© *The Psychoanalytic Quarterly, 2023*
Volume XCII, Number 3
http://dx.doi.org/10.1080/00332828.2023.2269940

MAKING THE BEST IN A BAD JOB: A PSYCHOANALYTIC PERSPECTIVE ON COMMUNICATION WITH CHILDREN AND ADOLESCENTS WITH SEVERE PHYSICAL CONDITIONS

BY ALBERTO STEFANA AND ALESSIO GAMBA

Ill children/adolescents who suffer from severe organic diseases have to cope with their inner experiences, therapies, and the global burden of the disease. Although sometimes depression, anger, and death anxiety are openly encountered in medical settings, other times they can be partially hidden by a reactive and defensive path. In these scenarios, psychoanalysis is challenged to contribute the best comprehension of the intimate communication, maybe hidden, and the needs of the ill patients to express themselves. The best way a child can talk *about himself is through spontaneous creativity. The adult's task is to facilitate the creation of an* empty space *and to recognize the child's mode of communication. There may be intense emotional reactions that the adult has to tolerate to not move the patient towards an over-adaptation. These over-adaptations entail the child being forced to* feel good *or* have fun, *thereby causing them to escape from their inner experience. The loss of the child's reality forms an additional burden to the child. The most valid indicator of this attitude is the ability to not take counterphobic attitudes but to allow the depression to be shared in a contact space between the child's true self and the perceived environment.*

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Keywords: Physical illness, psychoanalysis in medical care, creativity, oncological disease, communication, psychoanalytic approach.

> It is joy to be hidden but disaster not to be found.
> –Donald W. Winnicott[1]

INTRODUCTION

In defining psychoanalysis, Freud (1923) distinguished three levels: a method of investigation, a method of treatment, and a complex of psychological and psychopathological theories. Although psychoanalysis was initially focused on predominantly clinical and analytical applications, it has evolved to encompass a broad array of interests and the boundaries of applicability have expanded. Already with Freud, there had been an expansion of both the first (i.e., methodological) and second (i.e., method of treatment) level: towards art (1910), cultural anthropology, and religion (1929). This expansion approaches those *places* where the unconscious can find a form of expression.

Other authors contributed to that extension by developing a psychoanalytic dimension in new contexts, for example: Donald Winnicott (1941, 1945, 1960) added his reflections on non-pathological development, set situation, and the theory of the parent-infant relationship, which have been important additions to the psychodynamic understanding of non-clinical situations; Esther Bick (1964) contributed her method of infant observation; Wilfred Bion (1961) offered an understanding of group dynamics; and Michael Balint (1956) suggests training on the doctor-patient relationship. Whereas Elliott Jacques (1955), Isabel Menzies (1960), Selma Fraiberg (Fraiberg et al. 1975), and Franco Fornari (Fornari et al. 1985) have deepened the understanding of the affective processes that take place in hospital institutions. In the wake of Freud (1915), Erich Lindemann (1944), Kurt Eissler (1955), Armida Aberastury (1973), P. E. Hinton (1980), Colin Murray Parkes

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[1] Winnicott, D. W. (1963). Communicating and not communicating leading to a study of certain opposites. In *The Maturational Processes and the Facilitating Environment.* New York: International Univ. Press, 1965, pp. 179–192.

(Parkes & Weiss 1983), and E. Furman (1983) have analyzed some aspects of psychodynamic processes related to death.

PSYCHOANALYSIS IN THE CONTEXT OF SEVERE MEDICAL CONDITIONS

Previous investigations have only scratched the surface of understanding what patients experience when faced with a terminal illness and the process of dying. The area remained largely undertheorized and underreported by psychoanalysts (Cena et al. 2021; Kantrowitz 2017; Straker 2013). Two key challenges are, first, that defense mechanisms are activated during the encounter with a critically ill or dying patient (Despland et al. 2009; Di Giuseppe et al. 2019), and second, that there is a lack of psychodynamic training (Mintz 2013; Steinberg 2021), likely fueled by a self-marginalizing tendency of psychoanalysis itself (Stefana et al. 2021).

These situations pose issues related to communication, trust, compliance, and sharing of poor diagnosis/prognosis as well as the need to balance the *quality* of life and longevity. All these points become more salient when the patients are children and adolescents, as in the present article, which is mainly based on work experience in a pediatric oncohematological ward that could serve as a useful paradigm for other medical fields as well.

A life-threatening illness can present mild to severe relapses and multiple factors of distress. Distress can result from bodily weakness, physical disability, pain, changes in bodily appearance and functionality, separation from loved ones, isolation from one's peer group, and/or short- or long-term side effects. On a psychological level, one can observe fear of death or relapse, fantasies of isolation and abandonment, problems with sexuality and infertility, anger over one's fate, and recourse to fearful and prudent behavior, including unconscious strategies such as infantilism, regression, and narcissistic self-presentation (see Günter et al. 1997, 1999; Günter 2003a, 2003b). Furthermore, hospitalization separates the youth from the rightful ownership of their own body (Freud A. 1952), and especially in adolescence, physical debilitation negatively impacts self-esteem and ego-ideal formation (Schowalter 1977).

These psychological factors are accentuated by the prognostic uncertainty and fear of cancer recurrence (Han et al. 2021) as well as by changes in social and family functioning that is significantly disrupted and invaded by anxiety (Bakula et al. 2020; Lum et al. 2017; Moscato et al. 2022; Van Warmerdam et al. 2019).

Moreover, the necessary medical treatments, which can be long and demanding (e.g., bone marrow transplants and chemotherapy), can not only increase the child's—but also parents' and health professionals'—anticipatory anxiety and fantasies of death. These issues can also trigger the defensive mechanisms of clinicians within a medical setting, an environment (especially a highly specialized one) often unaccustomed to facing the logic of the unconscious *unheimlich.* All of these dynamics can easily interfere with the quality of care and patient-clinician relationship and can lead to increased feelings of isolation and burnout (Bernard et al. 2010, 2012). Patients, relatives, and healthcare professionals are catapulted into intense suffering and anguish that is further exacerbated when it involves pediatric patients. The persecutory anxieties and projective aspects elicited by the illness and related pain (Klein 1959) could saturate the intrapsychic and relational space of the subjects, urging everyone to defend themselves against the risk of breakdown between utter helplessness and suspended animation (Winnicott 1935). Furthermore, since pain may elicit rage and resentment, and since children may be unable to distinguish between feelings of suffering caused by their physical illness and those caused by the medical treatment (Freud A. 1952), those in pain may respond to ward staff with open antagonism. In turn, such antagonism might exacerbate their pain (Easson 1968). In the palliative care context, these experiences have been defined by Cicely Saunders as *total pain* (1964).

An obvious consequence is a need for regular psychological and psychiatric evaluation (and intervention, if needed) as a routine in the treatment of these young patients (Emanuel et al. 1990; Schowalter 1971)—evaluation that should be extended to parents and other family members (Weaver et al. 2016).

AIM OF THE CURRENT STUDY

The present study aims to propose some useful psychoanalytic reflections for adults who visit or work in hospital wards with dying children.[2] More specifically, the authors of this study comment on how creativity and *no-reaction* can be tools to help patients cope with the unbearable anger, sadness, and death anxiety while they are terminally ill, in order to sustain the experiences of ongoing existence (Winnicott's [1960] going-on-being) until the patient's (inevitable) death. Obviously, caregivers (parents and healthcare personnel) are asked to be able to tolerate their own anxiety and the depressive feelings evoked by their relationship to children with severe somatic illness; these children suffer profound and basic failures in bodily and emotional containment. Facing death can lead to feelings of being alone (e.g., "it's me who is going to die, not you"), but there should be loved ones of the terminally ill patient and/or health professionals nearby to emotionally contain them.

COMMUNICATE AND NOT COMMUNICATE

In this framework, where "dar[ing] to be aware of the facts of the universe in which we are existing calls for courage" (Bion 1979), can psychoanalysis be of some help?

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[2] In the reflections presented in this work we refer also to spontaneous *clinical* material resulting from nonclinical settings: three different competitions, involving pediatric patients hospitalized in the medical centers belonging to the network of the Italian Association of Pediatric Hematology and Oncology (AIEOP), with the support of the Health & Society Programme of GlaxoSmithKline (GSK). The first competition, "Tutti bravi!" [All good ones!] (1996), collected drawings and poems of young patients, providing a small gift for all of the participants. The second, called "Favole, Favole" [Fables, Fables] (2001), asked for spontaneous fairy tales. The last one, "Oggi comando io" [Today I'm in charge] (2003), asked for a free composition, from the prompt "to be the head for a day," even from an omnipotent position. To our knowledge, these drawings, poems, or stories were not intended to be used as a mean to start a dialogue between the patients who produced them and a healthcare professional or caregiver. Both the drawings and the free compositions have been commented on by Gamba (respectively 1998 & 2003). Alongside these material from nonclinical settings, two proper psychotherapeutic situations are discussed.

We can ask ourselves: Where is, and how does the unconscious *talk* in these contexts? What can be said from a psychoanalytic perspective? Could psychoanalysis support patients, parents, relatives, and/or healthcare workers? Outside the consulting room, how does one say something useful about the intrapsychic and relational dimensions in situations where the body and the physical nature of both illness and care take precedence?

The fact that healthcare relationships are predominantly carried out by non-psychological professionals (i.e., primarily nurses and physicians) challenges psychoanalysts to return to bedside care (Lefer 2006). Psychoanalysts could perform critical services not only for the patients and their relatives but also for the health professionals. This article highlights that it is imperative that adults not lose the ability to recognize how and what a child is communicating. This effort further challenges the defense mechanisms of all those who work in healthcare, especially when the reality of death is certain. Consequently, encouraging the receptiveness of adults may be the major contribution of psychoanalysis in a work context often unprepared to consider unconscious dynamics. Seemingly futile or *childish* communications can therefore become *chosen facts* (Bion 1950), that is, meanings and communications that come alive because they have found an interlocutor in health care personnel or family members.

BEING ABLE TO BE "HEAD OF EVERYTHING, FOR A DAY"

In her narrative, eleven-year-old Silvia would like to subject the doctors to the same treatments she underwent:

> Dr. X. starts screaming because he doesn't want to do either Rachicentesis or Marrow transplant. So I call the nurses to hold him. As soon as I insert the needle he moves, so he comes out, and I have to drill another hole in him. Then it's the turn of the doctor most hated by the children and mothers in Pediatric Hematology. [quoted in Gamba 2003, p. 43]

She is very happy because she has taken "revenge for all that I have suffered these eight years and to have tortured them as they have tortured me from time to time" (Gamba 2003, p. 43).

WHERE DO THE GHOSTS OF HATRED AND TORTURE LURK IN A HOSPITAL WARD?

Vincenzo, age 10, tells of wanting to "Stop time: I would like to stop time so that all the children in the world could play all the games. I wish it never became night to play more" (quoted in Gamba 2003, p. 40). An everyday reading might suggest that this child just wants to play, wants to stop time to never stop the play. A conscious look at the darkness of the unconscious and the night allows one to see the need of this child to find someone to talk to him about the persecutory anxieties that loom in the darkness of the night, an intrusion one would like to stop.

It seems to us that for hospital environments, in their complexity made up of people and emergencies, it is extremely difficult to be capable of seeing, for example, the experiences of *torture* or the ghosts that hover inside certain patients.

CLINICAL ENCOUNTERS

The first vignette presents a drawing (see Figure 1), a *spontaneous gesture* that a child—Alberto, 8 years old—drew during his hospitalization for an oncohaematological disease. The drawing in Figure 1 reflects on life and death and challenges caregivers (parents and healthcare personnel) to face his intimate questions. The second vignette is also a drawing (see Figure 2) and is made by Alessandro who is 13 years old. In it, something unthinkable, resembling a storm, seems to be laying on the white sheet, possibly symbolizing the turmoil and breakdown leading him to question his personal identity. The third vignette describes what happened between a young resident pediatrician and Daniele, a sixteen-year-old adolescent patient with terminal cancer. They spent long moments playing checkers as a means of staying active while facing the collapse of the adolescent's body right up to the very end. After those final moments, the pediatrician looked for the consultant psychologist to share his experience. Lastly, the fourth vignette is about psychoanalytically orientated work done with the 7-year-old child, Stefano, after he was hospitalized for checkups due to a congenital heart disease that required three surgery in his first years of life and

FIGURE 1 Martian mouse

FIGURE 2 Stain

implies an increased risk of cancer (Karazisi et al. 2022; Mandalenakis et al. 2019). He was waiting for a donor so he can receive a life-saving heart transplant.

ALBERTO'S MESSAGES FROM CREATIVITY

The drawing shown in Figure 1 was produced by a child named Alberto. It was titled "Martian mouse" with the following inscription: "PENSO - SONO - INNAMORTO[3] DELLA - TERRA" (translated: I THINK - I AM - IN LOVE/DEATH WITH - THE EARTH," capital letters are original). Attached to this very anthropomorphic mouse is a string and a red heart that is reminiscent of a bag for blood transfusions that looks like a balloon that can "fly up into the sky"—an Italian metaphor to express when a person crosses over to the other side.

When first seeing this drawing—like discovering a fresco painting while renovating a house—the observer has an emotional experience. This was a personal message, so true and intense. Such intimacy evokes observer's thoughts and emotions through the *lapsus linguae* in the Italian words (i.e., the misspelling of *innamorato*—being in *love*—with *inna/morto*—being in *death)* and the heart drawn as an IV drip. We can imagine Alberto relating to this mouse, seeking to explain his feelings, the experience of death, and his sense of being like a Martian—someone from another planet (or perhaps in or going to another world?). He thereby imagines losing his thoughts and affections, everything that has kept him part of this world.

Alberto's drawing challenges the observer to explore the depths of its meaning: Who was Alberto? How did he feel? Could he speak to someone about his drawing and the thoughts it embodied? Perhaps the drawing stood for something he was not able to articulate (Bollas 1987) yet promoted his physical and mental health and without which he would have lost a piece of his past and present? What could we (and psychoanalysis) have told Alberto and/or his parents upon receiving his drawing? We do not know whether he died or is still alive, but it is difficult to let go of the questions this one piece of art generated.

ALESSANDRO'S FEAR OF BREAKDOWN

When a pre-adolescent named Alessandro filled an entire white page with something representing an "emotional storm" (Bion 1979), he is

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[3] 'INNAMORTO' is an invented Italian word combining the notions of *being in love* (*innamor-a-to*) and *being in death* (*innamor-to*). In capital letters is the original spelling.

expressing an impassioned message. The paper contained a stain, an obscure magma of strong chromatic and dynamic impact; bodily tension seemed to overwhelm everything and everyone (see Figure 2). A shapeless stream of violet spots and flows—perhaps resembling a dark bloodstream?—like a Jackson Pollock painting, seems to overwhelm all the white and empty space; this could represent Alessandro's feeling of being without containment or losing all control and his identity. No shapes, nothing that can be recognized, a set of violet cluttered brushstrokes, his drawing is titled "Pazzoide" (in English: "A loony one"): maybe something similar to *madness* could be the right word to describe his inner world, which is filled with a sense of loss and fear of breakdown (Winnicott 1964). We can easily imagine that the title he chose poses implicit questions such as: how crazy/insane am I? How mad can I get? What is happening to me and my body? Is there anybody out there able to listen to me? Who do you say I am?

DANIELE'S STRUGGLE TO PLAY UNTIL THE END

Daniele, a 16-year-old adolescent with B-cell acute lymphoblastic leukemia, received a bone marrow transplant from a matched sibling donor in autumn 2016. Initially, the transplant seemed to have been successful, even after a graft-versus-host disease (GVHD) had caused some complications. Several months later, Daniele's condition worsened and he eventually passed away in summer 2017.

Daniele presented a depressive and restless mood, often complaining even though the physical pain was under control. As said by Daniele's doctor, R:

> During a nightshift I was able, I do not know how, to calm him down … .We started talking about a lot of different things, such as sports, films, music … .We found out that we were both interested in playing Chinese Checkers … .During the following night-shifts, when it was possible, we often met to play Chinese Checkers, and regularly he won. Two months after his dismissal from the hospital, I met Daniele during his medical controls. He asked to be visited only by myself, and therefore we went on talking again. Daniele's mother often

> brought cakes she made for me. But things were not going well. In May 2017, hepatic *Graft-Versus-Host-Disease* worsened and heavy immunosuppressive treatments were adopted. I was beside Daniele and his family trying to explain to them what was happening. I was worried about my inexperience, but they didn't care about it. They trusted me and wanted me beside him. His fragile health conditions rapidly worsened: the last night I was with him he had an epileptic crisis that lasted all night and didn't respond to our treatment… .In some moments, he was alert… .I held a syringe in one hand, and his hand in the other… .Early Saturday morning we decided to transfer him to our intensive care unit… .Then my shift ended. When I arrived at the hospital on Monday morning, I was informed that he died the day before. After a long uncertainty, I went to Daniele's room where his parents and brother were collecting all the objects that he took into his hospital room during the long stay. I cried like a child… .It was a strange thing… .They thanked me for my friendship and closeness toward their son. His parents supported me.

Some days after these events, R. asked the psychologist for a moment to discuss what had happened. In this supervised session, R.'s inner experience emerged clearly. He was (maybe fortunately) not experienced enough to respond defensively to the situation of seeing a dying boy where both doctor and patient needed and desired to play Chinese Checkers together. Two living and capable players were meeting and had to face each other. "I was uncomfortable, I felt like I was wasting time playing with him, while his life was at stake… .Should I have told him about the disease?" asked R. "What would you have put between you two?" replied the psychologist. After a few moments of disorientation, R. replied, "I would have put my fear there… my fantasies of what could happen, of suffering, of losing him … .I would have stopped playing with him." It was difficult (for both R. and Daniele) not to feel the weight of these contents. Perhaps, within limits, this play facilitated the creation of a *potential space* that replaces the *disease space*.

STEFANO, BETWEEN ARIEL AND THE MONSTERS

Stefano's parents requested a psychological consultation on the suggestion of a nurse who had been very impressed by the child's request to stay in the room with him in the dark and by the sense of not having a *whole* or coherent image of that child. On the one hand, the child seen during a brief hospitalization for check-ups was very adjusted and sometimes anxious to receive the usual medication, even to the point of reminding the nurses himself. On the other hand, the child described by the parents was always on the move at home—almost unable to be quiet—to the point of running around their table several times a day or running away from the school classroom. The thoughtful gaze of this nurse prompts her to look beyond the image of a *very good and nice child* with evolved language: the best patient for her colleagues and medical staff. Because of this heart problem of his, Stefano tires easily when he makes important efforts. Despite this, "Stefano does what he wants, he doesn't sit still, he runs, runs, runs," his parents recount.

The interactions with this child followed in psychotherapy[4] were very rich, in part due to a complex family situation (father who became an alcoholic after a period of unemployment, central female figures in the extended family unit, physical disability issues in a cousin). However, the passages below let two strands emerge more clearly, closely intertwined with each other. The first concerns the possibility of working with fantasy—through functional identifications to keep alive hopes for life and evolution—and to somehow master the situation. The second concerns fears of being in the foreground.

These two dimensions interrogate the medical, psychotherapeutic, and psychoanalytic worlds about the possibility of a common dialogue, outside the specific setting of each (perhaps reductive and certainly much easier to manage) and within the real integration that takes place in the psychosomatic unity of each.

In the first encounter, Stefano says that he gets bored of sitting still and wants to play. Once his parents leave the room, he says he cannot go

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[4] One of the authors (AG) saw the parents and supervised the work of the therapist (Dr. Luca Pasquarelli) treating the child.

outside alone because someone might catch him, “There are so many humans who think I am a child in trouble and they catch me.” To a question aimed at better understanding this thought, Stefano responds in a confusing way, using complex concepts but mixed in a way that makes them hard to understand. He speaks of two different “species.” “Small to big, one to the other, big to small, if you lose weight you become small,” he says. He explains that he wants to get big and that it is the most important thing for him. The therapist asks if he is afraid of not getting big, and Peter replies, “if someone says I won’t get big, I tell them I will, that I can make it.” He told his father about being half human and half robot: the heart is human, true, and the rest is robot-like with bones that do not break. He also likes the WINXX fairy characters, fairy-type creatures that can fly, very much.

He is also very passionate about the character of Ariel from the Disney movie *The Little Mermaid*. In a session, he explains that Ariel is a mermaid who wants to be human and wants to see the land, but her father is against it. When prompted to say more, he tells that he, instead, happened to be scolded by his own father when he jumps into the water because he has “a bad heart.” He would like to be a mermaid because she can “swim in the water and have many friends,” while he only has human friends and has to walk. He says he dreams of being a mermaid. He asks if the session time is almost up. The therapist comments that maybe sometimes, having a bad heart, he imagines that he will not be able to do the things he wants to do. Stefano repeats that he dreams of being a mermaid or a fairy and that sometimes dreams come true.

In a later session, exploring the room Stefano sees that the blinds can be controlled by switches as can the light. He says he likes being in the dark, although it is not so easy to be in the dark. He makes it dark by closing the shutters. He says he likes the dark because “we can pretend to be monsters.” He says monsters are scary and sometimes you need to know what they look like. “If we stay in the dark for a while they appear, in the light they don’t,” he explains.

The next session, he turns off the lights again and “it gets so dark you that cannot even see.” He asks if the room is safe because of the possibility of monsters coming from outside. He turns off the lights and approaches the therapist, waiting for a monster to come out. He then checks around the room that monsters have not appeared. “The dark,” he says, “makes me so afraid.” The therapist comments that it is important to know what scary things look like and asks if Stephen is interested in them. “So much more, yes,” he replies. In the darkened room, Stefano begins to describe the various objects in the room, which gradually become more and more disturbing: the crocodile cries, there is an invisible bear, the little house becomes haunted, there is a vampire that can come. He then says he no longer wants to play the “who’s scarier” challenge. He turns on but then turns off the lights and says he wants to do “the challenge of not being scared anymore” and adds that maybe the doctor will be scared as well.

It is a well-known fact that hospital healthcare declines at night, and night is the most difficult time for all hospitalized patients. It is then worthwhile for psychoanalysis to help ask what comes alive at night and how to take this into account during the day. After all, the night is the night of dreaming, nightmares, and separation. Over-adaptation is a symptom that something is missing (e.g., depression and death anxieties) and that what happens in the hospital (where important life-and-death issues are at stake) must be correlated with what is missing outside the hospital. One might wonder how it would have been if this nurse had not seen it. A psychoanalytically informed look helps to give the right space for the search for and emergence of what the child feels within and thinks about themselves. Doing so reduces the risk of a mechanical replacement of a part, as with a car. Essentially, it is like taking care of preventing rejection of the new organ, not only on a physical but also on a psychic level. This kind of looking is even more important considering that it is unthinkable that everyone underwent a psychotherapy to talk about it.

SHOULD THERE BE A SPACE FOR SADNESS?

Medical professionals in hospital wards and, more generally, in the daily lives of patients and their relatives, can strive to support and increase general well-being, even when death is imminent.

In trying to accomplish this, what can be learned from Alberto’s (Figure 1) and Alessandro’s (Figure 2) drawings? How valuable and important were the Chinese Checkers games for Daniele? Were they merely a competitive pastime lacking any clinical value or a futile use of time? Or perhaps, did the games serve a therapeutic purpose (beyond any medications doctor R. could have prescribed)? Reviewing relevant psychological literature uncovered some papers (e.g., Jörngården et al 2007; Phipps et al. 2005, 2009) that presented an optimistic and reassuring view about children's response to having a severe disease.

What meaning can it have for Stefano to have a human heart and for everything else to be a robot? Or to want to be Ariel or a flying fairy? Are they futile childish activities or attempts to bring order and find a space-time-body to inhabit and humanize? What use can be made of being in the dark? Can a health professional accept being in the dark with a little patient without thinking of wasting time behind a whim, but rather with the awareness of being in the midst of a clinical act?

Many studies based on self-report measures show that after diagnosis children with cancer report significantly better psychosocial adjustment and higher health-related quality of life than their healthy peers (Jörngården et al. 2007; Phipps et al. 2005, 2009). These children "appear exceptionally well-adjusted" (Phipps, 2005 p. 1056). Moreover, mixed methods research studies (e.g., Günter et al. 1997, 1999; Günter 2003a, 2003b) have shown that before and during hospitalization for a bone marrow transplant, children were able to adapt to the needs of treatment, suffer only slight depression, tended to avoid the subject and to regress a little, and often put up a facade of tranquility. They wanted to demonstrate that they were not afraid or depressed, that they were extroverts and communicative, and that they were confident that everything would be all right. During treatment and hence in isolation, this *hyper-normalization* was even greater. It should be noted that some authors suggest that these findings might be biased due to a pediatric cancer patients' tendency to deny difficulties of their socio-emotional functioning (O'Leary et al. 2007).

There is also strong evidence that supportive approaches to health and family environment can increase resilience (Rutter 1987; Luthar, Cicchetti & Becker 2000; Steele et al. 2015). Meanwhile, the current treatment paradigms are oriented toward interventions designed to help increase the patients' and their parents' coping and resilience through "family-systems informed cognitive and behavioral therapies that are delivered individually… with strong theoretical frameworks based in social ecological psychology, resiliency and illness-specific coping models," as well as "problem solving skills training" (Kearney, Salley, & Muriel 2015, p. 633).

It is increasingly recognized that:

> [The] expression of the myriad of emotions children and adolescents experience at end-of-life warrants encouragement and responsiveness. Exploration and expression of emotion are captured by mediums children are used to, ranging from painting/drawn art, video collages and testimonials, to website making and blogs, as well as music, writing/journaling, and talking. [Brand et al. 2017, p. 13]

Each of these mediums allows the patient to express certain emotions that would not have otherwise been able to find a voice; these tools also create a space for potential conversation in which the patient feels free to be, to speak or stay silent (Stefana & Gamba 2018). Such an exploratory encounter should be characterized by the clinician's purpose being to reclaim (Alvarez 1980) the patient as a subject with a more active role in the encounter as well as to give the patient feedback or insight through verbal communication characterized by careful attention to its non-verbal elements. In other words, the above-mentioned media and tools encourage conversations that are *non-analytic* and in fact help the patient explore the emotional meaning of their unique experience.

But what kind of emotions and thoughts can or should be expressed? A major approach by medical professionals seems to look for something *outside* the illness to experience. This redirection is known as *diversional activities* (Wheeler & Houston 2005). Particularly in the pediatric medical setting, there is often an attempt made to offer the patient a distraction from their medical condition, providing different contexts from the ones that are specific to the illness. These *diversional activities* are based on the idea that any situation too intensely focused on the disease can cause psychic imprisonment and then claustrophobic anxieties. The patient may feel persecuted and imprisoned by both his illness and the required treatments. Activities such as pet/art/book-therapy and clown therapy are methods "utilized as a form of distraction that allow children to cope with painful or stressful situations" (Aguilar 2017, p. 176). By "distract[ing] these young patients with therapy [that the professional] may also assist in preventing permanent traumas from treatments, procedures, or the illness itself" (Aguilar 2017, p. 176; see also, Urbanski & Lazenby 2012). Similarly, in a review on the role of clowns in pediatric intensive care units, it is said that the "literature suggests that hospital clowning may limit the negative impact of children's hospitalization and have positive effects on children by demystifying and distracting from painful procedures, reducing anxiety in stressful situations and providing hope through humor" (Mortamet et al. 2017, p. 672).

While theoretical models need to be further refined and elaborated and with the understanding that diverse psychological responses can coexist (Shapiro 2007), it is difficult to believe that experiencing a severe illness that could result in death does not have negative repercussions for the subjects (young and adult persons), even when resilience is improved or reinforced by that experience. Making resources (e.g., outlets for creativity) hopefully would improve the patient's ability to cope with the illness. However, an additional strategy is to leave some space in which sadness, fear, and pain can be freely expressed, acknowledged, and—if clinically appropriate—shared with an adult. If this does not happen, dissociation, pseudo-adaptation, or maniac defense may result. Looking deeper into this issue, two questions arise:

1. Why should diversion be important?

   Obviously, diversion should reduce the anxiety of being confined to a hospital bed. Logical thinking suggests that when the child is not undergoing the difficulties of the strict medical treatment, they should not be left in a void. Instead, the time available should be filled with good things: the child can play if that is what he/she/they want to do or watch a movie or a magic show performed by a clown. But what theories underpin this approach to play and suffering? How exactly do play, laughter, and unusual experiences help a sick child undergoing chemotherapy or facing a bone marrow transplant, even though the underlying anxieties about suffering and death always exist at some level?

2. Is it enough to alleviate the suffering of a child by getting the child to smile? Does he also need support in his moments of despondence? What should the adults be better aware of ?

> From a psychodynamic point of view, this question can be answered by concentrating on the imaginative faculty of the child and adults. In essence, a willingness to work with the imagination in a way that is specific and tailored to each individual involved in the disease process is fundamental. First, adults can usefully address the child's dreams if the reality of the situation (in its broadest and most subjective sense) first has been dealt with. Before laughing clowns, it is necessary to consider and observe what happens, how doctors and nurses (along with parents and relatives) can handle smiling but also sadness.

Faced with the alternative of running away from the disease or inhabiting it, the professional is required to learn what types of behavior are adopted to face suffering, as well explore the value of drawing, playing, doctor-clowns, etc. in an environment where pain and speaking to doctors are daily occurrences. Do these alternative activities help the patient to think about something other than the illness itself or to think *differently* about the illness and its risk of death? In meta-psychological terms *thinking about something else* means activating defense mechanisms of various intensities; it involves staying as far away as possible from one's inner world of fantasies, anger, and anxiety, which the threat of death amplifies. This is the most common emotional reaction to serious illness; it corresponds, in diagnostic terms, to calling a tumor a *cyst.* Whereas, *thinking differently* involves a new way of approaching the illness, which does not include flight (from anxiety) but allows contact with a different reality (the entire world)—i.e., taking the necessary distance from concrete facts and from the diagnosis itself to get closer to the child's feelings, fears, and fantasies. The care environment's challenge is to find or create tools and resources to inhabit and animate a world that survives the intrusion of the disease and the sense of uncertainty and alarm about the outcome.

From this perspective, speaking of *diversional therapies* could not be completely appropriate. What matters is not *diverting* thoughts but *converging* thoughts. Everyone involved with the child's care should try to enable him to embrace the experience, or a part of it, by giving value to creative abilities. He can thereby share the toughest experiences without succumbing psychologically. The time and space given to playing can therefore be thought of as not only a container of pleasant, relaxing events but also as a *re-creative* environment where part of the experience could be managed and even transformed. In a classical way, we can also interpret Alberto's picture or Stefano's staying in the dark as a dream where the oneiric?—work transformed (through a *durcharbeitung* [Freud 1914])—the latent content within a manifest content, and maybe an analyst could have interpreted this *dream* in an analytic situation. But how do parents or health professionals interpret this picture? What do those outside the analysis room see? It is difficult to imagine a container for the thoughts and feelings Alberto has condensed into the figure of a mouse. This mouse is in love/death with the earth, a container that radically and immediately expresses a profound question:

> Am I dying? Do the blood transfusions give me life/love or, like a balloon, do they carry me to the sky? Can you be in love with someone and still be dying? Can I die, since I'm in love, engaged, with the earth?

But these issues do not exhaust the questions that we can and should be asking ourselves, based on a basic general question: what does a child 'do' when they are ill, whether at home or during hospitalization? And what can the adults do in these psychic landscapes?

Stefano wonders what monsters are made of. Who has the courage to turn off the light to loosen control and thus be able to see these monsters in a situation where the distinction between reality and fantasy does not have such clear boundaries? (Stefana & Gamba 2024).

The emphasis on play and psychosocial support isn't enough, given that nobody can solve the uncertainty about the illness outcome (life *vs* death), wipe out the disease, as if by magic or find a cure. Who wants to play in these circumstances? Isn't there the risk of deluding the child by allowing him to dream? When does the prognosis prevent dreams from even occurring? In addition, what is the mechanism to reduce anxiety? Are diversional techniques the right way to reduce anxiety during hospitalization, especially when things are going wrong?

The complexity of dealing with these issues makes it impossible to try to alleviate the psychological weight of the illness as quickly as possible. An emphasis on *feeling better* can cast a shadow over the equally necessary focus on *where we are* and how the child feels in his bad moments (Winnicott 1968).

When you are sick, *feeling better* involves, at least partially, a psychic transformation of bad feelings when medicine offers no cure. To feel better also requires transforming the raw sense data (Bion's *beta*-elements) of an emotional experience into (*alpha*) elements that can be used for psychological work (unconscious, preconscious, and conscious)—i.e., the ability to dream (Bion 1962; Ogden 2003). Through this work, the patient brings the experience of the sick body into the psyche and sense of self. After all, we believe "play is an imaginative elaboration around bodily functions, relating to objects, and anxiety" (Winnicott 1989a, p. 60), suggesting that creative arts such as drawing, writing, and playing are not merely diversional activities. They are a fundamental way that a sick body can join the thinking psyche in a more integrated manner. Sensations accompany feelings, fantasies, and thoughts.

However, moments of silence and peacefulness are also necessary and should be provided by adults so that the child—*lying fallow* (Khan 1977)—can experience himself, even in a condition of suffering. In this way, defense mechanisms can be more dynamic where the *need to survive* does not overcome *the possibility of occupying the area of living* (Gaddini 1977).

In connection with *the ability to feel bad,* Winnicott (1958b) writes that "The environment must remain supportive over a period of time while the working-through [mourning] takes place and also the individual must be free from the sort of attitude which makes sadness impossible" (p. 168). In this context, mourning is related to losing the sense of well-being and the breakdown of the fantasy of being safeguarded from anxiety, deterioration, and death. Experiencing sadness and pain is unavoidable, especially for terminally ill patients. When it *happens* the child should be free to live that experience, because it embodies what is ever-present, day in, day out (i.e., the illness). Therefore, a psychic place for sadness has to be made available.

Hence, the focus no longer remains predominantly on an *objective* outer world (e.g., the number of white blood cells and the response to treatment) but also incorporates the inner world or the inner world of the patient (i.e., fantasies and experiences) and the patient's relationships (i.e., the bond between the child and others, the linkage between fantasies and the inner worlds). The child's ability to use his imagination and to produce creative creations is an indicator of health (as important as lab results) and has dual functionality: the first understands and *tames* the experience of the illness without denying it; the second is able to hold up subjectivity without feeling that the body is burdened with sickness or that the illness is a *ball and chain* preventing flights of the mind.

Faced with a child who may be dying, an adult who is frightened and unable to accept human vulnerability cannot respond to the child's fear of death. The identity of the suffering child exists only if the adult can accommodate the child and his/her/their experience: "If I can't talk to you about my suffering and fear of dying, I cannot exist for you as a living, suffering being," the dying child might say.

In this context, adults can interact with children who are seriously ill by taking an interest in their drawings and games only if they are able to perceive, tolerate, and contain their affection, including their personal suffering (Bion 1962; Raimbault 1978), and if they are able to reconcile the realm of reality with their (i.e., the adults) creativity (Stefana 2011, 2019).

Sometimes the drawings, games, and fantasies of the child are treated as futile, meaningless, unrelated to the experience of the illness. The child's creations cease to be a way of communication because they are devoid of his/her/their self, or rather because they are emptied by their caregivers' defense mechanisms and inability to appreciate the child's creativity. This failing in Bion's (1962) alpha function and *rêverie* leaves the child unable to dream their emotional experience; and hence the child "is unable to change, or to grow, or to become anything other than who he has been" (Ogden 2005, p. 2); i.e., he is destined to remain a child filled by the disease, even if cured. Without the ability to grow from these emotional experiences, personal relations become empty and artificial. Time stops and the sick child is placed in a state of *suspended animation* (Winnicott 1935) or in a *no man's land* or a *non-place* in an anthropological view (Augé 1992). It is a process that is blocked, potentially for a long time, a sort of black, frozen time, seemingly static but slowly tending to implode. Finally, the ongoing illness withdraws the body of the child from this subjective world, and everyone has to face reality, disappointment, and collapse.

LIVING THROUGH CREATIVE EXPERIENCING

In this framework, children's play and drawings are not only a way to spend time but a way to express themselves and their perspectives and/

or experiences (Di Gallo 2001; Farokhi & Hashemi 2011; Gamba & Stefana, 2016; Klein 1932, 1955; Stefana & Gamba 2024), sharing feelings and thoughts. This requires the adult's ability to create and hold onto an *empty*, unstructured space and time in which the child feels free to speak, act, experiment, or not, as they wish (Stefana & Gamba 2018; Summers 2008). This is what can happen in some oncology work experiences with adolescents, where creativity (thanks also to a certain amount of courage) is combined with listening: "a way to open a window to their inner world" (Ferrari et al. 2023, p. 2; see also Ferrari et al. 2012). The drawings made, games played, and dreams told have "real existence in the outer world and at the same time, in their content and their form, [come] entirely from herself and her inner world, they were a non-discursive affirmation of her own reality" (Milner 1969, p. 242)—they are a fragment of external reality where communication can take place. In terms of the ability of the child to represent their experience, the organization of time and place is not merely a matter of just allowing the child to be creative with drawings and poems; this organization also involves the capability to make *use* (Winnicott 1969) of the environment, the family, and the health professional team to receive an *imprint* (Bertolini 1999) by the patient. They can accommodate and be transformed by what the patient projects.

These last issues are a significant indicator of the quality of the care the child receives. They cannot be considered as only secondary to the urgent need for medical therapies.

In situations where threats to life are real and impending, children need to be allowed to express themselves without their drawings necessarily being viewed as messages to be decoded. The object-drawing requires a space between the child and the caregiver in which creativity is viewed as spontaneous space (Stefana & Gamba 2024). Importantly, this creativity can be destroyed if there is too much insistence on trying to feel better. Just as a healthy child can be alone in the presence of someone else (Winnicott 1958a), also a sick child can be helped to surrender to his feelings in the presence of another (or not to another; Ghent 1990) and to express himself without anyone taking control of his feelings and thoughts, interpreting them or forcing defense mechanisms upon them.

Faced with Alberto's drawing of a mouse that is in love/death with the earth or Alessandro's statement about madness, craziness, healthcare providers (or relatives) may become disoriented. They may clearly see the reference to death but not know what to do with it. Despite the fact that adults might not know how to react, little is required. The adult needs to be there when Alberto draws, look at his drawing, and take care of *the mouse in death* (a shared transitional object[5]) while realizing that the drawing is Alberto's attempt to come to terms with his experience. The adult should protect the child's ability to represent that experience and to create symbols and illusions in the presence both of another person and the illness. As for Alberto, speaking about the mouse means containing and temporarily taking care of feelings and thoughts (some spoken, others unspoken) discreetly and respectfully. Alberto will establish a relationship with the mouse according to his needs, which are only known to him. Fortunately, this happened with Daniele thanks to a *living doctor* who was able to stay there, both with Chinese Checkers on one hand and *a syringe in the other* (Raimbault 1975).

In the act of playing, "the child manipulates external phenomena in the service of the dream and invests chosen external phenomena with dream meaning and feeling" (Winnicott 1971, p. 69). Here the dream is seen as a means of expression, a phenomenon which can be made to take the shape of one's own fantasy. Play and (night as well as waking) dream are outcomes of creative psychic work in the child's own world and, at the same time, constitute a space in which to work through personal experiences (Stefana 2018; Stefana & Gamba 2016). If adults are caught off guard and if they consider the child's play and dream irrelevant or bizarre, the child will not befriend his/her own unconscious and give credence to his/her dreams (Ogden 2005); the child will experience only uncanny elements (Giannakoulas 2010). As a matter of fact,

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[5] Winnicott (1953, 1967) defines the transitional object as representing a *bridge* between inside and outside, me and not-me, or even—in Bollas' (1987) understanding—known and unknown. Here we propose a slightly different definition: a point of *intersection* between inside and outside. According to our reading, Alberto's drawing of the 'Martian mouse' or Stefano's body containing both human and robotic parts represent a symbol-object that merges the conscious parts of Alberto/Stefano with an external character, a bearer of parts of himself (without these being explicitly recognized or interpreted). See also the Teddy puppet mentioned by Hinton (1980) and Ogden's (2018) work on the feeling of real.

in such a scenario all that dreams, drawings, and creative activities can communicate is lost. And, as a result, the process of sharing and working through, with the accompanying effect of giving meaning to experience, is blocked. Because of the caregiver's failure to accept the child's feelings and give them meaning, the child has no way of dreaming about his own emotional experience, causing undeniable stressful and dramatic consequences on the child. Employing both dream and play processes to represent a good-enough attitude "neutralizes the external persecutions and prevents the feelings of disintegration and loss of contact between psyche and soma" (Winnicott 1952, p. 99). Therefore, by no means is play a distraction or diversion from the child's experience.

When patient care triggers hyperactivity, forces optimism (therefore a manic defense, or rather the unfamiliarity of a part of the Self to itself) or being elsewhere (a defense based on avoidance), or encourages shutting oneself off through denial and so on, care has failed. On the other hand, when a caregiver waits and allows himself to be *used* (Winnicott 1969) by the child, the child is free to modulate the time, rhythm, and intimacy of the meeting, all in relation to his suffering. Such an approach exemplifies good care.

Work also needs to be done, in small doses, by the child (and, if possible, his relatives) to take time to share concepts and integrate them—a psychotherapeutic time—to treat the psyche in the sense of "a psychological-interpersonal process intended to enhance the [patient]'s capacity to be alive as a human being" (Ogden 1996, p. 888).

In the case of physical illnesses, a patient's emotional health derives from the capability/possibility to establish an oscillation between sadness/suffering (which is the state that the ill patient experiences the most) and distraction/enjoyment, as well as to strike a balance between internal and external persecutors (experiences of a painful nature are experienced as persecution and in turn might increase the child's sufferings [Freud A. 1952; Klein 1946, 1948]). If this does not happen or if it does not occur often enough, *physiological* pain/suffering can be transformed into an emotional disorder. There needs to be a kind of transitional space in which enjoyment and sadness can coexist and where the subject can live both inner and outer realities.

SOME INSIGHTS TO CONSIDER

Seriously ill children experience intense and troublesome emotions that they should be able to communicate to someone if they wish to do so. They should also be free to feel bad emotionally without being *forced to feel good* and without needing to be *distracted* from their emotional state. In this context, the quality of pediatric care is measured on the basis of how healthcare personnel listen and handle the psychological issues involved, including quality of life. From Freud to Britton (2005), psychoanalysis shows that trauma is not always the result of concrete events. Winnicott (1931–56, first part) noted that children who lived through the London blitz of World War II and felt emotionally supported were less likely to be afraid of the bombs dropping from the sky than would be expected. The best way for a child to *tell their story* is through creativity, i.e., through play and drawing. These are not *diversions* or ways to think about something else, but are creative means of expressing emotional states for which words are lacking (Lemma 2000). Play and drawing come from the (bodily and psychic) experience of the child, whether consciously or unconsciously. A child would never have said he felt he was *in death*; however, he was able to represent this feeling creatively in his drawing. The caregiver's task is to be with the child to contain the suffering so it can be thought about, no matter how difficult that challenge is. Perhaps the best way to help sick children is for adults to manage the sadness they feel with and for them, then to provide some *free space* in which the child's fantasies can take shape. The presence of someone able to receive communications (in the various forms invented by creativity) and understand what the child is expressing allows the child to give shape to something that would otherwise be impossible to grasp and would remain unthinkable. That support gives some relief from emotional pain and suffering. In this sense, Daniele needed someone to challenge him on equal terms and share the feeling—at least in Chinese Checkers—of the possibility to win against an object (i.e., the young doctor, or maybe his fate?); therefore, Daniele could perceive himself to be outside the area of impotence and persecution. The young doctor was *used* (Winnicott 1969) as a means to share the struggle for life. And because the young doctor remained with Daniele until the end, they even shared the experience of being defeated.

And what about Alberto's drawing of his mouse? Hopefully, someone has asked him: "What do you think about your pet? Can we do something for him to make him feel better? Will he say something to us?"

Again, the psychoanalytic contribution to using spontaneous creativity as a valuable tool needs to be further examined. Death anxiety and physical and psychological suffering move everyone—both patients and caregivers—far from the illness experience and from its impingement. Words, activities, and leisure proposals may be supportive but also can become an escaping defense strategy, both for the patients and the caregivers. This last path carries the risk of losing one's self. On the other hand, an ill person can sink into a deep state of suffering without an internal space of living experience. A psychoanalytic presence can give some aid on a personal level, but much more important is the action of the caregiver to foster the affective atmosphere where people find it safe to stay, especially for adults. The essence of facing a child's death depends on the adult's capacity to stay open to and tolerate the full range of the child's painful physical and emotional experiences. The adult should share the failures and triumphs the child has without losing sight of the ineluctable end (Hinton 1980) or being blinded by the specter of death. In Winnicott language, we can say that the sense of a psychoanalytically-oriented approach is to learn to recognize when a (seriously ill) child wishes not to be found and when, instead, he/she/they want to be found/recognized but—as Ogden (2018) says—without being exposed.

The caregivers' capacity to maintain the omnipotence of the child who creates the breast (i.e., a subjective reality) by hallucinating it is critical. Ideally, the child will find the gaze of an adult just when he or she wants to be looked at. Such an adult supports the child in his or her ability to going on being, instead of reacting to illness and fate (more than to pain and symptoms), thus producing an experience of impingement that interrupts/destroys the continuity of being (i.e., the line of life). Perhaps it was R's ability to get involved with Daniele to play chess that made R the person chosen by Daniele to go through the external and internal events of his illness.

Child patients need adults help them feel free from any concern about their caregivers' needs or pressure. The desired empty space can therefore be made available to the patients for their creativity, words, sadness, pictures, anger, and silence as well; a space where the illness doesn't occupy—nor do words—the entire area of living and living together. This is the same mechanism described by Hinton (1983, p. 111) after mentioning the patient's reference to the short time he expected to have remaining to live, to wanting to play a game, and to not wanting at all to talk about his feelings.

Ogden (2018), working on the communicating/not communicating Winnicottian idea, writes: "We 'behave ourselves' by 'waiting' (as subjective objects) until the patient in his 'own time' is ready to experience us as separate objects" (p. 1297). But what can be *objective* when death is impending?

In a sense, psychoanalysis could support the caregivers in their ability to be silent, respectful, and to allow the child to choose to be (or not) with himself, but not alone.

In order to be able to perform a function of psychophysical care of the person, it is necessary to ask what our ability is to see that truth that sustains healthy growth, even under conditions of illness. Behind this approach is a twofold assumption: on the one hand, that "the substance of experience is what we bring to what we see, without our own contribution we see nothing" (Milner 1950, p. 33); and on the other hand, that "healthy mental growth seems to depend on truth as the living organism depends on food. If it is lacking or deficient the personality deteriorates" (Bion 1965, p. 38). It follows that the primary contribution of psychoanalysis in a medical care setting is to support professionals to look at the child's spontaneous gestures and acts of creativity, in which—as John Keats wrote—the most intense and "beautiful words are often unspoken ones, those who are shipwrecked in the silences."

Acknowledgment: The authors would like to thank Raffaello Cortina Editore from Milan (Italy) for permission to reproduce the drawing, originally published in Gamba (1998). Furthermore, they would like to thank Carolyn Habbersett and Diane Youngstrom for their careful reading and copy editing of this paper.

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