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TOP

Pediatrics mourning: writing words in the void

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Abstract

Mourning is a radically painful experience connected to death or loss. The types of loss tied to disease vary significantly and make mourning a relevant psychical process in the roster of emotional impacts endured by children, adolescents, families, and health care providers. Given the relevance of this topic in the care of grieving individuals, this paper aims to discuss the psychical aspects of mourning from the standpoint of psychoanalysis. The method chosen to look into mourning considers fragments of the narratives used by grieving individuals faced with disease and death. We found that by listening to and witnessing their suffering we can help them address their pain as they build their own unique fictions around it. Patient suffering and helplessness before death are sources of distress to health care providers. Following one's work of mourning implies in avoiding two extremes: on one end, the demise of a wishing subject; and on the other end, the condemnation of grieving subjects to helplessness and solitude. Finding a good measure of care seems to be a relevant challenge to health care providers, and one that calls for constant self-care.

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INTRODUCTION

> "However a hole now exists where his gaze once was. I realized that aging and losing also means to learn to walk around with a body emptied of the gazes we no longer have. We become beings loaded with absence (...)"[1].

As he goes into cardiac arrest for a second time, his hesitant mother signals, albeit subtly, that it is time to let him go. She does not want him to suffer anymore. Yet, she knows she must soothe his pain. She lies by his side, and sings him a lullaby. Davi, Davi, do not be afraid, Jesus is here! She sings close to his ear, holds him in her arms, her heart sinking. She feels she has done everything possible, but cannot escape the pain of having to live and dream without him. All bags are now packed. She leaves the hospital empty handed after staying there for 12 months. People tell her that time heals all wounds. Unable to accept it, she thinks of interrupted dreams, the lost fight. Will she be able to survive after the death of her son? Will she be able to wish for what she has not wished for yet? Not knowing how to live, not knowing the way home, she leaves. Just carry on, though without knowing how.

Scenes like the one described above happen every day in pediatric care units of high complexity hospitals. Amid the daily fights for life, people running around the ward aisles, the timid laughter to clown jokes, and rounds of Uno, to some death appears to be an unexpected, undesired visitor. The void of losing a loved one hurts not only the individuals directly affected by it, but also those who witnessed it. Illness breaks the line of life, takes individuals by storm, introduces a sense of loss, and invites them to utilize psychical resources to build a new meaning to existence. The types of loss tied to disease vary significantly and make mourning a relevant psychical process in the roster of emotional impacts endured by children, adolescents, families, and health care providers.

Given the relevance of this topic in the care of grieving individuals, a task that permeates the work of health care providers, this paper aims to discuss the psychical aspects of mourning from the standpoint of psychoanalysis. The method chosen to look into mourning considers fragments of narratives of grieving individuals and excerpts from larger clinical cases while preserving the identities of patients and focusing solely on their psychical constructs[2].

On the trails of mourning: the fabric of resignification

> "I felt nothing, only a weighable transformation. Many important things have no name" [3]

Mourning is a radically painful experience. It involves a process of resignification that presupposes renunciation and resumption. It encompasses reactions that reach far beyond the psychical, to include a range of physical, cognitive, and behavioral manifestations. Grieving individuals experience feelings of sadness, loneliness, and the inability to see meaning in life, and may present physical symptoms such as chest pain and weakness, in addition to memory disorders, confusion, hallucination, social isolation, and sleep disorders, to name a few[4].

The multitude of symptoms presented by grieving individuals draws them close to a state of illness and causes them to resort to unique psychical defense mechanisms as they try to preserve and protect themselves against devastating loss. While they attempt not to succumb to grief, their minds retrieve a wide range of symbolic and imaginary elements not always consistent with the social precepts regulating what constitutes "normality."

In his seminal essay "Mourning and Melancholia," Freud writes of the risk of mourning drawing close to a state of disease. According to the author, mourning "is regularly the reaction to the loss of a loved person, or the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal and so on"[5]. Therefore, mourning reflects losses in a broader sense, not only in concrete but also in symbolic terms. When someone or something important is lost, grief concerns not only the concrete absence of this someone or something, but also what the object of grief represents and how it has been internally appropriated by one's self.

Life inflicts losses in succession. Children have to deal with them from the day they are born and in different stages of their lives, as they are weaned, lose deciduous teeth, see their bodies change with the irruption of puberty, and gradually lose their youth as they advance into old age. These experiences may have physical, social, and familial repercussions. When faced with loss, individuals feel helpless and retrieve psychical mechanisms developed throughout their lives.

While loss is painful in any stage of life, we cannot forego its constitutive role in human psyche. The frustration babies experience when their mothers are away for longer than expected helps them become wishing subjects. In this process, they learn to use their psychical resources to cope with the absence of their mothers[6].

In Freudian terms, mourning involves intense work and the self-absorption of the mind or, in other words, the withdrawal of the subject. Grieving individuals shut themselves off from the outside world and concentrate their energy into "exclusive devotion to mourning"[5]. By withdrawing their energy and libido[1] from the outside world, they attempt to keep the object of their desire alive internally. The levels of withdrawal and attachment to the lost object may vary and present in the form of psychopathological events such as hallucination and delirium.

Manifestations of this nature materialize as repeated attempts to call the phone number of a deceased person in hopes of listening to their voice. Although apparently odd and decompensated, this behavior speaks of someone's attempt to confirm that the object of desire is still alive, and that the whole situation is nothing but a nightmare or delusion. However, the frustration stemming from unanswered calls gives birth to compulsive additional calls so that reality may

eventually corroborate that which the subject sees internally: life in a dead object of desire.

Thus, if in the inner world of memories the lost object can still live, the chores of daily life, the empty bedroom, and the empty seat during dinner will radically insist in the ever presence of the loss, requiring the subject to withdraw libido from the lost object so that it becomes available to other investments and the formation of new bonds. One must separate from an object of love that no longer exists.

It is as if

> Each single one of the memories and situations of expectancy which demonstrates the libido's attachment to the lost object is met by the verdict of reality that the object no longer exists; and the Ego, confronted as if it were with the question whether it shall share this fate, is persuaded by the sum of the narcissistic satisfactions it derives from being alive to sever its attachment to the object that has been abolished[5].

The response to the call for reality does not occur immediately but gradually, as time and energy are invested, which makes it difficult to define how long the process of mourning "normally" takes. Each process is unique and dependent on the history of each individual, their psychical organization, and the place the lost object occupied in their lives.

Individuals see themselves trapped in a dilemma: should I let it go or lose myself in the wreckage? This is not an easy journey, since it brings forth other losses and retrieves unique psychical resources erected throughout the constitution of the subject. Mourning is often a painful process. Feelings of guilt and ambivalent emotions emerge, and grieving individuals must work through their constructed relationships so that they can eventually be allowed to go on with life, without forgetting or abolishing the lost object. In symbolic terms, the lost object must be re-appropriated beyond its concrete meaning. In the words of Cortes & Sirelli (2016):

> In short, mourning is not synonyms with forgetting. It is directly connected with the appropriation of the pain of absence, serving as a path to resignification and a glimpse at the possibility of moving on in spite of the absence. The subject changes with this experience and with the loss[7].

At the end of the mourning process, the grieving subject does not dispose of or forget the lost object, but takes ownership of it and everything it means, touches, and teaches. And since it is kept alive as the effect of something that has been transmitted, its concrete presence is no longer necessary. Freud wrote that it is not enough for the object to disappear for one to separate from it. True psychical work is needed - the "work of mourning," a slow and painful process through which the Ego[1] not only renounces the object and instinctively detaches from it, but also transforms and reorganized its ties with the object. The pain experienced throughout this process is a sign that relevant subjective work is in progress, digesting the loss of the object and commencing the remodeling of the Ego by integrating traces of the lost object. The subject is therefore given permission to carry on with life while carrying their object of love with them. The grieving individual emerges reconstructed at the end of this process, as someone with renewed perspectives toward existence.

Children, their parents, and adolescents: on the trails of death, in words and fiction

> "Any abyss can be sailed on a paper boat"[8].

Patients with potentially fatal conditions are often seen in the pediatric wards of high complexity hospitals. Children and adolescents in this situation are forced to experience the losses associated with death and the disabilities imposed on them by the disease or its treatment at an early age, including events such as losing parts of their bodies, seeing the image they had of their bodies change dramatically, losing function, and becoming unable to perform basic everyday life tasks such as eating or breathing without help. Illness is a rupture in life, which from this point is defined as life before or after the disease, an event that changes the order of magnitude of helplessness as experienced by the subject until its onset. It is an experience eminently connected to the traumatic events the subject has endured throughout life in varied versions. An important idea in psychoanalytic theory, helplessness has been associated with situations

> in which we depend on others to survive and live better or situations in which the subject and others are helpless before imminent death and suffering[9].

The communication of a diagnosis of disease, hospitalization, repeated painful procedures, and coexisting with the death of other patients reveal the primordial helplessness of human existence. The deterioration of the body and the gaze of a parent sunk in immeasurable pain are clear indicators, even to young children, of their weakness and the possibility of death. It is surprising how young patients can learn from and take ownership of their experiences in illness, even when all is quiet around them and no word is spoken. When children are listened to in their unique ways of communicating such as when they play, it is possible to realize how they understand and express grief and develop strategies and solutions to cope with loss.

[1] The *Ego* is one of the psychical instances in which Freud (1920), in his second theory, subdivided the psychical apparatus. It relates to the defensive side of personality, in which defense mechanisms emerge upon the perception disagreeable affections. (LAPLANCHE & PONTALIS, 2003, p. 132).

A five-year-old is playing during a session with a psychologist. Pirates in a ship are battling a storm, and fight desperately to hang on to the ship so they are not thrown overboard. They ask for help: "call the storm experts" so we can live a little longer, since "the storm always comes back." Role plays with ill dolls, many at risk of dying, and the attempts to save them are present in the stories told by children, not only while they play during sessions with a psychologist, but also in plain sight for everyone to see as they try to communicate in their peculiar ways.

Children speak of loss and use their psychical resources to recreate new lives and ways of understanding existence in their fantasies despite the disease. They characterize the irreversible nature of some losses to corroborate their grief, as seen in the words of a nine-year-old: "The Doctor said that my hair will grow back, but that it will never, never look the way it did before. It used to be curly, now it is straight." In this case, the loss of hair is a metaphor and evidence of the loss of something greater: a part of the patient, a part of the identity of the patient. Therefore, one must rebuild their way of being and living, a task that requires time and energy to live through the pain of loss.

In order to carry on, one must mourn many "deaths" - the losses experienced through life - now intersected by the disease. In the words of Brun (2003), "children threatened with death are imbued with two tasks: facing the danger by their own means and keeping their mothers company so they can endure the demise of a child"[10]. Amid the devastating pain of parents faced with the imminent death of a loved child, dying children often seek assurances that their parents will keep living after they are gone.

Nine-year-old Gabriela, after a life of loss (the death of her mother) and upon her own death, advises her father: "I would love to teach my little sister to walk. But I want you to teach her to walk if I am not around. Please bake her a birthday cake and sing her the Happy Birthday song." Although young, Gabriela was acquainted with the pain of losing a loved one. Although children may not comprehend what dying entails, when they see death nearing through the eyes of their parents, they seek ways of dealing with the ensuing distress by re-creating their fictions and constructs around their demise. Freud (1915/2010) described how the world of fiction nurtures grieving individuals by providing them with a chance to live different lives, dying, and being born again without rules or limitations[11].

Five-year-old Mateus incorporated elements from his parents' religion when he started to ponder about death after his clinical signs worsened. Death was not a subject he would discuss with his parents or doctors. The boy chose to do it with his psychologist, by inviting her to imagine what heaven might look like and sharing his thoughts on how beautiful it must be to live in a place without pain, in which he would meet his kitten Snowflake. His dreams evinced his psychical efforts to cope with death: "I was in heaven! Do you know what I did the moment I got there? I held Snowflake so tight he could barely breathe!" Although "skinny" in life, Snowflake was really well and "chubby" in heaven. In the absence of a representation of death, the imaginary offers a way out, a comforting fantasy for the crossing based on a promise of peace and serenity.

Revolted and disillusioned, parents try to bear the void introduced by the premature death of a child. In spite of their telling eyes, they try to hide the pain and desperation resulting from the impossibility of finding a cure for the disease and the possibility of losing a child. According to Freud (1914/2010), "The child shall have a better time than his parents; he shall not be subject to the necessities which they have recognized as paramount in life"[12]. The death of children and adolescents seems to subvert the natural order of life. After the death of her three-year-old son, young Maria protested: "This makes no sense! How can a young child suffer so much and live so little? I cannot understand it!" Involved in an apparently senseless event, parents must learn to carry something from the lost object with them. The fear of forgetting reactivates a sense of guilt: "I started to work and study, but I eventually stopped. It felt strange. I am afraid that M might think that I am letting go of him, that I am forgetting him. It hurt me and I simply quit."

The memories of little Artur made it clear that it was impossible to forget him and stick to being the same old self. "I have learned so much with him. He made me grow. He never wanted to see me sad. He would kiss me whenever I was sad. I cannot let go of him. Today I removed the ear phones and it felt good." As she drew closer to the outside world, she realized that although Artur was gone, he was still present in her life.

Adolescents experience illness and death in rather specific terms on account of their stage of psychical development. French psychoanalyst Lacadée wrote about the peculiarities of adolescence:

> As they seek tutelage and autonomy, young people experience the best and the worst of their status as subjects. They test the lines dividing the outside and the inside, play with social prohibitions, and study their place in a world in which they cannot fully recognize themselves. Incomprehensible to themselves and others, they inscribe unspeakable experiences mostly through ambivalence and provocation[13].

Adolescence is a crossing bordered by exile and loneliness in which individuals mourn idealized childhood parents, child bodies, and roles and identities of children. Illness is a contingency in the process of going through adolescence. Facing the finitude of the known world causes rupture and invites individuals to seek new meaning to their lives or succumb to non-existence. The loss of identity references secondary to the onset of disease forces adolescents to question the possibility and otherness of their desire, with the added risk of becoming the object of their parents and health care providers.

When the sole possibility of surviving resides in the submission to medical knowledge regardless of their desire, adolescents see themselves in an impasse: should they recoil, give up, or find a point in which they may concurrently live and make decisions? There lies a possibility of revitalizing the subject, of interjecting their desire vis-à-vis the knowledge of others and the limits of existence: who am I, this adolescent subject filled with limitations and threatened by death? What matters to me? What do I want? What do others expect of me? How far should I abide by what they say? Alice, a 13-year-old adolescent, denounces:

> "I have no life. I live in this hospital. I come here every week to have blood transfusions when I am not hospitalized, see? My parents will not let me out for fear that I might bleed. They do not allow me to go out with anyone, because it is too big a burden to take me anywhere. No one invites me to go out. But there is one day when it is safer to go out: the day after transfusion. But something always comes up and even when it works, my mom comes along with me. Now tell me: how am I going to kiss the boy that I am going out with if I have my mom hanging on to me? It is so hard to find a boy who accepts my disease. I am always in hospital. This is no life for an adolescent."

Living with disease during adolescence appears to be challenging, since freedom of choice is not always a given. Inconsistencies in this area often leave adolescents drifting as they struggle to survive. Imminent finitude stresses the impossibility of thinking about the future, a situation imposed on otherwise wishing subjects prevented from engaging in thought processes typical of adolescence. The symbolic separation from parents, a fundamental development in adolescence, becomes actual separation in the face of death. Adolescent subjects are helpless and vulnerable before the ambiguity of their parents and health care providers, who by their turn are lost amid attempts to protect their children/patients and grant them the subjective space needed for them to think about their future.

Adolescents are left with the option of seeking strategies to have an "adolescent life," be it by not complying with treatment or by joining groups and bonding with their peers in hospital. The immense desire to live and experiment has led some adolescents to experience the proximity to death with anger and revolt. Such is the case of a 17-year-old who asked his palliative care physician to "fix" his leg with an osteosarcoma even if it "looked like a stick" because he had to "do his thing." Time seemed too short for him to live everything he wanted, revealing the powerlessness of the team before his imminent death.

Thirteen-year-old Alice was deteriorating quickly but decided to plan a party for her fifteenth birthday. Although she was unable to experience it in reality and after having refused the idea of "advancing the celebration," she said: "I am scared! I am afraid of dying! I have told my mom to stop giving me that look! At least my sister looks happier. But we have to plan this party, because I do not have much time. I don't like stalling." Death was a constant presence in her sessions, along with her fears and preoccupation with her mother. But to endure death, she had to speak of life and develop, albeit internally, the plans for the day when she would become "a young lady." It was not about having an actual party, but the desire she had of enjoying her adolescence and femininity.

She planned everything during her sessions, and never told anyone about it: the two dresses she would wear, the song list, the cake, the guest list, and the actor she would dance a waltz with. The disease was present even in her fantasy. She said she would not be able to dance for too long "on account of feeling tired because of the disease." She lived every detail of her party, smiling, singing the songs she picked, and completing the guest list one day before she passed: "Now everything is ready! Everything is right! Now it is just a matter of time!"

When faced with the abyss, the trauma, and the pains of life, people seek solutions and devise unique constructs referred to as psychical reality. It encompasses the internally coherent truth of each individual, considering their desires and fantasies, no matter how far they might be from external reality (Laplanche & Pontalis, 2004). Alice knew she did not have much time based on the wounds in her body and her mother's gaze; she did not have time for the outside world, but is not planning a way of living internally? Her fiction provided her with psychical support ad protected her from the devastating feelings connected with death. After all, as writer Clarice Lispector (1969) wrote, "is there a way of saving oneself other than by creating one's own realities?"[15].

Care for the suffering: presence and testimony

> "Each rows their own boat, each in a different river, though it seems we are close to each other."[3].

Pain manifests in myriad ways in illness and death. It is not only the body that hurts. Our souls ache. In the words of an elderly patient, "The soul hurts. Life becomes colorless. And the minute you start to get better you feel like eating again, you want to go out and live." Thus, we might ask the following question: what does it mean to preserve life - the goal in palliative care? The philosophy of care seems to embody what ethics might require of us: to do all we can so that patients can be themselves in their essence, in their sense of identity, without losing sight of the meaning they have assigned to their lives and what they consider a dignifying death.

This is not a simple endeavor, since when we draw closer to human suffering we tend to shut ourselves down and offer invasive care measures in an attempt to offer our

patients that which we would like others to offer us. And as we act paternalistically or aggressively, we shut down the subjects before us, preventing them from manifesting their authentic wishes. If patient suffering may lead to excessive care, the opposite may happen as well: helplessness before the pain of others may lead one to shut themselves out and enter a state of "deauthorizing indifference" as described by Austrian psychoanalyst Sándor Ferenczi (1933). Therefore, subjects with disease[16] "instead of finding a sensitive individual able to witness their suffering, they find indifference, that is, the traumatic abandonment that deauthorizes their testimonies"[17]. In this case, health care providers become unable to listen to the unspoken pain endured by their patients, since they are distressed and paralyzed by a state of helplessness.

Finding ways of comforting without invading or deauthorizing patients appears to be a constant challenge for individuals providing holistic care. When the patient is a child or adolescent, it is harder to maintain clear boundaries at all times, and health care providers must constantly engage in self-care. The proximity to death faced by children and adolescents introduces the individuals witnessing these sad events into a state of grief. Nine-year-old Otávio had an ulcerated osteosarcoma in one of his arms and represented impending death in paintings. An imperious volcano, about to erupt and "kill everything around it," surrounded by beautiful fields and fruit trees with a bright sun making up the scene of a glorious afternoon. He gave the painting to his mother, who put it on display in the ward.

The discomfort and distress evoked by the painting was clear among his caregivers and medical staff. The volcano about to erupt with its smoking crater eclipsed the beauty and lightness of the scene. While contemplating Otávio's work, one cannot help to remember the summer walk through the countryside described by Freud in "On transience"[18]. Although beautiful, the scene around them gave his poet friend no joy on account of its transient nature and the fate that awaited it with the arrival of winter. Freud associated the disturbance of the poet caused by the fragility of beauty with two different impulses: "aching despondency" or "rebellion against the fact asserted".

It is as if

> The idea that all this beauty was transient was giving these two sensitive minds a foretaste of mourning over its decease; and, since the mind instinctively recoils from anything that is painful, they felt their enjoyment of beauty interfered with by thoughts of it transience (FREUD, 1916/2010, p. 250, my emphasis)[18].

There was life beyond the confines of the menacing volcano. After all, as Freud wrote, "since the value of all this beauty and perfection is determined only by its significance for our own emotional lives, it has no need to survive us and is therefore independent of absolute duration"[18]. Health care providers are faced with a constant challenge. How can one be close to a dying child without becoming blind to the point of not seeing the sun and the clouds in Otávio's painting or not hearing the endless fictions and stories built by living and wishing children and adolescents in spite of death?

Even when immersed in "aching despondency," health care workers cannot cease to support the subjects they treat. In the words of Lacadée (2011), "uniqueness can only be heard if everyone is allowed to describe with their own words what is going on in their lives. Therefore, the effort revolves around creating a place where individuals can be in touch with what makes up their impasse"[13]. This appears to be the challenge for those who choose to listen to children and adolescents facing the prospect of dying but who are nonetheless living, wishing subjects.

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