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Original Research Article

Ethical and communication issues in advanced stage retinoblastoma – challenges of clinical reality

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Abstract

In the context of an oncologic disease delivering bad news always represents a challenge, but a diagnosis such as a retinoblastoma can raise additional problems. Retinoblastoma (RB) is a malignant tumor of the embryonic neural retina network affecting children. It can be either hereditary or sporadic; in advanced stages, it can invade the optic nerve. Approximately 90% of cases are sporadic, with no RB antecedents in the family. Familial RB is present when there is a positive history in one of the child's parents. Though it can affect the quality of life, the literature usually describes an excellent prognosis for RB patients if the disease is discovered and treated in time. Approaching RB cases must therefore be a holistic, complex, and a multidisciplinary endeavor to ensure the comfort and a better quality of life for the patients and their families. Communication with the family plays a crucial role in achieving this comfort during the entire treatment process. This paper aims is to present three cases diagnosed with RB in our clinic, the ethical dilemmas, and the communication issues that arose while working on these cases and how the different approaches influenced the treatment's outcome.

Keywords: Children, Communication, Ethical issues, Physician-patient relations, Retinoblastoma

List of abbreviations: ICU = Intensive Care Unit; **RB** = retinoblastoma; **SPIKE** = **S**etting, **P**erception, **I**nvitation, **K**nowledge, **E**motion, **S**ummarize

INTRODUCTION

Finding out that their child has an oncologic disease is a traumatizing experience for not only the parents but for the entire family. Pediatric cancer therapy necessitates long-term, frequent hospitalizations for both the infant and his caregiver. Delivering bad news under these circumstances is of paramount importance, being difficult for both families, patients and healthcare specialists. The family's reaction can be very different, depending on the stage of treatment, the prognosis of the disease, the existing vulnerabilities within the family, the support and resources the family has, etc. While a comprehensive presentation of the reactions a family can express facing a life-threatening disease such as pediatric cancer is beyond the purpose of this paper, it is worth considering the impact the diagnosis has on the entire family as a system. For a more detailed presentation of the experience a family goes through while under treatment for pediatric cancer and the path to resilience see Radu et al. (2014).

This moment, enhanced by the empathy felt for the patient, may cause emotional stress on the oncologist and other medical team members. (Stenmarker et al., 2010)

Delivering bad news in medicine

Doctors ought to concern themselves with issues such as communicating bad news, since they are the ones finding themselves in the difficult position of delivering news concerning the presence of a life-threatening disease and the long series of complications that might arise during treatment. The importance of receiving information is reflected in the contribution it has in establishing coping plan and the adherence to medical procedures (Mark and Joffe, 2014).

According to Robert Buckman (1992) sad news is information that affects ones outlook on ones future.

Communicating the diagnosis of cancer can be regarded as a meeting between two sets of experts. On the one hand, the medical staff with their expertise in treating the disease, on the other hand, the patient as an expert in suffering (Mosoiu, 2009).

Watzlawick et al. (1967) emphasized the importance of non-verbal communication and the adverse effects stressful situations have on the capacity to receive and understand these messages. The non-verbal cues between doctors and their patients influence the way the latter perceive the medical professional as a caring presence.

Valuable tools in delivering bad news are Professor Robert Buckman's SPIKES, touching on a few essential points regarding patient information and communication. With regard to the initiation of a relationship with the patient, the following should be taken into account: establishing a connection with the patient, informing the patient about his/her condition and treatment options, the doctor should show empathy during the process, and create a context in which there could be a collaborating alliance with the patient. The following six steps are proposed by the SPIKE protocol:

1. Setting up the interview, choosing a quiet and private room, involving the primary caregivers and the patient and avoiding as much as possible any external interruptions
2. Assessing the patient's perception about their situation and what they think is going to happen by asking open-ended questions.
3. Obtaining the patient's invitation for information. The clinician has to find out how much information the patient wants to know. In order to achieve this an open dialogue and sincerity are vital.
4. Giving knowledge. Offering information to the patient keeping in mind the previous point and trying to alleviate the patient's distress, by giving them a warning before delivering any bad news.
5. Addressing the patient's emotions with empathic responses and validating their feelings.
6. Strategy and Summary. Formulate a plan, offering treatment options for the future need to be done with the patient in order to decrease their anxiety level regarding the unknown that tomorrow will bring and sharing responsibility for future choices, so that both parties involved will have to gain (Kubbler-Ross, 1983).

An extension to the SPIKE protocol is one devised in South America to better suit the local needs of the patients called PATIENTE, which adds to the above-mentioned aspects the importance of not abandoning your patients regardless of their decisions or the outcome (Pereira et al., 2017).

Faulkner (1994) considers that bad news are successfully shared when communication facilitates accepting the situation and the start of the adaptation process while minimizing the risk of denial by creating realistic hopes, not generating a negative emotional state or a conspiracy to silence (Faulkner et al., 1994)

The needs of the families of children with cancer are different regarding the way they want to be informed about the disease, and the doctor should adapt accordingly.

In current practice the ethical principles governing the medical profession in regard to communication and decision making are:

- The paternalistic model, in which beneficence is the dominant ethical model – the doctor acts as he/she feels is best for the patient. The medical staff decides and then communicates with the patient or their family.
- The partnership model, which operates according to the principle of autonomy-the doctor shares information regarding the disease and treatment, and the patients share their values.
- The boundaries model, in which autonomy is the dominant ethical principle. The patient consents in advance and names a proxy who will enforce his/her previously stated decisions in situations in which the patient will be unconscious (Charles et al., 1999).

Romanian legislation reinforces the autonomy principle. The legal code does not mention anything related to cases in which refusal or withdrawal of consent for treatment of a minor would jeopardize the life of a patient (Romanian medical deontology code, 2014).

I.A.G raises the question of the role the medical professional plays when confronted with an adamant refusal of treatment. (Mosoiu, 2009, p. 67). The oncologist as a treating physician has difficulties accepting that the disease can be incurable and there is need for palliative care, he/she experiences helplessness in front of the family which refuses treatment (Morgans and Shapira, 2015)

Objectives

An advanced stage case is particularly stressful for the patient, the family and for the medical staff, because a late diagnosis decreases the chances of recovery, involves invasive procedures with unpredictable outcomes and therefore a reduced quality of life. RB in advanced stages can involve invasive, mutilating procedures, frequently resulting in the loss of the eye and thus changing the body scheme. It can also result in a decreased or complete loss of sight (in bilateral RB). From this point of view, RB cases are particularly challenging. Sometimes advanced cases require palliative care and the patient might die. We were interested in seeing if the quality of life of the patients is influenced by an honest, correct communication with them and their families.

METHODS AND MATERIAL

We have done a retrospective analysis of advanced stage IV RB in the 3rd Pediatric Clinic of the "Louis Turcanu" Emergency Clinical Hospital for Children in Timisoara. The studied sample contained 12 cases diagnosed with RB between 2002-2017. From the 12 studied cases, 3 were stage IV at diagnosis. 2 of these cases resulted in the death of the patient within 5 years after diagnosis. Among the adverse factors affecting the prognosis were: advanced stage at diagnosis, non-adherence to treatment or initial refusal of treatment which lead to worsening of the disease and the patients' condition. Communication was conducted according to the SPIKE principles.

Our multidisciplinary team included ophthalmologists, pediatric oncologists, radiation therapist skilled in the treatment of RB, genetic counselors, pediatric psychologists, art therapists, social workers and nurses. During communication meetings, the team of doctors and the family met to communicate the diagnosis, the evolution and the prognosis. These sessions took place at critical points during treatment and included information regarding the therapeutic response, the risks of therapy and end-of-life problems. The psychotherapist was a key player in facilitating the patients' understanding of the situation while offering much needed psychological support.

The protocol used for diagnosis and staging were determined taking into account the Reese-Ellsworth Classification (Reese and Ellsworth, 1964) and International Classification of Retinoblastoma (ICRB) (Murphree, 2005; Shields and Shields, 2006).

The goal of the treatment was primarily to save the child's life and the therapy was individualized by combining enucleation with photocoagulation, intra-venous chemotherapy or radiotherapy in accordance with the protocol applied (Charles et al., 1999) with good results in 75% of cases.

Case studies

Case 1. Patient I.A., male, born in 2005, coming from an urban area, was a registered patient in the clinic from the age of 4 months, being diagnosed with bilateral RB, stage III B. His father had bilateral RB, which was treated through bilateral enucleation at the age of 1 and radiotherapy.

Communicating the diagnosis generated reactions in the family, such as despair, frustration, hopelessness and guilt. The family members were affected differently; the most affected being the paternal grandmother, who was living this drama for the second time. In the same time, she was the most motivated to start the therapy, since she had a previous experience of a disabling but successful treatment of RB with her own son.

In the beginning the recommended treatment was enucleation of the right eye combined with systemic chemotherapy and photocoagulation of the left eye, in order to preserve sight. The first local relapse occurred 18 months after treatment, which resulted in a new set of chemotherapy and photocoagulation sessions. 6 months after restarting therapy there were signs of progression of the disease which resulted in performing left eye enucleation also.

The patient survives, but for the family the situation was very difficult, since they relived the father's drama, and the family needed psycho-emotional and financial support, having now to support and care for two people with severe disability.

The problems and challenges that occurred were related on the one hand to the disability which resulted as a consequence of the disease and the child's adaptation to the status of being sightless. Communication with the child was initially very difficult, since the child was very keen on being in groups and playing with other children. The child became dependent on his mother and grandmother, which involved further emotional and social problems (the grandmother being the support) and financial problems (since the child needed eye prosthesis which had to be changed periodically). The family balance changed, the mother being the sole financial provider of the family, at the same time having a lot of family roles to cover and chores to do. Despite all difficulties both family and medical staff were happy the child survived. Although the family experienced hopelessness, frustration and guilt they showed a keen understanding of the situation and were compliant and motivated. In crucial decisional moments (the double enucleation) the family as a whole needed psychological support.

Case 2. Patient J.E., male, born in 2003, coming from a rural area, having as antecedents a father with a malignant testicular tumor is diagnosed with RB stage IV with cerebral metastases at the beginning of 2005 (age at diagnosis – 2 years old).

Communicating the diagnosis generated dissatisfaction and denial from the family. Despite having the diagnosis presented by specialized medical professionals, the patient's parents refuse any intervention. On the 2nd of December 2005 the patient is admitted in the

3rd Pediatric Clinic of the "Louis Turcanu" Hospital in an aggravated state. The diagnosis is communicated to the family, who agrees to start treatment with chemotherapy, according to the protocol. During the admission in the hospital, the patient has an unfavourable evolution, his general condition worsens, and the patient presents organic seizures, due to the development of cerebral metastases with cerebral oedema. The patient is transferred to the ICU where, under treatment and monitoring, develops other convulsive episodes. On December 19 after tonic seizures, the patient died.

The challenges that arose: did we have an inefficient communication? The initial denial of reality, then acceptance and even wanting the treatment are these legitimate reactions that need to be respected and accepted as a fact by the medical professionals? The level of understanding may be a barrier in communicating with the family, which the medical staff must learn to confront with honesty and openness.

Case 3. Patient D.A., male, born in 2005, coming from an urban area is diagnosed with unilateral stage IV RB in 2008, without a family history. Upon communicating the diagnosis, the family manifests reactions of denial, anger, hopelessness then acceptance. He begins treatment with chemotherapy combined with enucleation, but interrupts therapy against medical advice at about 6 weeks after surgery, being confronted with the clinical reality (enucleated child with loss of hair after chemotherapy). The child is symptom free for 11 months, and then presents signs of relapse with intense migraines, phenomena of intracranial hypertension which required palliative care until the end of life, opioids for pain control, brain depletion substances and anti-seizure medication.

Towards the end of the patient's life, communication with the family improved, it became more open and the family understood the impossibility of curative therapies, the limited prognosis and the importance of palliative care. The patient died at home with controlled symptoms.

The unfavorable evolution of the disease generated a rupture in the initially good collaboration between the medical staff and the caregivers. Were these situations avoidable by better understanding the treatment and its side effects? Could such outcomes have been avoided by a better communication?

After the first signs of progression the dialog was taken up, with honesty and in full understanding that the only option left was palliative care.

DISCUSSIONS

The therapeutic approach must be holistic, complex and multidisciplinary in order to ensure comfort and a good quality of life for the patient and his/her family.

Communicating the diagnosis, the prognosis, the recurrence of the disease, beginning opioid treatment, a mutilating surgical intervention, in our patients' cases enucleation, all represent bad news, and the oncological patient is prone to more of these during the evolution of the disease[19].

In Romania a study regarding communication in cancer was conducted on a focus group made of oncologists, hematologists and palliative care doctors (Mosoiu, 2009).Who is in charge of the communication? How is the communication handled? When is the information communicated?

As mentioned before the dialog between patient (patient's caregiver) and doctor can be seen as a communication among two sets of experts. This often leads to incongruences between the goals of the doctor and the expectations of the patient. The doctor often has the tendency to discuss medical elements or alternatives, thus focusing on the disease, while in pediatric cases the family is interested in how the disease will impact the child's life, therapeutic resources and the future, an approach centered on the patient (Ptacek and Eberhardt, 1996).

Problems facing the parents

In order for patients and their families respectively to be satisfied with the communication between them and their doctor, patients need honesty, clarity, interest, and time to adapt the information and care by the medical professionals. Understanding the disease and the course of action which needs to take place during treatment is crucial for the family.

Identifying the degree of involvement in the decision making that the parents are comfortable with is essential, due to its significance in shaping the parental compliance to treatment, keeping in mind that the attitudes towards parental involvement change during treatment. A study showed that almost 1/3 of parents where dissatisfied with their involvement in decision making, the parents feeling they either played a too active role or on the contrary a less active role than they would have preferred (Sisk et al, 2019).

As medical professionals we need to make sure we have respected the protocols of communicating bad news.

We also need to direct the family towards psychological support when facing such devastating news. Despite the fact that treatment and diagnosis are mostly thoroughly discussed with the patients and/or their parents many complained that some aspects of the disease fell under the table such as: impact on daily life and quality of life, the emotional impact of the diagnosis and the treatment, pain management (Levine et al., 2019).

Patients have the right, but not the obligation of finding out about their diagnosis and their prognosis. In our cases, patients are small children, under the age of 4, who cannot fully understand such a diagnosis. In such cases, parents are the ones who need to consent to treatment (Keith, 1989).

There is an ongoing debate whether a child should be told and to what extend. A study shows the divergent views of doctors and lay people regarding this topic. Aspects such as age, severity of the disease, the child's interest in it moulded the optimal approach. An important trend is the medical professionals' tendency to choose an autonomy centered rather then paternalistic view (Munoz et al., 2014).

As a doctor it is important to keep in mind the fact that the primary objectives of the caregiver do not have to overlap with those of the medical team, a parent's options can be more concerned with aspects of quality of life while a medical professional can emphasize life-saving procedure.

Two models of processing loss and grief have been developed by Kubler-Ross (1983) and Simms & McBride (2001). Both models state the fact that the first stage of processing grief is denial in the Kubler-Ross model (1983) and shock in the Simms and McBride (2001) model, which are accompanied by feelings of numbness, mechanical activities and emotional distress. While this stage of processing is normal and serves certain psychological benefits, it is counter-productive in advanced stages that require urgent and drastic measures in order to ensure the success of the treatment.

Emotional blockage of the family facing child cancer needs to be understood and addressed in order to ensure treatment compliance.

Birchley (2010) addresses situations in which there is a conflict between parents and medical staff regarding the course of treatment. Cases which are diagnosed in an advanced stage are sensitive also because they involve an overlap between the parental stage of processing the news of the diagnosis and the need for immediate and oftentimes mutilating treatment.

RB parents are facing an almost impossible choice – to decide for their child who is too small to be making that decision for him/herself and take drastic measures, like consenting for enucleation in the hope of saving the child. The delay some parents have in consenting for such procedures is sometimes difficult to accept by the medical staff, aware that any delay could jeopardize the child's life, but most parents are using this time in trying to find other solutions which would not affect the child's quality of life so much .The medical staff ought to bear in mind the possible difference in goals so as not to blame the parents and to keep a non-judgmental attitude towards them.

Problems facing the medical staff

As medical professionals facing such mortality rates in two of the three cases previously described, we are confronted with a number of concerns. Did we ensure medical care in every possible way? Did we communicate correctly? What are we doing in order to help families who are living this drama twice? How can we support non-compliant families? What can be done in order to support families who have lost their child as a result of the disease? Where can medical professionals find comfort in facing such difficult cases?

Communicating the diagnosis is a demanding process, which requires certain abilities and techniques which can and must be learned.

A study conducted on medical staff regrading their communication skills shows the importance of experience. That is an extra reason for providing many opportunities for doctors to acquire the necessary communication tools, starting as soon as possible even since medical school (Ferreira et al, 2017).

Advanced stage RB, ending in the death of the patient, was it due to the inappropriate medical approach? Was it generated by the lack of knowledge and acceptance of the family, which resulted in the delay or initial refusal of treatment? Should we use aggressive therapeutic measures in wanting to save the patient at any cost, even if this means causing the loss of sight? Should controlling the symptoms in cases which have limited prognosis and preparing the family for the loss of their child be enough?

Different approaches

Despite the fact that the families' reactions to the news of the diagnosis were various, the main limitation of this present study is the low number of included cases.

According to the model described above, making decisions in our analysis followed the paternalistic model in cases 2 and 3, in which the doctor decided, then tried to convince the family, and the refusal of treatment by the family was seen as a failure. In the 1st case the applied model was the partnership model, which was successful and consolidated the relationship between doctor and patient's family, which lead to collaboration and long-term support with careful follow-up. It is worth taking into account at this point the case of patient C.S., which underlines the relationship between the severe prognosis of the disease and patient non-compliance to treatment.

Zygmond and Boorhem (1989) discussed the application of Kitchener's (1984, 1985, 1986) ethical principles to family therapy (autonomy, non-maleficence, beneficence, fidelity and justice) with reference to situations in which these principles are conflicting, arguing for precedence of one principle over the others under special circumstances. In our cases as the patients were too young to consent for treatment their parents were the ones who took that responsibility for the children and therefore their autonomy was respected when they initially denied or delayed treatment**.** Would such situations justify an overruling of the parents right to autonomy? Was their refusal or delay of treatment harmful to the children given the tragic end? Did their parents' intentions involve malice? We believe not, since in the intervals between being diagnosed and returning to treatment, the parents sought alternative treatments for their children, trying to save their eyes, preserve sight and prevent the negative effects of treatment. In fact, even if the children would have undergone the treatment, there is no guarantee that their life could have been saved.

CONCLUSIONS

RB is a major medical problem on one hand because of the complicated medical, surgical, and prosthetic treatments involved, as well as the psychological pain and severe physical impairment it causes, and on the other hand because of the genetic threats this type of tumor poses. All these require serious psychological, emotional and social support.

The cases discussed address the need for further preparation of the medical staff not only in early diagnosis of cancer, but also in being more aware of the profound psychological and ethical implications involved in dealing with such cases. Communicating is paramount in this process and conducting it in a proper manner could ensure better adherence to treatment and a greater chance of survival.

Another important aspect is being more knowledgeable regarding the ethical dimensions involved in dealing with cases in which the parents could not consent or withdrew consent for treatment.

There is a need for agencies and structures where such challenging cases could be referred to so as to ensure a better care and follow-up.

Finally, oncologists dealing with challenging cases should be more aware of the effects that dealing with advanced stage cancer cases have on themselves and should seek ways to manage their own distress or sometimes even helplessness in saving a child's life.

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