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Decision-making and Consent of Paediatric Cancer Patients: Between Guidance and Promotion of Child Autonomy

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Author's contribution

This whole work was carried out by author MB.

Original Research Article

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ABSTRACT

Aims: Assessing how medical teams in a paediatric cancer hospital cope with the legal requirement to search for the child's consent for an inclusion in a clinical trial and children's participation in tough medical decisions.

Study Design: Anthropologic Field Study.

Place and Duration of Study: Department of Paediatric Solid Cancer of La Timone Hospital (Marseille, France) between August 2004 and February 2007.

Methodology: The author attended medical staff meetings, visits and conversations between doctors, children and their parents. About 200 patients were included in the study. Numerous interviews took place with staff, parents and children, as well as with two cancer-survivors, who were cured of their childhood cancer 30 or 40 years ago. Two "blogs" written by mother of young patients were read in order to assess how medical information was disseminating towards families.

Results: The announce of a cancer diagnosis, the search for the child's consent or participation in tough medical decisions, imply new kinds of relationships between medical teams and children. That modification of positions is not easy for several reasons. First, children do not always feel free to express their views and choices. Besides, these changes disrupt the traditional model of a "medical paternalism", where physicians would know by themselves what is good for their patients. Above all, confronting children with medical choices may be of the utmost psychic violence, since children are faced with impossible choice or "double bind". Thus, medical teams have to recognise the child as a person capable of autonomy but also to provide special protection regarding their

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vulnerability. They experiment different ways to establish a dialog with children, through picturing, “discursive avoidance” and symbolisation.

Conclusion: Looking for the right balance between guidance and promotion of child autonomy, medical staff can create some “protected areas”, where children are sheltered from the naked truth by symbolisation and “discursive avoidance”, and where a genuine dialog may be established.

Keywords: Children; cancer; consent; participation; decision-making.

1. INTRODUCTION

Each year in France, 2000 children develop a cancer. Of these, 70% are solid tumors (bones and soft tissue), the rest are leukaemia. Solid tumors are heterogeneous with 40 different recognised types. Thanks to medical improvements and therapeutic progress, 75% of children currently are cured (compared with only 25% in the early 1970's). At least 60% to 70% of paediatric cancer patients are included in clinical trials. Being cured has been proven to be linked to the treatment centre where the therapy is performed, with highest survival linked to: treatment coordinated by a specialized team, in a centre big enough to treat cases regularly and participating in clinical trials with evaluation [1].

Evolution in the participation of children in their health care decisions is related to changes in the way modern society perceives minors. The introduction of several laws in France reflects these changes, both in the field of children's rights in general, clinical trials in particular [2] and more precisely in paediatric oncology treatment. Paediatric cancer patients, depending on their reasoning capacities, are now to participate in decision-making processes concerning their own treatment [3].

New kinds of relationships between health care teams and the children concerned are needed, regarding the pronouncement of a cancer diagnosis, the presentation of an individualised course of treatment, the desire for a child to consent to inclusion in a clinical trial and the child's participation in difficult medical decisions [4].

Changes in traditional attitudes are complicated for several reasons. First, children do not always feel free to express their views and choices (because of an interference of parental preferences, and also because of the child's own cognitive development). Moreover, these changes disrupt the traditional model of a “medical paternalism” [5]. They also raise the question of the right balance between child autonomy and protection of their vulnerability. Giving more autonomy to children in the medical process may raise conflicts of interest.

Care personnel are not alone in passively receiving directives concerning public health. They have to combine technical norms with practical realities while meeting their responsibilities: this opens a field for investigation into the disparity between norms and practices. In this context, medical teams try to find a balanced approach taking into account attitudes and emotions, which play an important role, as well as linguistic tactics (performative sentences, euphemism, discursive avoidance or even lies) used by medical teams in order to diminish the shock of reality.

2. METHODOLOGY

This paper presents the results of a field study in a French university paediatric hospital in Marseille, France. This hospital is one of the highly specialised centres. Seventy to eighty patients are seen each year, with approximately as many girls as boys. The youngest are just a few days old and the oldest just over 18 years old. The average age is seven.

Using anthropological methods and mainly through direct interviews with children, actual children's participation and its feasibility in the field of decision making in cancer therapy have been studied. The author spent 30 months in the paediatric oncology unit attending medical staff meetings, clinical visits and private conversations between doctors, children and their parents. Time was also spent in the hospital school and in the unit play room making observations. Conversations and interviews took place with parents and children. The author also stayed overnight on several occasions. Two cancer-survivors, who were cured of their childhood cancer 30 or 40 years ago, were also interviewed which allowed observation of the evolution in the way children are involved in their treatment. Two "blogs" written by mother of young cancer patients were regularly read. One of the two died of the disease: the blog was followed in parallel to the weekly medical meeting reporting the evolution of the tumor. It was then possible to measure the differences between parental understanding and medical knowledge at any stage.

Two hundred patients were seen during the field: main of them directly through interviews, and the rest of it through case reviewing in the medical staff. Just a few of them are presented here, because of their particularly relevant statement for the study.

Performing that study was complex and emotionally difficult: many of the children died during the study, relationships are intense and there is a constant feeling of urgency. The presence of an anthropologist could have added to the complexity of the events; however, there was no indication of adverse effects. Maybe the author's previous experience as a hospital director in several French cities in addition to a training as a psychoanalyst allowed a quicker understanding of the hospital units custom and patients relationship. The question of being too close to the research topic was also addressed.

The kids interviewed gave me an oral acceptance for writing and developing their messages. I made an oral promise to the children that I would speak out their experiences. The publication of the doctorate dissertation was required by the admission jury. A member of the jury, chief of service in paediatric oncology (field study), decided to place the dissertation freely on line¹. It then was published as a book, whose main results are presented in this paper [6].

3. RESULTS AND DISCUSSION

3.1 Children's Refusal or Lack of Acceptance

According to the law, paediatric cancer patients are to be informed about his/her disease and treatments. Informed consent is required regarding certain therapeutic choices. In pain from both the disease and treatment, combined with the aggression of medical information

¹ Available at : http://www.cpp-sudmed2.fr/IMG/pdf/TheseMarieBonnet_sans_annexes_.pdf

the weight of medical dialogues and dealing with their parents' distress, the child reaches the limits of his/her vulnerability.

The results of the study show how difficult it is for children, and their parents, to express themselves regarding the treatments they undergo. In most case, they are grateful for the explanation given by the medical team, and chose to rely fully on their advice. The rare situations of "refusal" or "non decision" are interesting to analyse:

- G. (3 years old) whose parents chose to avoid surgery (because of high risk of mortality), afterwards greatly doubted their decision and explained they no longer wished to make decisions: *"Everyday we live with the horror of it all"*. Following the death of their child the parents were haunted by their decision and the feeling that they had made the wrong choice.
- A. (13 years old) refused to be included in a clinical trial, and consequently was unable to benefit from the latest reference medication, because she was afraid of side effects of high dose chemotherapy and the risks related to fertility. She died as a result of her disease.
- B. (8 years old) had to consider brain surgery as the tumor was growing. Would it be preferable to remove a large section with the risk of reducing her motor skills, or would it be preferable to remove less, with the risk that the tumor would grow? She died following disease progression.
- T. (14 years old) could have preserved his sperm so that, in the event of radiotherapy making him infertile, he could procreate later thanks to the sperm preservation. However, he refused. In fact, he was feeling very stressed, modest and embarrassed to discuss the topic with his mother.

These cases reveal the complexity of such decisions: are the children and their family in a emotional position to make a choice? What do these "refusals" stand for: positive choice of one option? Refusal of the very necessity to choose? Refusal of the reality of illness? Medical teams are involved in informing the family and the child of the reality but these refusals are distressful for them. In light of the difficulties in these highly charged situations, medical teams use daily the strategy of discursive avoidance, which closely resembles the "white lie".

3.2 Discursive Avoidance

The strategy of discursive avoidance [7] is related to the idea of certain words and expressions being unmentionable. It appears that in private conversations, discursive avoidance is intricately linked to the discussion between the clinician and the child or the parent and child. These subjects concern references to illness, relapse; disease progression, end of therapy and transition into palliative care. It sounds like taboos about the idea of death.

This strategy allows the clinicians neither to avoid face-to-face nor to avoid announcing the gravity of the situation but to soften the impact of this frightening and devastating news. The use of omission, euphemism, progressive unveiling depends on the capacity of the patient to integrate information concerning their condition. These tactics ensure a bearable daily continuity for the sick child and his/her parents [8]. Some clinicians have used the metaphor of a "couple dancing" to express this method of giving progressive information [9].

Here is the case of a young girl with an uncontrolled disease with metastases leading to lung failure. The only solution for this child was surgery, but in light of her condition, surgery had a fatal risk.

The girl was largely opposed to the surgery. The mother was torn between the daughter's refusal and the conviction of the medical team. A number of long and arduous discussions took place between the medical team during staff meetings concerning the best choice of therapy: to graft or not to graft? surgery or not? prescribe cetuximab or not? The extent of these deliberations was never fully revealed to either the parents or the child. A much simplified summary of these discussions was presented to the parents and child.

The medical decision was presented with the objective of reducing the gravity of the situation and allowing hope to be maintained. The medical team fixed limits for the unmentionable elements. (Quote: "*The operation is risky, the girl refuses; we cannot tell her that she could bleed to death in 36 seconds.*"). Then, in a face-to-face meeting, the medical decision was announced using performative speech [10]: "*We'll operate*", "*We must operate*", "*She'll go into surgery on Tuesday*". She died while under anaesthetic.

This case illustrates the difference between discursive avoidance and lying. At no time did any of the medical team lie to either the girl or the mother. At no time, the medical team offered the refusal of the surgery as an option for the patient. At one point, the mother (only half-jokingly) asked if there was not a clairvoyant available, implicitly acknowledging her incapacity to make a decision by herself.

On one hand, official rhetoric of *transparency* functions like an ideology [11]. Parents to whom the reality was explained directly, scientifically and without any precautions, stated that the "cold truth" was awful. They felt it damaged the relationship between paediatric patients and doctors. The risk is also to traumatise children and their parents. On the other hand, it shall be reminded that the lack of communication with the patient is equally pernicious. One of the two cancer-survivor who were interviewed, testimonies how awful it was in the 70's, when she went hospitalized. Nothing was explained to her, and she describes a form of "conspiracy of silence". She developed psychological symptoms which might be included in the PTSD syndrome [12].

3.3 Picturing, Symbolization, Rituals and Narrative Function Until Adulthood

Generally, the experience and the feelings of a seriously ill child are difficult for him or her to communicate [13]. This is particularly true where the child is in great pain which is a specificity of paediatric solid tumors, and consequently gives these cancers their severe reputation.

In such a unit, to care for the pain constitutes a contract of which the terms must be reformulated each day. In order for the suffering to be treated in its multifactor aspects [14] the dialogue with the child obviously requires a discrete attitude on the part of the therapist in relation to the patient.

To deal with this kind of difficulty, the Pain-Man is widely used [15] in the unit, in order to indicate the area of pain (from about the age of 6 years). The children colour the Pain-Man (Fig. 1), helped by a carer. This allows the child to express his own vision of the disease and pain.

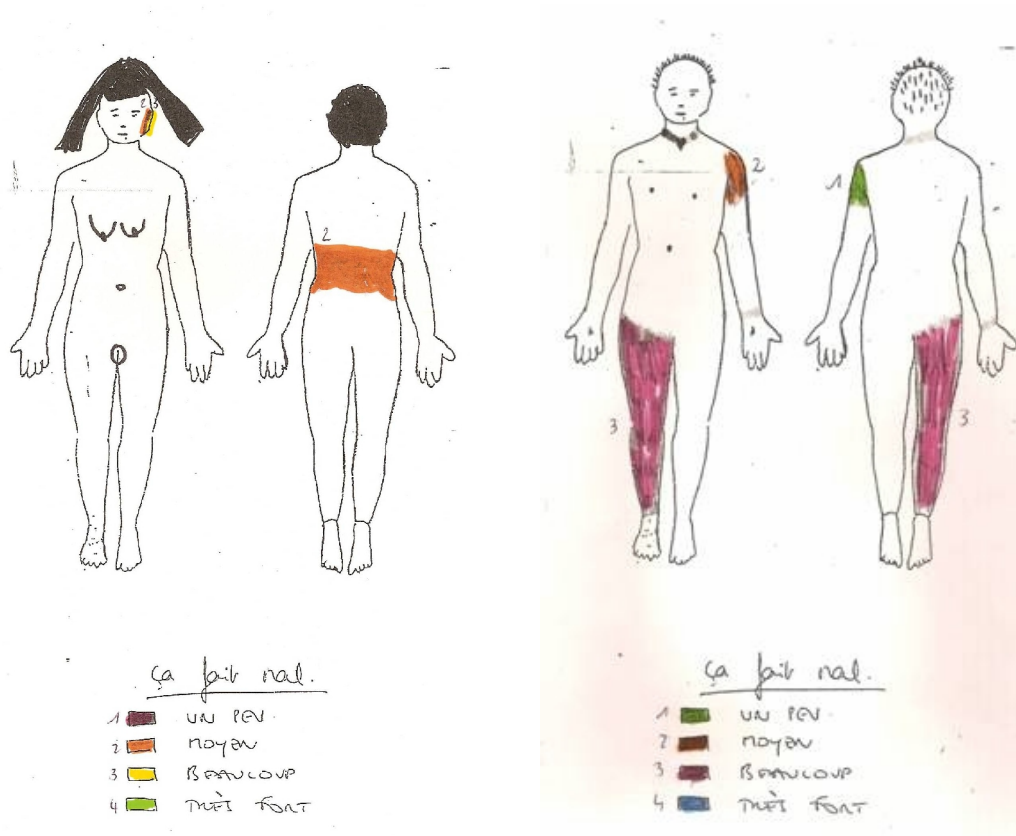


Fig. 1. The “Pain-man”

Legend says: “It hurts: A LITTLE/MODERATELY/A LOT/VERY MUCH”

The carer, in private conversation with the child attempts to give elements of symbolization, which help the child to understand what is going on in his/her body. Metaphors used by carers allow children to find words in order to describe their pathways.

Thus, an explanation of medullary aplasia² as a “devastated army which has to be reconstructed” thanks to a period of protection, separated from others, helps the child to accept the long period of isolation in a sterile atmosphere. It can be related to what Levi-Strauss stressed in his study on the Shamans Cuna [16] and the search for symbolic efficiency.

The importance given by the carers to ritualised moments and symbolic elaboration helps the patient to reduce anxiety. It helps also when words are difficult to find, because of the unbearable truth. This symbolisation-work gives key to the survivors in order to explain to

² This is a state where the patient lacks immune defences due to the absence of polynucleotide neutrophils in the blood. These polynucleotides are a type of white blood cells which are directly implicated in the defence against microbes. As soon as their level is below 500/mm³ the state is known as aplasia and there is a heightened risk of infection. Aplasia generally arises in the days following chemotherapy. This state may last from a few days to a few weeks. Aplasia ends once the medulla begins to create polynucleotide neutrophils which are found in the blood. Prolonged aplasia requires hospitalisation. The patient is under surveillance for any signs of fever, examinations are performed and antibiotic perfusion may be prescribed.

anybody the course of the disease. Surviving children will have to deal with this phenomenal event for the rest of their life. The narrative process will help them.

Another possible research topic is evoked by this study: how important is it to maintain a narrative function [17] with the child about his/her cancer until adulthood? Carers may be in the best situation to help meet this question.

4. CONCLUSION

This work shows the difficulty for health teams in dealing with the notion of truth. The current trend in the field of medicine to deliver open and transparent information concerning diagnosis and therapeutics becomes an impossible task, and the truth unattainable. This unachievable junction between the legal expectations (transparency) and the medical ethics that a doctor can reasonably maintain (to accompany the patient as far as he or she is able to go) creates double-bind [18].

The pursuit of a wider and too early autonomy of the sick child reinforces its vulnerability. The body is then affected not only by the illness but also through language, through the words "*who couldn't enter the head*" and who generate a psychological disease even when the biological disease appears to be cured. When appropriate *signifiers* haven't been given to the child, then the adult desperately look for them, in order to integrate them in a narrative process.

The issue for paediatric oncology staff is to create some "protected areas" where, through picturing, "discursive avoidance" and symbolisation, a true private conversation may be established with the child. The purpose is to recognise the child as an individual, a future adult, capable of a type of autonomy but also requiring special protection regarding his vulnerability.

This opens new fields of study, but also enlightens the needs to improve ways and means to take psychological matters into account.

CONSENT

Oral acceptance.

ETHICAL APPROVAL

Non applicable.

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COMPETING INTERESTS

Author has declared that no competing interests exist.

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