufer¹³ use the term "*presencing*" (presence + sensing) to describe the capacity of *being present* with our mind, heart and will, while also "*sensing*" the possibilities that are about to emerge in the immediate future. Given that the immediate future involves separation and loss, we create "*present moments*" with the child, family and team to trans-

form suffering into the enhancement of comfort, vitality, meaning, and growth⁸. Present moments involve a reciprocal understanding of our own, the child's and the family's inner worlds; they contain elements of a story about loving and parting that is extremely dense in subjective experiences and meaning. This story is being *lived* rather than verbalized and it remains engraved in memory. Present moments do not lend themselves to measurable outcomes, yet they have a profound impact that renders the reality of loss "survivable", meaningful and sometimes extraordinary.

THE ABILITY TO CONTAIN THE OTHERS' EXPERIENCES

It involves the establishment of a relationship that is experienced as a "safe haven." Within this "haven", children and family members experience a sense of security, predictability and continuity at a time their trajectory is filled with ruptures, losses and impending separations. The darkness, the chaos, the agony, the rage, the fear of the unknown are contained without criticism or judgment (i.e. "you shouldn't feel that way", "you are too emotional to make rational decisions"), and without the urge to offer our own point of view or guidance. We embrace all sorts of feelings and remain available, yet in the shadows, by keeping our own feelings, thoughts, and responses to ourselves without intruding on the child and family's experience.

At the end of life: Tiziana and her mother (figure 2).

Tiziana was a 7 years old girl with cancer, raised by a single mother who had serious psychiatric problems. This little girl flourished in the hospital and developed close bonds with members of our team. As Tiziana's condition deteriorated, the team informed the mother of her daughter's impending death. Overwhelmed by terror, she accused the physicians of abandoning her daughter and threatened to leave the hospital and seek cure among religious healers in remote monasteries. Tiziana, who was protective of her mother, grew silent and did not object leaving our unit. However, she expressed her needs in a drawing that she gave to me. In this drawing she painted a house and wrote on the roof "*The name of this house is Danaï*". In the house there were no people, but only a fireplace generating warmth and light. A colourful curtain covered the front door. Outside the house, she painted rain and snow and printed the words: *wild jungle*. Nevertheless, on the top of the house there was a big, bright star, similar to the star over the crèche where Jesus was born. Tiziana's mother continued to express her rage against the clinicians who had informed her of her daughter's dying. I reflected how painful it must have been to learn that her daughter was not going to get well. When Tiziana's condition deteriorated and death was immi-

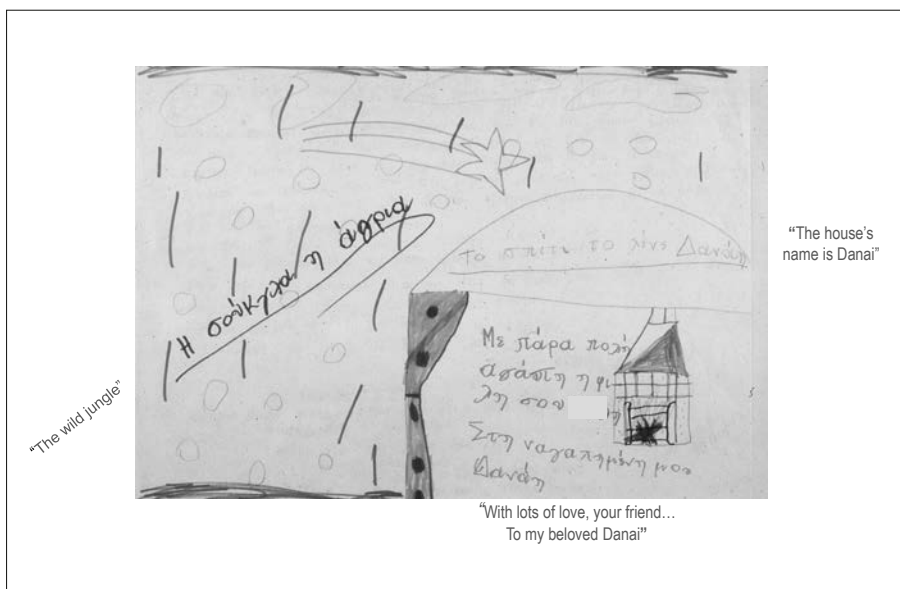


Figure 2. At the end of life: Tiziana and her mother.

nent I put my arm around the mother's shoulder, and simply said: *"It's time now to prepare ourselves"*. It was the first time I saw Tiziana's mother cry. In the days before Tiziana's death, mother and daughter who remained at the hospital, found refuge in a room that became their own crèche. Tiziana died peacefully in the arms of her mother, who was held and supported by the nurses and me.

THE ABILITY TO FACILITATE EXPLORATIVE PURSUITS AND MEANINGFUL EXCHANGES

This ability involves the exploration of options, the engagement in decisions, the facilitation of communication and exchange of farewells. It requires a focus on both the present moment as well as on the conditions of separation that lie ahead. When parents are too consumed by their anxiety over the imminence of death, they may be unable to consider the child's wishes or understand his or her symbolic expressions. Our task then, is to ensure that the child's voice and symbolic acts are heard, understood and addressed by facilitating meaningful exchanges.

Panos' desire to die at home (figures 3-5).

When Panos, a 14 years old adolescent, was informed of another relapse of his leukemia, he stated that he did not want to consider further therapy and insisted on returning home. While his parents and the physicians were meeting about the option of a clinical trial that could possibly prolong his life, I spent time with Panos. On a paper divided into 6 squares, I invited him to draw a story with a beginning, middle, and an end. In his story the protagon-

nist is a shipwrecked man who lives on an island. A threatening shark that circles the island reminds him that there is no hope of escape. One day the man throws a bottle into the sea, with a message indicating his location. The bottle is found by a sailor of a big ship who informs his captain. Following the directions in the message, the captain finds the island and sends four sailors ashore. They locate the shipwrecked man and together celebrate his rescue. During the party, the captain receives an order to immediately return to port and the ship goes away, leaving all the men on the island. Panos ended his story by stating with a feeling of relief: *"At least my hero is NOT alone to face an unsolvable reality"*. With Panos' permission, I shared this drawing with his parents who honored their son's wish, and returned to their village where he died peacefully surrounded by those he loved the most.

Regardless of our field of expertise, our task is to discern *when* to create a safe haven, in which family members can share their experiences no matter how extreme, powerful, explicit or implicit these may be, *when* to encourage explorative pursuits, and *when* to step back and allow children and families to manage on their own. We do not have the right to become protagonists in the family's story, to intrude uninvited into their world or to impose our opinions and decisions. Nor do we have the right to abandon them.

THE CHALLENGE OF BEING "VULNERABLE ENOUGH"

To accompany the child and family to the borders of life is not a task to be assumed by an individual professional. Rather, it is the responsibility of an entire



Figure 3-5. Panos' desire to die at home.

interdisciplinary team that functions as a connected system. Such a team supports its members, cultivates resilience, acknowledges individual and collective intentions to serve seriously ill, dying children and their families, and provides an environment in which colleagues can explore their responses to death^{8,14}.

Our relationships with children and families are not only shaped by our knowledge and skills but also by the awareness of how we affect and are being affected by them in the face of death⁸.

Some professionals are determined to *protect themselves from suffering* when caring for seriously ill and dying children. They experience intense vulnerability and as a result suppress or numb their feelings, freeze their responses, or resort to action in an attempt to avoid emotions (e.g. engage in practical matters, unconsciously create emergencies, assume extra responsibilities). These professionals build rigid boundaries by “hiding” behind professional titles, expertise, and extremely busy schedules. Unaware of how deeply they are affected by their relationships with dying children, they avoid exploring their responses or addressing personal loss or trauma issues which may have remained for long unexplored. This “distancing from self,” is reflected in a similar “distancing from children and families,” which often results in the provision of stereotypical, by-the-book care and the prescription of clinical services to which families are expected to fit¹⁵.

Other professionals *over-extend their involvement*. They tend to cross boundaries in their relationships with children and families to such an extent that the level of their involvement becomes so intense that they burn out, while families are also negatively affected. Consumed by their suffering and reluctant to engage in introspection, they project an image of “heroic caregiving.” Behind this façade, lies an intense vulnerability and suffering that they avoid at all costs given that it often reflects an unresolved traumatic experience associated with feelings of utter helplessness or hopelessness.

Finally, some professionals engage in this field with a *conscious awareness* that they are inevitably affected, and perhaps even transformed. Clear about their motivation to work in pediatric palliative care, they accept both their strengths and limitations, explore how they affect and are being affected by the children, and acknowledge their vulnerability.” Rather than being driven by the need to be perfect, in control, or heroic and defend themselves against suffering, they develop a capacity of being “vulnerable enough”⁸. These professionals are able to acknowledge both their resilience and vulnerability, and thus they are able to establish committed, authentic and empathic relationships. In the face of face of death, they remain fully present and unafraid to engage in an intimate relationship with a child who is struggling to let go. In such a relationship they maintain the *illusion* that *together*, professional and dying child, will be carried into the unknown of death¹⁶. Not an easy task, because it requires on the part of the care provider a

willingness to face the threat of death, to tolerate the anxiety that such illusion evokes, and to acknowledge that through this process he or she will unavoidably be affected^{8,17}.

In conclusion, weaving a pathway at the end of life, involves encounters which occur when we *truly connect*. Such an authentic connection requires the letting go of our pre-conceived ideas about how things “should” be at the end life, of our role as “experts”, and of our need to guide, to control, to make or impose decisions. It involves slowing down and opening up to whatever emerges within ourselves and in our relationship with the dying child or grieving parent in the present moment. We learn that we do not have to know or act according to prescribed expectations, but guided by the unfolding of a process encompassing ourselves, the child and the family. Through such a process we may come to the awareness that despite the extraordinary challenges of caring for children who die, we are privileged to participate in meaningful and fulfilling human encounters¹⁸⁻²¹.

Conflict of interests: the author has no conflict of interests to declare.

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