Interfaces of the relationship between physician and mother-child in a public hospital

Interfaces da relação entre o médico e a dupla mãe-filho em um hospital público

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Abstract

Purpose: *To investigate the perception of physicians about the experience of ambulatory with children who have a serious eye disease and how they understand their interference in the mother-child relationship.* ***Methods:*** *Semi-structured interviews were performed with ophthalmologists (sectors of retina, glaucoma, anterior segment and pediatric ophthalmology), and observation of outpatient appointments of a public hospital during three months.* ***Results:*** *Idealization of the physician's and mother's role; physician's difficulties on giving the diagnosis; and the acknowledgment that the professionals have an influence on mother-child relationship during the assistance.* ***Conclusion:*** *The challenge for physicians are giving information on diagnosis and treatment; being accessible to listening, clarifying and guiding showing that the child has others capabilities beyond vision.*

Keywords: *Physician-patient relationships; Mother-child relationship; Communication; Eye diseases/diagnosis; Deficiency*

Resumo

Objetivo: Investigar a percepção dos médicos sobre a experiência de atenderem ambulatorialmente crianças com doença ocular grave e como compreendem sua interferência na relação mãe-filho. **Métodos:** Foram realizadas entrevistas semiestruturadas com os oftalmologistas (setores de retina, glaucoma, segmento anterior e oftalmopediatria) e observação das consultas ambulatoriais durante três meses. **Resultados:** Idealização da figura do médico e da mãe; dificuldades na hora de transmitir o diagnóstico; e reconhecimento de que o profissional interfere na relação da dupla durante seus encontros. **Conclusão:** O desafio do médico está em dar as informações sobre diagnóstico e tratamento; ter disponibilidade para escutar, esclarecer e orientar e nos casos graves mostrar que a criança tem outras potencialidades além da visão.

Descritores: Relações médico-paciente; Relação mãe-filho; Comunicação; Doenças oculares/diagnóstico; Deficiência

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Introduction

The discussion about the doctor-patient relationship is still a central issue in medical practice. It is important to remember that the meeting between physician and patient is above all a meeting between subjects; as such, from the first moment it is loaded with the meanings and expectations which each person has in relation to the other[1].

In addition, facing another person's distress also causes the health professional to suffer, as the physician is responsible for diagnosing and communicating bad news (in severe cases) to the patient, which is an extremely delicate situation. However, professionals are ill-prepared as to how, when and where to convey this kind of news[2].

Against this backdrop, a new relationship model is discussed, based on dialogue and a combination of scientific knowledge with life experience and common sense. This model also stresses the need for the physician and patient to see each other as partners, thus promoting patient and family cooperation and participation during treatment[3].

According to this model, physicians needs to take into consideration the patient's experience of the illness, their perceptions and representations, thus developing their sensitivity and the ability to listen beyond the biological dimension.

In humanised child healthcare, it is vital for the professional to understand the patient's suffering by valuing the experiences, expectations, values and needs of the child and their family, as well as the limits which exist in the relationship between the physician and the patient/family[4].

It is important to consider that a severe eye condition can have consequences ranging from reduced visual acuity to total blindness. When this happens during childhood, it interferes with the life of the child, the family and the mother-child relationship[5-7].

Nevertheless, because academic training itself is still restricted to the biomedical model, physicians often feel unprepared to deal with the anxiety and the feelings of frustration, helplessness, limitation and awareness of our own mortality[8-10] which emerge especially in severe cases.

Because conveying a diagnosis is a special moment in medical practice, studies have shown that the way it is done has direct repercussions on treatment[11].

Communication interferes both with the relationship between physician and patient/family and how they will relate to the process of diagnosis and treatment. That is to say that dialogue and partnership are vital in this process[11] .

In fact, caring for children with severe eye disorders is considerably challenging. On the one hand, the situation involves pain and suffering by the child and their family. On the other, the professional is under pressure to respond to demands which often go beyond their possibilities, due to the lack of specialised services in the public healthcare network and high patient demand.

This study tried to investigate how physicians perceive their experience of caring for children with severe eye disorders in outpatient units and how they affect the relationship between the mother-child pair and a severe eye disease.

Methods

The study was conducted in a federal hospital in the municipality of Rio de Janeiro. This large general hospital is a reference centre for paediatric ophthalmology and treats a large number of children with eye injuries and severe eye disorders.

The qualitative method was chosen because the study deals with a relationship between subjects. This allowed us to carry out an in-depth analysis of relationships and experiences and to capture their subjectivity[12].

The participants of the study were physicians (staff and residents) in the ophthalmic clinic of a general public hospital. The inclusion criteria were: caring for children under the age of five in the service's retina, glaucoma, anterior segment and paediatric ophthalmology departments; not being on holidays at the start of the study; being available and consenting to having their consultations observed (by an observer in the room).

We were interested in assessing the relationship between the physician and the mother-child pair with a severe eye disease, the experience of providing care for this type of child in a public hospital, the difficulties encountered by the physician and the hardest moment during child care.

These areas were chosen because the children in this clinic were followed-up for a lengthy period of time, which could affect the relationship between the physician and the mother-child pair.

Based on initial field observations conducted over a period of three months, the necessary adjustments were made for data collection. Two techniques were used: Observation of outpatient consultations and semi-structured interviews with physicians, using a combination of open and closed questions.

We stopped collecting information based on the saturation criterion, i.e. at the time when no new significant information emerged[13].

Both the physicians and the children's mothers gave their informed consent. The study was approved by the hospital's Research Ethics Committee.

The collected material was assessed using adapted and systematised content analysis, giving preference to the Thematic Analysis technique, which classifies the material into themes. Analysis of interviews sought to integrate the identified themes within the underlying theoretical framework[14] .

Results

A total of 13 physicians (4 staff doctors and 9 residents) were interviewed, of which 9 were men and 4 were women. Among the residents, 1 was in their first year of residency, 3 were in their second year and 5 were in their third year. The age of participants ranged between 27 and 55 years. The longest time a physician had worked in the hospital was 30 years and the shortest was 4 months.

Based on the observation of consultations in the outpatient ophthalmic clinic, we noticed that, despite the work overload, physicians were considerably careful and attentive to their patients: they greeted the mother and child as they entered the room; they talked to them making eye contact; they offered guidance and answered questions in accessible language; they scheduled another visit, remembering that guaranteeing continuity in care is extremely important in supporting a mother whose child has a severe eye disease and who will need medical supervision throughout their life.

The link between the participants and the service was based on familiarity (they had been residents or had family members working there) or the quality of service (both as a place to do residency and to work).

The fact that the hospital offers a residency programme requires teams to constantly update and refresh their knowledge, thus promoting their professional development. In addition, in

this public hospital a wide variety of cases is seen and major and minor surgery is performed, offering a unique experience in terms of learning and improvement.

Nonetheless, despite the quality of clinical training, the vast majority of participants pointed out that physicians were unprepared to deal with emotionally difficult situations, such as severe eye disorders whose treatment and cure are difficult, causing feelings of helplessness and failure.

They also pointed to the need for physicians to know more about how to establish an empathetic relationship with the mother and child, helping her to deal with the child's disease and to look after them. According to the participants, adherence to treatment depends on how the physician communicates with the patient and their family.

- It depends on the physician's approach, so that the person knows how to better deal with the disease (subject 8).

- The physician always has to be as clear as possible and make themselves understood. It is part of the physician's role to make themselves understood (subject 5).

Difficulties in child healthcare

Analysis of the results pointed to a broad theme related to the specificities of providing care to children, which requires a special approach as well as the physician's desire to provide this kind of care. It is important to highlight that these are not professionals who chose to work with children from the start (like paediatricians) — they are ophthalmologists, most of whom were trained to deal with adults. In this clinic, first- and second-year residents need to work in all sectors, treating both adults and children, unlike third-year residents who choose which sector they want to specialise in.

Nevertheless, whether they liked it or not, they all recognised the importance of specialised care and the need to improve the care provided to their clients. For specialists, providing care to children is often considered a challenge insofar as it requires their cooperation (which does not always occur), teams are required to offer more time and availability, and a good interaction must occur between the physician and the family.

-[...] the child cries, does not respond, does not cooperate during the examination, it is more difficult (subject 3).

-With children it is more difficult. You have to be more patient and dedicated (subject 4).

In our study, one factor that might affect the encounter between the physician and the mother-child pair is the rotation of residents through different sectors every three months. Despite being necessary in order to offer more experience to residents, this is not favourable to monitoring cases over time, as stronger bonds are not created. Because of rotation and depending on the frequency of consultations, the patient is often seen by a different professional every time. Thus, the patient is referred to a sector and not to a physician and is therefore more closely linked to the institution than to the professional.

There are also different factors that occur during the outpatient consultation which compromise the quality of the listening process and the fluidity of the dialogue. During observations, we found many physicians providing care in the same room, with no privacy and with frequent interruptions. They often needed to queue up to treat a patient (many residents using the same device), and it was not uncommon for physicians to deal with more than one patient at a time in order to speed things up.

Particularly with regard to residents, we observed work overload and, in some cases, a lack of motivation for working in sectors they had not chosen themselves.

Despite these difficulties, participants highlighted the importance of establishing a good relationship with the family, due to the close dependency relationship between the child and the family. The professionals noted the extent to which family members were affected by the child's disease, especially the mother, who is generally responsible for providing and obtaining adequate care.

- I feel that I am providing benefits not only in caring for the child with a severe eye disease, for the relationship between the two, but also in helping them understand the relationship between the disease, the mother and the child (subject 3).

However, if on the one hand providing care to a child is difficult (according to some participants), on the other it is very gratifying — for health professionals as well as, naturally, for the child and family — to diagnose and treat a disease in time, thus preventing blindness in a child.

-[...]treating a child brings results and benefits because they have their whole life ahead of them (subject 3).

We observed that a severe eye disorder during childhood impacts the family (because the child is no longer the idealised child they had dreamed of), the child (because of the limitations and repercussions caused by the condition) and the physician (because of the feelings of frustration and failure which emerge when a cure cannot be found).

-The hardest moment is when we think we cannot do anything to save a child's sight, or when the only option is to remove the eye, and sometimes an eye which can still see (subject 9).

The physician's distress while caring a child with a severe eye disease appeared to be mainly due to the perception that their patient's childhood would be marked by a series of obstacles and restrictions generally associated with these situations.

- The hardest is when you cannot reverse the situation… You try to act in one way and cannot reverse the disease… A premature baby who is losing their sight, you go there and use the laser but they still stay the same and lose their sight… and then the physician has to inform the family that despite their efforts, they could not save the child. This is the hardest moment because there is always the possibility that the family will not believe you and think it is your fault. For the physician, in the case of very serious disorders, you try to save one of the eyes and can't and have to remove it ... In premature babies, you try to save it, you can't and lose it... All of this puts the physician in a difficult situation because they have to relay this to the family which has hopes and cannot accept blindness, and thinks that you could have done something that you didn't (subject 12).

The professionals also expressed feelings such as frustration, helplessness and having to deal with the loss of the idealised figure of the physician when dealing with severe, difficult-to-treat cases which could cause serious consequences. One example of this is the fact that, when asked about emotional situations they had experienced, one third of participants mentioned the same case, highlighting it as the most striking in their practice.

When asked about the hardest moment in providing care to a child with a severe eye disease, they emphasised the moment of relaying the diagnosis to the child's parents. All participants recognised their difficulties in treating more severe cases and those with a bad prognosis, which bring them face to face with their helplessness and limitations.

- The hardest moment is when you first have to give the news to the mother and father that the child has a tumour, that the eyeball will have to be removed, that the child cannot see[...]. The parents hope that you will bring them good news, that you will say there is a treatment and a cure, and you destroy that illusion. This is the

hardest moment to deal with (subject 2).

- The hardest moment is when you have to give the diagnosis that the eye disease is severe, that it is not a condition that we can treat or cure (subject 4).

When physicians face the most severe cases they experience feelings of anxiety which, due to their occasional inability to deal with them, cause them to appear cold, adopting a merely technical position and avoiding long conversations, not leaving room for questions which they might be unable to answer.

Discussion

The way physicians perceive their responsibility with regard to adherence to treatment brings us back to the issue of dialogue and exchanges in human relations[3,15,16], but also to the association between the practice of medicine and the gratification of helping others and feeling indispensable.

The nature of physician-patient interaction depends on several factors such as: setting, psycho-social aspects of the patient and physician (fears, expectations, anxieties, etc.), previous experiences, personality, psychological factors (stress, frustration, etc.), and the professional's technical training. Generally speaking, during their training physicians are not encouraged to think of the patient as a bio-psychosocial being nor to understand what it means for the patient to fall ill[17].

The professional has to be sensitive and to understand the patient's situation, listening to their complaints and trying to find strategies together with them, so as to help them adapt to the lifestyle imposed by the disease[8].

It is important to establish a partnership to promote adherence to treatment. For this, the physician-patient duo needs to communicate, to understand and to recognise each other as partners. And the physician needs to demonstrate that they value the patient's cooperation and participation[3].

Two individuals are only linked through dialogue and only look to each other if they understand that they mutually influence one another and if they understand each other[16].

Within the context of humanising healthcare, the communication process emerges as one of the challenges because it involves the possibility of creating understanding through dialogue. This does not imply a consensus of opinions and ideas but rather the possibility for professionals and users (patients and families) to be willing to build something[18].

When performing technical procedures, a professional should be emotionally commitment to understand the subject's values, experiences, expectations and limitations[4]. However, work overload and the fact that professionals do not chose the type of patients they will care for (as is the case with children) are other factors which can also prevent an empathetic relationship between the physician and the mother-child pair. We must remember that empathy is vital for a good relationship between the healthcare professional and a patient in the hospital environment[4].

At the same time, being close to the suffering of others has an impact on the physician, especially in the hospital environment and when faced with certain situations, such as a severe disease in a very young patient[4]. In addition to personal difficulties, physicians are generally not prepared during their academic training to deal with suffering[19].

When it comes to dealing with children, this situation can be worse, since we learn through culture that childhood is a time of development and achievements.

In fact, regardless of the patient's age, when the physician faces their own limitations in severe cases they can experience feelings of frustration, disappointment and a loss of omnipotence, leading to the loss of their own idealisation of the physician's figure[20,21], which can affect their narcissism[22]. On the other hand, it brings them back to personal values and affection and to their human dimension[23].

It must be remembered that, above all, the physician is a person who looks after others[24]. Despite the fact that they have to identify the disease and find a cure, severe cases and irreversible situations which may result in death make them confront their own limitations and insignificance, as well as their own mortality[4,9,23,].

The most striking cases affecting health teams during health care make us think about the physician's vulnerability and how much emotion is present in a relationship, in addition to the empathetic identification which permeates medical practice[12].

Physicians are trained to cure and to save lives, and one of the expectations when they embark upon a medical career is to be omnipotent and to cure all ills[21,23].

Despite the difficulties which arise in more severe cases, it is vital to manage information appropriately because the way in which it is disclosed directly interferes with the patient's relationship to the diagnosis and treatment[2,3]. However, physicians are often ill-prepared when it comes to communicating bad news[2,19,20].

Conclusion

The vast majority of physicians considered that the way a professional listens and speaks, as well as their posture, affects the relationship of the mother-child pair with a severe eye disease. Nevertheless, professionals tend to idealise both the figure of the physician and the mother. Thus, the physician emerges as the only person responsible for the mother's understanding of the child's illness. And the mother is seen as being able to overcome all difficulties and, if provided with correct guidance, she works as a mirror to the child's behaviour.

The length of a consultation is a factor that can interfere not only with the physician's relationship with the mother-child pair but also with their ability to listen and the quality of care. In the public healthcare system there is still a gap between the number of patients and the required number of professionals. In addition, professionals are under pressure to meet certain productivity targets, which can affect the medical encounter.

However, differences in physicians' points of view and positions do not seem to be limited to the time factor alone. They are also related to other factors, such as sensitivity and the ability to listen, which takes us back to the issue of medical training, the personal distress of the professional faced with severe conditions, the narcissistic injury caused by impossibilities experienced as failure, as well as each person's own characteristics.

It is not enough for the physician to provide information to the mother about the diagnosis and treatment; the professional also needs to be available to listen to her doubts and fears, to clarify and provide guidance in such a way that allows her to understand the severity of the disease and the need for medical follow-up, usually throughout the child's life (in the case of severe conditions).

Professionals need to be aware of the impact of their actions and words. In the case of ill children, particular attention should be given to the relationship established with families, generally represented by mothers. From the moment they receive the diagnosis and are informed about the severity (or chronicity) of

the child's disease, mothers have new duties to bear which will lead to changes in their personal and family habits.

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