Pain in Paediatric Oncology and Spontaneous Drawing: Clinical and Psychological Concerns

The Experience of Pain in Children with Cancer

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Abstract: *Objectives*: Approximately 50% of children with cancer experience pain. Pain may be due to the presence of the tumour or to effects of the different treatments (surgery, radiation, chemotherapy) utilized to treat it. Drawings can be useful tools to collect hidden messages.

Methods: The children drawings collected at the Division of Pediatric Oncology of the Catholic University in Rome have been reviewed and analysed by the psychological staff.

Results: Pain is an unpleasant experience along with psychological and emotional impact causing psychosocial consequences including depression, anxiety, and mood disturbances. Our experience has shown spontaneous drawing with metaphorical representations is an invaluable aid able to express hidden feelings of children.

Discussion: Along with the use of proven scales and techniques for assessing pain, drawings can enhance the modes of children' communication on their deep emotions and fears.

Keywords: Children, drawing, cancer, pain.

Children with cancer can experience pain as a result of their tumour progression, treatments (surgery, chemotherapy and radiotherapy) or needle medical procedures [1,2]. Pain is a subjective phenomenon reported as an unpleasant sensory associated with actual or potential tissue damage. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience.

CLINICAL CONCERNS

Pain during the paediatric years differs greatly from that in later stages of life, both in terms of the types and frequencies of the symptoms and with regard to the manner in which moments of pain are expressed and experienced. There is no minimum age for suffering, as symptoms of pain can take hold and be perceived at every stage of life, starting from the last three months of pregnancy. During their paediatric years, many children experience some form of pain that can be caused directly by illness, by treatments, by invasive procedures or by psychological suffering (Table **1**) [3].

It has been widely found, especially by those operating in the paediatric sector, that repeated physical and psychic pain, if experienced over an extended period of time, but without being properly managed, can ultimately compromise the normal development of the system for sustaining pain, leading to behavioural and cognitive alterations in the adult years.

Table 1: Clinical Classification of Pain in the Paediatric Age

1. Pain from procedures: this is the pain that accompanies numerous diagnostic and therapeutic manoeuvres, be their impact relatively limited (rachicentesis, harvesting of bone marrow ....) or more significant (positioning of central venous catheters, procedures of drainage, biopsies, small-scale surgery, bronchoscopy...), with the procedure at times constituting a more traumatic, more feared event than the underlying pathology itself.
2. Acute pain: accompanies many pathologies of the paediatric years, such as traumas, surgical operations, burns, acute illnesses whether infectious or otherwise.
3. Chronic pain: places significant limitations on the quality of life while exerting a noteworthy disruption, due to the emotional and psychological component of the symptom.
4. Terminal pain: the complex condition that accompanies the child in the final stage of illness, when the pain is joined by anguish and fear. The related therapy proves particularly complex and must include both a pharmacological and psychological component.

The establishment of a "shared" language to measure pain, as well as consultation of guidelines able to provide useful indications with regard to the types of drugs for controlling pain, along with the procedures for their use and dosage, in addition to the availability of non-pharmacological techniques to reduce the intensity of the symptom and the anxiety that it engenders, constitute the irreplaceable cornerstones for properly treating small patients [4].

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PSYCHOLOGICAL CONCERNS

A child affected by a tumour experiences a deep-rooted suffering, above all else physical, with respect to both the illness and the diagnostic procedures. Pain is often an important signal for the initial diagnosis, a very meaningful factor when it comes to pointing to positive or negative developments in the condition, and one that accompanies the majority of the diagnostic procedures [4].

The different causes of pain we can identify, and which are often found in combination with one another, include:

a) pain related to pharmacological therapy, radiation therapy or surgery (peripheral neuropathy, infections, dermatitis from radiation, post-operatory pain).

b) pain related to diagnostic or therapeutic procedures repeated during the course of the treatment (blood and specimen sampling, rachicentesis, bone marrow harvesting, biopsies).

Along with the medical reality, there are the equally imposing, complex psychological implications related to the perception and evaluation of the child's symptoms of pain as an ongoing reflection of the fear and anxiety brought on by the overall experience of the illness [4].

Chronic or complex illnesses, such as oncologic conditions, expose the child to a traumatic experience that extends over time, influencing or complicating his or her process of development. Extended hospitalisation, continuous clinical controls, procedures, therapeutic protocols, bodily changes, side-effects and the sudden interruption in the normal day-to-day routine (school, sports, social life) are only some examples of the events that mark a radical change to be dealt with by the child, making necessary a phase of adjustment not only on the part of the patient, but of the entire family unit as well [5].

This is the complex scenario in which bodily pain is experienced, with ramifications that expand and become more intense, blurring the boundaries between body and psyche [6]. As a result, a summary of the distinctive features of oncologic illness, plus the accompanying emotional manifestations, can prove extremely worthwhile (Table **2**).

Over time, the many medical procedures that simply cannot be avoided may heighten the experience of pain generated by the combination of the psychic and bodily components. As a result, the difficulty in distinguishing factors of physical pain from those of psychological pain can make any objective perception of the symptoms themselves all the more complex.

Table 2: Distinctive Features of Oncologic Illness in the Developing Years (Modified from Bertolotti & Massaglia, 2011)

Changes of the reality:
– uncertainty of prognosis
– aggressive treatments
– repeated hospitalisation
Bodily experiences
– suffering
– the body becomes unfit
– the self image is altered
- " monstrous state "
Emotions
– suffering
– loneliness
– exclusion
– dependency
– uncertainty
– anger
– dread of death
– hope

Chemotherapy, radiation therapy and surgery have not only therapeutic effects, but side effects that can prove aggressive, such as anaemia and mucositis, eventually leading to noteworthy transformations in appearance, starting with hair loss, weight gain and other changes that can give rise to an especially severe identity crisis.

Along with the indispensable attention that should be focused on utilising techniques with increasingly lower levels of invasiveness, favouring approaches that stress preservation, so as to improve the quality of life in the physical sphere, steps must be taken to safeguard the young patient's psychic capacity to deal in a satisfactory manner with his or her experiences, preserving the capacity to think and understand, thanks to direct, open and sincere communication with the team providing the treatment, something that cannot be replaced with measures that constitute mere "distractions". Unless the child receives a suitable welcome and support from the medical operators, he or she will perceive the invasive acts tied to the necessary therapy as forms of aggression and torture, meaning wholly negative experiences, even when the end result is a practical advantage for the patient, as in the case of the positioning of the central venous catheter. In contrast, children who encounter hospital staff capable of "taking care of them" will feel better understood, finding it easier to trust such staff and place themselves in its care [7].

It is important to note, however, that in cases where psychological treatment is neither sufficient and/or possible, at least not initially, then support from psycho-pharmaceuticals may prove necessary. Such situations of emergency/urgency can be dealt with, as a first step, by a therapy meant to limit the manifestations of the suffering temporarily, in order to place the patient in a condition better suited to "all-encompassing" (psychotherapy, psycho-social initiatives, support for the family etc.). Of course, in the great majority of cases, the psychological approach, whether in the form of prevention or therapy, proves adequate and appropriate. However, at the same time, the scarce inclination (due to cultural outlook, prejudice or simply habit) to use drugs *"for the mind"* during treatments that surely find patients bombarded with antiblastic and support pharmaceuticals, combined with the emotional impact of the illness, appear at times to explain away any manifestation of psychological suffering, without due consideration being given to the significant differences between one individual and the next.

The availability of teams with multidisciplinary skills and know-how in the field of mental health makes it possible to limit the vulnerability of patients faced with the illness while increasing their resilience and ability to adjust [8].

In therapy addressing pain, therefore, it is critical that an all-encompassing approach be taken, addressing all the different variables that come into play. Along these lines, mention should be made of the research carried out by Lonnie Zeltzer as part of the Pediatric Pain Program of the Children's Hospital of the University of Los Angeles, in California, a study in which she points to the need to use a *bio-psycho-social model* to assess pain in paediatric oncology [9].

CONSIDERATIONS INVOLVING HUMAN RELATIONS

Our reflections also touch on the ramifications of the management of pain in paediatric oncology in terms of psychology and human relations, considerations that involve the child, the family and the team providing the care.

In reaction to a diagnosis of a tumour, families adopt a defensive strategy destined to replace the approach that characterised family relations up until the time of the diagnosis with an outlook better suited to dealing with the imminent danger (Figure **1**) [10].

Gaetano, the 6 year-old brother of Gino, a patient with a medulloblastoma, comments: "There is a bomb exploding in this drawing"

Figure 1: Diagnosis of a tumor.

A reversal of the general roles, a tendency to be overly protective or enter denial, are some of the common defence mechanisms used by families to this end [11]. All the same, the symptoms of pain, an unwanted companion throughout the therapeutic process, stands as a constant threat that, by casting the child's suffering in real, visible terms, threatens to make the family's defensive efforts pointless.

Seen in this light, the child's chances of projecting outward manifestations of his or her physical or psychic pain are closely tied to the *protective function* carried out by the child with respect to his or her parents, as a result of the reversal of the generational roles. The more the child feels obliged to protect the parental figures, the less he or she can express either physical or psychic pain, seeing that such manifestations would threaten the defence mechanisms being constructed by the parents.

Our experience has shown spontaneous drawing to be an invaluable aid when it comes to allowing children to freely express their deepest emotions, seeing that the metaphorical representation both cloaks and protects such feelings (Figure **2**) [12-15].

The use of the drawing tool was found to be particularly beneficial in assisting children to express the existential challenges that they had previously been unable to articulate in words.

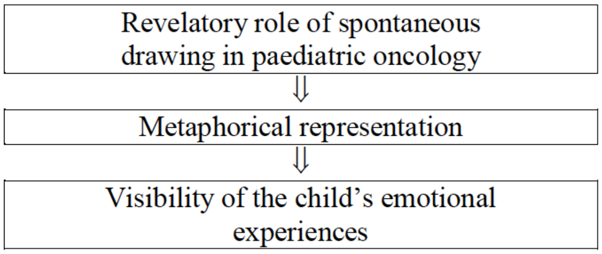

Figure 2: Spontaneous drawing.

The active engagement of children's imaginations through the use of the drawings may have significant therapeutic value for children with cancer by offering the chance to reveal the existential concerns experienced by children.

As a rule, the young patient, finding it impossible to express his or her deepest emotions (Klein, 1923), which are too excruciating to be shared with the parents, amplifies the symptoms of pain tied to the procedures or the side-effects of the therapy (nausea, vomiting....), assigning to the physical pain the task of channelling the psychic pain as well [16,17].

In such situations, which represent the vast majority of cases, the emotional suffering of the child, which finds expression through the body and non-verbal language, can easily be given a limit and a support mechanism by the parents, assuming that they, in turn, receive psychological guidance and aid.

Compliance with treatment depends in large part on the young patient having an adult intermediary capable of providing an outlet for expressions of the child's suffering, so as to mobilise the resources needed to deal with the most trying moments of the therapeutic process [18].

At the same time, our experience has shown that there exist other scenarios of interpersonal relations which, though they occur in only a minority of cases, present peculiarities that can prove seriously misleading, with the risk of committing serious errors when it comes to assessing pain.

The presence of a parent who is depressed or distraught can push the child, in a protective reaction, to minimise the symptoms of pain, in an attempt to reassure and restore the spirits of the parent, with the externalisation of bold aggressive attitudes that ultimately amount to a denial of pain. A keeping to oneself, shunning relations with others, or, on the contrary, an aggressive, hostile attitude, can be signs, in such case, of a deeper suffering that cannot be revealed.

In other instances, the upbringing proposed by "*perfect*" parents call for a heroic response even in the face of the most difficult trials presented by the illness and the treatment. In such cases the child, in order to satisfy unrealistic parental expectations, is forced to display a misleading mask of wellbeing, resulting in a complete negation of his or her physical and psychic pain.

In similar situations, the oncologist, drawn in by the effects of cooperation and gratification resulting from the child's efforts, runs the risk of colluding with the parents in seriously underestimating the suffering being stoically absorbed by the young patient.

Other complex situations can arise when overly frightened children fail, even over time, to make any adjustment to the hospital setting. Their terror in response to the experience of the illness persists, and they close themselves off completely to relations with others. The intensity of their reactions to stimuli of pain is abnormal, out of proportion with the level of pain or discomfort experienced: swallowing a syrup, undergoing an aerosol inhalation or having a cut medicated all cause the same amount of distress. In such cases, we often find ourselves dealing with other family figures who are equally frightened. The parents, in a equally fragile, anxious state, may themselves have trouble coming to terms with the reality of the illness and arriving at some form of adjustment. Once again, helping the child depends in large part on providing the adults with support: helping a parent to express his or her fragility or fears can allow them to gradually tolerate, and even limit, their child's suffering, without falling apart.

CLINICAL TRIALS

No matter how complete the information provided for the informed consent may be, the proposal of new pharmaceuticals naturally alters the process of psychological adjustment to the failure of the original therapy to obtain results [19].

This keeps the parents from having to deal with the "limit" to treatment, accepting the idea that there is nothing more to be done, resulting in an abnormal amplification of the margin for illusion, with the result that the adjustment to palliative care, should it prove necessary, can turn out to be unexpected and unpredictable.

For that matter, there is a complete lack of tools of communication designed to inform the young child or the adolescent (informed consent), though these should play an indispensable role in gauging both the emotional and clinical sustainability of a new therapeutic proposal.

Unguru *et al*. (2010) carried out a study of the ramifications of consent to experimental treatments, focusing on 37 patients between the ages of 7 and 18 [20]. The results showed that 51% of the children either did not know or did not remember that their treatment was part of a research project, while 86% had not understood the explanations provided by the physician when the experimental therapy was discussed.

Faced with an additional trial filled with uncertainty and pain, in some cases the child can feel the need to amplify the symptoms of pain, simply to express how unbearable it would be to have to go through a further test that offers hope only to the rest of his or her family (Figure **3**) [21].

Lorenzo (15years-old) suffers from a progressively worsening medulloblastoma. After undergoing a series of operations and different therapeutic approaches, he comments on his parents' illusory search for new pharmaceuticals, with a drawing that asks, in a manner which only appears to be ironic, for a "final" release from the headache that gives him no peace.

Figure 3: Unbearable pain.

In such critical situations, the role of the team providing the treatment can potentially limit the suffering to a significant extent, in addition to having a curative or palliative effect, though there is also a noteworthy risk of becoming entangled in the often dysfunctional approaches taken by the family to moving from the therapeutic project to palliative care [22].

In such cases, the risk of collusion on the part of an "omnipotent" medical team can leave the child stranded in a cone of invisibility filled with suffering, depriving him or her of the resources of palliative therapy needed during this most critical phase of the illness.

However, data from different authors suggest that children have hope and a solid desire to recover from their tumor. The adoption of drawing tool may enhance the understanding of the internal psychological suffering faced by children hospitalized for the treatment of their cancer along with the reduction of the children's state anxiety. [23-26].

CONCLUSION

Our reflections are meant to draw attention to the complexity of assessing pain among paediatric patients. Of key importance is the need to recognise the close correlation between factors of physical and psychic pain, given that infants and young children, regardless of differences in their diagnoses, their ages, genders or socio-economic conditions, find it hard to express the quotient of suffering tied to their awareness of the seriousness of their physical conditions [27,28].

Along with the use of proven scales and techniques for assessing pain, modes of communication must be found to facilitate the establishment of a relationship of empathy between the team providing the care and the child, and one that need not always be channelled through the parental figure, but that can provide the young patient with a constant, effective guarantee of care regarding not only the physical sphere but the emotions as well.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest or financial disclosures.

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