

Relationships between oncohematopediatrics, mothers and children in communicating bad news

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Abstract *We present a study about the relations between pediatric oncological haematologists, mothers, and children in sharing bad news (BN) in a public hospital in Rio de Janeiro. The text emphasizes the intertwining of technique and emotions for the treatment of children with diagnoses in which the fatal outcome is always a probability. We used a qualitative approach, privileging participant observation and open interviews with oncologists (at this service all professionals were female) and mothers. We sought to understand the importance of communication which includes expressions and control of emotions; bioethical issues that require sensitivity, serenity, and truth about approaching the end of life; and how the professionals balance proximity to children and families and objectivity in their activity. The main results showed: intense exchanges on BN among professionals; relapse of children who were evolving positively as the most difficult news; constant update of BN facing terminally ill children; quality of communication influencing the treatment; professionals permanently balancing between closeness and distance from patients and evidence of their irreplaceable role to secure the family and the child.*

Key words *Truth disclosure, Oncology, Communication, Physician role, Child*

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Introduction

This paper presents the results of a survey which sought to understand the management of emotions involved in the relationship between doctors, mothers, and children in sharing the bad news experience (BN) in a haematological paediatric oncology service. It continues a previous study¹ on the meaning attributed to ND by family members of children with cystic fibrosis, a fatal genetic disease. From this first study, arose the interest in the study of the experience of doctors in these communicative relationships, since they're the main messengers of these news.

The term BN used by the Instituto Nacional de Câncer refers to the communication about the diagnosis, prognosis, or failure of treatment; it is this information that affects adversely and negatively the routine, the future vision and plans for a person². The experience of communicating BN depends on the understanding of self and sense of life of those who transmit and may lead to reflection, having developments on language which, in turn, do not bring the experience itself, but comes bathed in interpretation of first-order conditioned by the culture that predates the narrated and the lived³. This task involves the emotions resulting from the combination of physiological, psychological, and sociological⁴ aspects, as well as habitus⁵ of the professional category.

Considering that hematologic cancer is the second leading cause of child death in the country⁶, teams have to deal with the BN and many of them will unfold in decisions on the course of treatment, its risks, the chance of recurrence, the indicators for transplant, and continuation or not of treatment in cases of its failure.

Throughout the treatment the communication interferes in reducing anxiety and depression in the accession process and in the search for disease coping strategies to improve quality of life, and it can be a valuable therapeutic tool to promote personal contact⁷⁻¹¹. Thus, Cassell considers the spoken language the most important diagnostic tool and an indispensable partner in therapy medicine. The words do not just represent something external, but the people who use them¹². Nevertheless, medical communication remains a challenge¹³.

In the social representation¹⁴, cancer and death are seen as synonyms. And to face the journey that lies ahead, families and children resent it when the care offered by the staff is impersonal and they consider the communication essential in construction of the bond of trust on the uncertainties and setbacks of the treatment¹⁵.

Underlying these communications are the emotions, that anthropology says are conditioned by aspects of culture and society of individuals¹⁶. The conviction of the universality and uniqueness of feelings is a construction of western common sense that treats them as part of human essence¹⁷.

The meaning of emotions varies within the same social group depending on the circumstances in which they occur, with consequences on the feelings in social and power relations, revealing its micropolitical character. For example, women remain strongly linked by common sense and medicine to emotions. Something seen by the male bias of labor market as something negative. The good thing is that they are considered more welcoming, caring and stronger in relationships than men. There is therefore a political aspect that involves qualification of people according to their emotionality and power¹⁷.

The choice of the medical profession is based on second order images that do not always come from a personal experience. Therefore, until the student combines scientific information with the outside world, there is a long blind flight, showing that science and skills do not make a doctor, it is needed to know what is expected and how people react to their words¹⁸. Because of their training and expertise, more is learned with doing it under supervision than with readings and lectures, getting continuously subjected to the *habitus* of the category¹⁷, especially if training and awareness of the doctor-patient communication is lacking. In this case, the student is subject to repeat a learned model of their preceptors¹⁹.

The practice helps them approach the attitudes and language of their own medical culture. Thus, death is not seen as a traumatic event as for the laymen, but as a problem in the use of medical responsibility, it does not mean that the student doctor becomes cynical or callous, but adequate in their reaction, language, and emotions in their social position. The way to deal with patients reflects the medical culture and it is also associated with gender and social class¹⁸.

Methodology

For this study the intertwining of technique and emotion in communicating bad news was considered, which constitutes an inter-subjective act entrained by both medical culture^{18,19} as well as by emotions¹⁷ through a comprehensive and critical research preceded by two activities: (1) the

literature on the BN subject that, in turn, fits into the interior of the analysis of relationships between doctors and patients^{7-11,20}; (2) and preliminary contacts for three months with the locale and with the team leading the service, in which it was possible to observe important aspects of their relational dynamics and their expressions of emotions. No professional refused the presence of the researcher in these spaces.

The survey itself took place between 2014 and 2015, in the sector of pediatric oncology of a public hospital in Rio de Janeiro and fulfilled requirements of ethics committees in research of the CEP/IFF. The sector studied was located on the floor of general pediatrics, it is served by hospital wards and a center of pediatric intensive care unit. It serves about 30 patients, from the first months of life to 18 years of age. The unit promotes training of specialists for the medical residency program.

The work had two qualitative procedures: interviews and participant observation, the latter occupied a preponderant place with main focus on relationships between doctors, mothers, and children. There were more than one hundred hours of accompaniment of the medical work process (in this occasion all professionals were women) following the waiting room, clinics, infirmary, meeting and chemotherapy room, attendances, clinical discussions, classes, formal and informal meetings. Proximity and dialogue were sought with the different agents, in a posture of putting yourself in the other's shoes, within the level in environment²¹⁻²³. To the participant observation strategy were considered the relations between the various people who circulated by the sector, all women, even those that were not the subject of this investigation.

All medical staff were interviewed: five doctors of the staff and four of the residency program. All had more than three years of practice in the specialty, long enough exposure time to BN, which allowed their inclusion in the collective research. There they were asked to talk about their experiences with BN. Five mothers of children under treatment were also heard, on their experiences with the illness of the children and relationships with doctors. For mothers, the exclusion criteria was the psychologist's contraindication, those whose children were critically ill or who were already emotionally unstable before the verbalisation of painful facts. All signed the Informed Consent Form (ICF).

Since the completion of the field work, a preliminary review process began, seeking: (1) collect and organize any material offered by the sec-

tor as guidance to parents and patients; (2) write down observations that would be a part of the study; (3) read the interviews to compose a set of statements that allow the understanding of the sharing between doctors, children, and mothers; and (4) possibly raise new issues.

All the material collected and researched supported the observation and analysis of the interviews through thematic analysis used both for systematical review²⁰ for deepening the lines and understanding and deepening critical narratives considering the relevant structures that made themselves present in the categorization of the material^{21,22}.

All of the information passed through a process of sorting, classifying, searching the relevant categories that made up the core themes and they showed the internal logic of the thought and action of professionals, children, and mothers. This collection was re-discussed having as parameter the studied literature, bringing light to the findings of the research²².

The relevance of the categories found refer to: assumptions and ethical activity; permanent challenges of clinical care; humor as a resource on emotions; how professionals act in the face of BN; how children react to BN; how mothers deal with BN. They are discussed below.

Results

Suppositions and ethics of the activity

The pediatric oncologist activity in this sector involves constant challenges: from diagnosis, which can change over the child's supervision to clinical complications and response uncertainty to treatments full of risks. It was possible to notice feelings of threat, anxiety, and suspense, both in the team, as well as in the mothers and children, which required from all a fearless and persistent posture before the challenges and surprises caused by the disease.

It was observed in all these agents a permanent state of alert. Out of the hospital, the professionals were available, since they provided their phone numbers, authorising calls at any time of the day in case of emergency. These professionals needed to support and be used to challenges under high pressure, to not fear them, resist in fighting cancer, in a tension between persistence and common sense, especially when it came down to whether or not to maintain chemotherapeutic treatment of children refractory to therapy.

This taste for challenge is influenced by the possibility of healing in the specialty, a common goal in the medical culture, says D: *Because the doctor has this healing thing. Especially the hematologist, because if a patient has a leukemia, we reset the bone-marrow, put in a new one, and the disease goes away!*

Often little recognized by the doctors, feelings of grief and attachment to patients pose a threat to clarity of thought before the very severe situations and decisions that they demand. Stenmarker et al.²⁴ warns that the oncologist's identification with the patient and family can cross boundaries and undermine the analysis of the clinical data and objective decision-taking and suggests a position he called empathic distancing, that suggests the search for balance between proximity and a technical behavior.

The proximity and empathy²⁵ of the group can ease the pain and anxiety caused by suspension of clinical development of children, having a positive emotional impact on the family. This empathy means an open, honest attitude: no lies, listen, keep your word when promoting comfort, consolation, trust, and instill hope, accompanying them to the end²⁴. As D says: *I think we always try to search, though it may be difficult, to always tell the truth. There are ways and ways of speaking the truth. But it has to be said. Because if you do not have trust...*

The suffering is constant and the risk of death permanent, demanding from the professionals more than technical knowledge, but an existential process concerning the attitudes towards patients and families and their own feelings and emotions, which come covered by a habitus of control and containment transmitted on medical training¹⁸ in the search for a proper emotional attitude. Although, for Herzlich¹⁴, the medical career choice is exactly an expression of grief and sensitivity to human suffering.

This attempt to control over emotions, often managed by staff with humor, can be found when a doctor says to another not to get too emotional, even in positive circumstances like a party, *But you're not going to cry?! Cry at home, take a sedative, but don't cry here!*. And added: *She cries too much, for anything and everything, cries through the halls.*

Or when, instinctively an intern expressed deep regret for the return of a child's cancer during a medical meeting and was warned not to be impressed and to keep control of the emotions before these events that are so common in the expertise in an effort to keep the team active and

able to make decisions, keeping adequate distance from patients²⁶. However, another doctor said, *And you end up getting attached! It's inevitable.*

The rational resources of the doctors coincide with the findings of Stenmarker et al.²⁴ on the improvement and constant technical updating; the exchange of experiences among peers inside and outside the country; the complete dedication for the recognition and consideration of the various component aspects of the patient (family, socioeconomic status, cultural and emotional aspects).

As a subjective feature there is the mutual support in the team and the union around the common goal of good care of the patient, that go beyond individual differences, strengthening the doctors against adversity. The "wearing the shirt" is a characteristic of the commitment of this group, aligned with the sector's origin myth which has a history of efforts for its creation, and technical and structural improvements.

The crisis of trust is seen as a serious problem in this field²⁴ and depends on the form of communication affecting positively or negatively the relationship with the doctor and the disease itself. Hope, fuel for all in this endeavor, can be shaken by how information is transmitted. Due to the uncertainty of outcomes, the team may feel constantly evaluated²⁷. The professionals need to combine affection and technical capacity to convey trust, comfort, and safety. A physician says: *You can fight, you have to have the urge. But if it is with love, the thing goes. But I have to pass a firmness to them [family].*

Therefore, it is necessary to be in charge, with determination, providing with clarity the information to establish the necessary trust between the agents, and providing partnerships on the long road of treatment that, despite the clinical protocols and evidence-based health, are only built walking.

Permanent challenges of clinical care

Treatment fraught with peril and death are events that mobilise emotions in the specialty. The death that is announced by clinical complications is painful, but the one that is unexpected intensely upsets the team and arouses feelings of insecurity on their own efficiency. A doctor says, *It's the [patient] that is doing well, and is in remission, is in the middle of chemotherapy, goes home and suddenly is back with a severe infection and dies. Wow! It upsets me absurdly! What else could I have done? Could I have done anything else?*

Although they consider they have a generally good relationship with families and patients, doctors also deal with their mood swings, because they live the “roller coaster” that treatment represents. They face resentments and anxieties caused by the BN and its consequent restrictive guidelines for the routine of the whole family. Socioeconomic aspects directly affect the outcome of cases, such as low education of the responsible, which hinders understanding and compliance with the requirements.

The lack of therapeutic possibility or the severe chronicity of the clinical condition concerning socially disadvantaged users also have an effect on the team. The professionals know the requirements of the case and the access limitations of these families to the most suitable conditions for successful treatment. Thus, they accompany with suffering the development of the clinical frame of the children, seeing their grim prognosis.

Before the uncertainty of the development of the frames, being aware of being updated scientifically and offering the best to the children mitigates the suffering of the professionals: *I have an obligation to know what is the best for that child. That is my obligation. So, you can not have one thing that is a consensus, that is unknown to me!*

Religiosity occupies a place in the response to unexpected results, good or bad, taking some professionals' assumption of full responsibility for life and death of the patient: *Within what I have to do, within what is my purpose I have to do my best. Further than that, no. I am not God.*

Humor as a resource before emotions

Good humor, if used properly, can be an ally in the coexistence along monitoring the patients²⁴. In the sector researched this humor, sometimes exaggerated, seems to work as a *flight to joy* in the search of transforming the painful emotions and circumventing the harsh reality, imagining overcoming it. But this underlying tension to good humor, if not understood and developed, can push boundaries and be considered by the speakers as inappropriate.

Sometimes in a humorous way, the doctors used the term *He was naughty* as a kind of blaming the patient for presenting clinical complications during treatment, as they were intentional shenanigans that frightened them: *You didn't need to do that! Do you want me to have a heart attack?*, suggesting a myocardial infarction. Thus, the professionals divert their perception of the

anxiety caused by the constant unpredictability of the way that clinical pictures can be taken.

How the professionals act before the BN

The BN are a part of day to day of the team that tries to transmit them based on the SPIKES² protocol and their own experience. The residents are always accompanied by the preceptors. Even the latter usually do it in pairs. Thus, they support each other, protecting them from possible physical or verbal aggression. They try to be accompanied by a witness, being cautious of possible legal consequences of misunderstandings with parents. Usually, family members are upset and can react to professionals as if they were the ones responsible for the situation.

The transmission and exposure to BN begin between doctors and occur by the information and updates of cases that follow. Sometimes, the strain relative to this exposure affects the physical and emotional health of professionals. During the clinic care, doctors receive firsthand the results of routine FBCs done to evaluate the response to treatment. They are subject to having to transmit an BN without having the time to personally assimilate the fact.

Where pathologies considered treatable are resistant to therapy sometimes professionals would wish forget them. Anxiety, frustration, feelings of powerlessness and anger mix before the limits, when the arsenal of knowledge, biomedical resources, and professional experience are not enough to save the child. This is an BN for professionals, felt in the practice of the activity. Such as when a specialist from another area was called to give their opinion on a case and said jokingly, *If it works, let me know, if not, you don't need to tell me.*

Although they showcase good humor and an “up” attitude, the professionals intimately relive the BN on every encounter with patients out of therapeutic possibilities or in high-risk conditions. In contact with them, they seek to divert the sadness in order to provide some relief to children in hard times or in what is left for them.

Despite the frequency with which it occurs, death is still a thorny issue and little worked on by the group. Although the emotional mobilization of doctors is visible, there were no formal discussions about it in order to favor a metabolization of repressed feelings that would help in dealing with and transmitting BN to family members and patients.

For professionals communication is key to the treatment. She builds trust with the children

and their families, which allows understanding and compliance with team guidelines. D explains: *They have to trust me, otherwise they won't bring in the child immediately when they have a fever. They'll think it's just a little fever and the child may die.*

When there is more resistance and denial of the family, the team tries to fine tune the speech in technical meetings, determining the same reference duo to act in the face of the case, trying to avoid misunderstandings caused by communication difficulties. For bioethics the improvement of communication in dialogue form is an important foundation that must integrate good practices in health²⁸.

However, doctors do not always realize the nuances of the ND occult in child development details. As an example: a child was being treated for leukemia and had skin lesions that would not improve, but did not characterise an immediate threat. The doctor said absently, *I do not know what to do with these scabs.* Serious and frightened, the mother said, *Do not say that, no.*

Not only does the team need to give the BN by verbal information such as insisting on a therapeutic project that is physically painful and risky, socially restrictive, uncertain, and, still, transmit, through strong attitudes, that it is necessary to keep it. As if to say: "We started the process, now we have to finish, despite the inconvenience and suffering it causes".

At times the intensity of emotions is not always noticed by the doctors or is strange to them. Like when one of them assigned her premenstrual stress to the fact of her having been very touched by the grief of a mother whose only child was in a very serious state. Fulfilling, thus, an almost unconscious task of maintaining her emotions under control so that they did not affect her ability to act technically.

For the team, the news of the diagnosis, although difficult, is not the worst. Currently, there are cures for conditions that were before fatal. The worst BN is a relapse, by undermining the hope of the children and family, increasing the presence of death. Communicate it *is like taking a stab wound to the chest*, says one of the doctors. It causes deep embarrassment to the professional who *did everything right*, but the disease returned, causing her to experience the unpredictability of individual responses of patients. As S said: *The treatment was working and, out of nowhere, [the child] relapses. It's a low blow, a tragedy.* D explained: *Sometimes a child with low-risk cancer dies and a high risk survives.*

Feelings of failure or impotence impact the response of oncologists to the demands of patients and can lead to inappropriate extension of futile treatments, preventing a frank and open discussion about the proximity of death²⁹. To accept the death of a patient, it is necessary to feel that the best and most current treatment within reach was offered, devoting every effort and affection to the child, treating them fully, in order to not feel guilty and overcome the pain of loss: *I say to the residents: if you do the best [technically] and engage [with family and child], you will have no problems with families.* Schramm³⁰ claims the same importance of a mixture of reason and emotion in contact with patients. *Gratitude, even from parents who lost their children, is the best return*, added C. To S, it serves as confirmation that their efforts have been recognized by the families: *This is one of higher returns I think we can have. Them [family] understanding that [the treatment] doesn't just depend on us.*

The residents exposed to the suffering of children and family, believe that longer experience will make them less permeable to pain and more skilled in transmitting BN with a certain distance, imagining that this is the attitude of a mature professional. Thus confirming the presence of a habitus of the category, challenged internally to keep the balance between emotional involvement and technical competence. However, the more experienced doctors of this group demonstrate that empathic distance suggested to professionals by Stenmarker et al.²⁴ does not mean coldness.

The many resources cited by doctors to handle the responsibilities of the activity coincide with Stenmarker et al.'s findings²⁴. Family, friends, religion, physical activities, interests outside of the medical field, psychotherapy, meditation, and the relay of the team in the care of children help to dilute the suffering emerging from the environment, allowing them a time of emotional recovery.

The fundamentals of palliative care help to reflect on the dilemmas of treatments and about the end of life, but do not offer a finished recipe. Leaving for parents the decision to stop or not a treatment of the child is felt by doctors as cruel. Helping them through clarification of the consequences of each of the options on the face of terminal situations would include them without leaving them alone.

Highlighting the dilemmas and the lack of consensus in such situations, S says: *From now on I understand that I don't have anything else to do, so I won't treat anymore. So if it's hard for a mother,*

it's hard for me as a doctor, and I don't know when to give up. Moynihan and Schapira²⁹ point to the lack of training of the doctors in the area of communication of ND, the desire to avoid painful discussions, excessive optimism on the effectiveness of some treatments and the pacts between them and their patients as factors that contribute to this impasse. The emancipation of patients and formulations about their rights led to the reduction of the traditional paternalistic attitude of doctors resulting from new technologies³¹.

For doctors, the most difficult question posed by children and especially by teenagers is: *Am I going to die?* It challenges the professionals who, evasive, answer: "We're all going to die" or *We're doing everything, don't talk nonsense*, trying, for compassion, to protect the children with reassuring answers.

How the children face the BN

The team informs children and adolescents of the diagnosis, as far as they want to know and explains all procedures during the treatment. They consider that the very small children are unable to understand the explanations; therefore, they focus on the families. Out of the bigger ones, the professionals expect understanding and participation in the acceptance of the procedures and fundamental constraints.

The BN for children occur during treatment demanding strength from professionals to communicate information in a human way so that children support them. It refers to physical, psychological, and social consequences such as distancing from school, some recreational activities, convivial impediments in closed spaces or clusters, the distancing of the brothers or of the house due to hospitalisations. However, the BN that makes them cry intensely is hair loss. That given seems to condense the picture of cancer, widely disseminated in the media.

According to the Estatuto da Criança e do Adolescente (ECA), parents are legally responsible for the patients³². However, when, due to serious social-familial issues, children are not accompanied by them, the team makes agreements directly with them, including in situations of end of life, offering procedures of relief of the symptoms of terminal states and respecting their wishes. The practice and studies of Kubler-Ross³³ make it clear that children are more aware of their disease than the professionals and even the parents notice. And information and agreements can be made with them.

The role of doctors goes beyond technical care. Befalls them expectations that put them in a central place in the family, such as when the sister of a patient wanted to go to consultation to ask for the medical authorization to go to a school tour the parents had vetoed. Before the doctor's astonishment, the child explained: "But aren't you the owner of the world?" For the child, the doctor was felt as responsible for life and death.

How mothers deal with the BN

The feeling of all mothers in relation to BN about the diagnosis is that "the ground opened up" under them, changing their life from one day to the next. If on one hand they feel relief with the discovery of the cause of the severe symptoms, on the other they feel the pain of the reality of the diagnosis. Afonso and Mitre¹ found the same verbal expressions and meanings attributed to BN for families of children with cystic fibrosis, a fatal genetic condition.

For mothers, to be prepared to receive the BN, given carefully, being accompanied by a family member, in an appropriate place, feeling availability both internal and of time of the professional, mitigates its impact². But mothers await understandable and honest information, not to be surprised by setbacks of the disease. When they see the involvement of the staff and their suffering shared with children³¹ they feel that the child is not just a patient, a number, a case³⁴.

Despite the team caring for the transmission of BN, sometimes they do not realize the weight of their words and the constant state of alert and threat of the child and family. Like when the doctor joked about the difficulty of removing the catheter from a patient who was already well and could do without it, saying solemnly: *We are before a case of attachment [of the patient] to the catheter.* Seconds later the mother noticed it was a joke, let out a plaintive sigh of relief and said: *She [doctor] says it so seriously that it almost gave me a heart attack, my legs almost gave out.*

After two years of treatment and suspense, even if the child responds well to therapy and enters the maintenance phase, good news may generate insecurity in parents. The suspension of chemotherapy brings fear as the child is unprotected from the return of the illness.

The BN can come in an indirect way¹. The conviviality in the support home for children with cancer provides a network of solidarity and exchange of experiences among mothers that assists them emotionally. However, adverse devel-

opments or death of other children lead to the assumption that the same can occur to their own.

The living each day and not thinking about *all* of the treatment is a shared resource between family members and doctors who, unable to give guarantees, cross along with families a route unknown to both.

Final considerations

The composition exclusively of women of this team speaks of the interference of gender in care, associating the female to emotions, affection, subjectivity, and to the relational, even though this group also seeks practicality, reason, and instrumentality, commonly referred to as male attributes, without which the coping with the disease would not occur³⁵.

Communication is seen as an essential part in the art, but it is not yet addressed in undergraduate school nor systematically in graduate school. It is still learned from practice without systematic and regular reflections. Even when it is studied, there is not a formula or a memorised text that embraces the uniqueness of people and the variability of their reactions. This finding suggests the need for personal aptitude and clarity on existential professional issues, and an opening for a constant and dynamic internal work on the emotions.

Bioethical issues, in general related to the end of life, are still permeated by the small acceptance of death, especially in childhood, considered something contrary to the supposed logic of the life cycle.

The closeness that touches the emotions needs to be known by the professional to ensure their proper operation and best performance with the patients and their families and to facilitate their staying healthy in the specialty.

For families, BN are pulverised during the treatment and include from the most serious symptom to even the simplest commitment, keeping them in a constant state of alertness. Even subliminally, the tension is always present for families and professionals.

Maintaining the balance between technique and emotions remains a challenge, since death remains a thorny and avoided issue. This issue could be faced by regular approaches with psychological support to all agents in the care scene. This combination also seems to worry the families waiting for such balance, fearing that the doctor has their judgment and technical skill blurred by their own emotions and intense impact of their professional practice.

The opinion of professionals highlighted the communication for its ability to generate interpersonal trust, fostering co-participation, membership and enabling agreements when faced with the dilemmas that occur throughout the therapeutic route.

Thus, communication and emotions are inextricably linked to it and deserve attention and critical analysis in the same way that physical symptoms or additional tests undergo a combined interpretation of the various aspects that focus on individualized and unique way to treat patients.

Collaborations

SBC Afonso was responsible for the field research, analysis, and drafting of the article and MCS Minayo oriented the research projects, and participated in the preparation and drafting of the article.

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