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The communication between a doctor and his patients' parents as a factor in the availability of medical care for disabled children

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Abstract

The purpose of this study is the identification of types of communication among physicians and parents of disabled children, who have congenital or acquired pathologies and who need treatment and rehabilitation. The focal point of the study is the assumption that the communication between the doctor and the child's parents should be based on trust. It is one of the factors influencing the availability of medical care for children with disabilities. The study uses a structured in-depth interview (19). There is much evidence that doctors and parents prefer a paternalistic type of communication unlike partner, contractual or engineering. Our conclusion is that in a medical institution within the established bureaucratic type of organisational culture, recorded in our earlier study, the conditions for the professional activities of doctors and parents with disabled children receiving help are perceived by them as the most comfortable, since they correspond to their value orientations and expectations.

Keywords: Disabled children, access to medical care, doctor, parents, communication.

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1. Introduction

There is much evidence that changes in the Russian state system of healthcare target not so much the needs for preserving and maintaining the health of disabled children, but rather intend to optimise public spending on medical care. A key aspect of this problem is that in these conditions, healthcare experts must differentiate patients considering that some of them face barriers that limit their access to the services of medical institutions, even though there are official guidelines for maintaining healthcare for such categories of people. It has been previously observed that although medical assistance is free and of much importance to disabled children, the accessibility is limited by the ongoing changes in the management of healthcare organisations, recommended procedures and the number of medical services. Regarding this, the studies of ways to ensure the availability of medical care to this group of children in the new economic and financial conditions of the functioning of medical institutions are becoming relevant. We consider the interaction between doctors and patients, based on a certain organisational culture of the medical institution, as one of the resources to ensure the availability of medical care for disabled children. Depending on the type of organisational culture established in a medical institution, its objectives can differently express the interests and needs of disabled children in maintaining health. Of much importance is the organisational culture of healthcare institutions, which is a system of values under the influence of which conditions and motives of professional activity of medical workers, their professional value orientations and ways of interaction with patients are formed. The study of the doctor–patient interaction highlights the mechanisms ensuring the accessibility of medical care at the personal level. In our case, we describe the interaction of the doctor and the parents of his patients. The purpose of the study was to identify the preferred types of communication by doctors and the parents of children in the context of a certain type of organisational culture in a medical institution, and to analyse the capabilities of each type in ensuring the quality and availability of medical care for children. We proceeded from the assumption that the organisational culture sets not only the conditions of professional activity and patterns of professional conduct, but through communication, coming from doctors, influences the patterns of parents' behaviour regarding the health of their children. We analyse the behaviour of parents, characterised by varying degrees of activity, as a condition that ensures the quality and availability of medical care for disabled children.

Communication about health refers to the traditional areas of sociological research. The beginning of these studies stems from the classical model of 'doctor–patient communication' introduced by T. Parsons, and is presented in the works by K. Roger, T. Breivin, R. Vich, M. Becker, I. Aizen, A. Bandura and others. We proceed from the idea that we investigate communication in a specialised healthcare facility for children with congenital or acquired health defects in the context of the organisational culture of the institution and the access to healthcare conditions. This approach develops a methodology for analysing the problem of access to healthcare and elaborates on the idea of real mechanisms for providing it to disabled children.

2. Methods and Methodology

The methodological basis for the study of accessibility of medical care is the model of accessibility developed by Andersen, Davidson and Baumeister (2014). It includes many economic, political, social factors of macro-, meso- and micro-levels, the interaction of which determines the possibilities of medical assistance to different social groups. In modern conditions, the development of this model is due to the inclusion of variables that characterise the resources of the medical institution in ensuring the quality and accessibility of medical care. Important resources include the characteristics of professionals, medical experts and ways of communicating with patients. For our research, we adopted the typology of communications proposed by R. Vich, which includes the engineering, paternalistic, collegial and contractual model of interaction between a doctor and a patient (Vich, 1994). We considered the ideas of P. Northouse and L. Northouse (1998) about the types and basic

constituent elements of communication in medical institutions. For our study, of much importance was the therapeutic model of communication about health, introduced by K. Roger. The model emphasises the psychological component of the communication process. There is a growing body of literature that recognises the importance of the patient's satisfaction with the interaction with the doctor. It significantly improves the quality of medical care provided to the patient, aims at achieving positive changes in health status, which is an important characteristic of the availability of medical care (Roger, 1951). The significance of such communication stems from the ideas about the personal dignity of a patient, the principles of empathy and acceptance of the client, respect for his right to decide on the ways of achieving health.

The purposes of our study determined the methods of research and the selection of our informants. To gain important insights, we conducted in-depth interviews (19 participants), in which we interviewed doctors from a children's hospital (nine participants), parents of children (seven participants) and adults who were patients of a medical institution in their childhood (three participants). Children had the status of disabled persons because of congenital or acquired maxillofacial pathology and underwent rehabilitation in a children's rehabilitation treatment hospital. All interview participants related to a medical institution in which we conducted a study in 2016. The study proceeds from the results of our previous research of the organisational culture of this medical institution in 2015. The choice of the medical institution was not accidental. Its formation and development as a major children's rehabilitation centre in one of the largest industrial regions of the country started back in the 1990s and continues up to the present day. Its development embodied the main trends that characterised the institutions of national healthcare during the period of social transformation of Russian society.

3. Results

The major finding of the research was the fact that doctors choose authoritarian and paternalistic type of communication when interacting with the child's parents. It should be emphasised that the communication that the doctor sets up with the parents of the child is professional in nature, because he has special knowledge, education and professional experience. At the same time, communications set by parents are not professional. Describing the ways doctors interact with their patients' parents in a specialised medical centre for children born with severe health problems, our doctor-informants said, '… we give instructions. Do it this way and nothing else. And if something bad happens, then come and see me again' (Informant 5). 'We have to deal with them harder. … Sometimes I just say, 'Do it this way. Full stop ... I know how to do better' (Informant 6).

The paternalistic type of communication is characterised by the fact that professionals act in relation to parents in the role of strict mentors who better know what is good for their child. 'We do not even show compassion, we are always tough in a tone of speech, so that parents might concentrate and begin to help' (Informant 1); 'I listen to parents, but I never show compassion, I explain how to act further' (Informant 4). When initiating communication, doctors expect parents to trust them completely in making decisions about their child's health and should be involved in the rehabilitation process of the child in the role of those who implement the treatment recommendations of doctors. At the same time, doctors clearly understand the psychological state of parents who have a child with pathology of development, but the authoritarian type of communication, in their opinion, is more effective for achieving the goals of restoring the health of the child. Comparing the behaviour of the parents of the sick children who do not have pathology of development with the behaviour of the parents of children whose illness leads to disability, they noted, 'Parents of healthy children are less focused on the problem, the parents of children with pathologies are immersed in them. This is normal, and they understand that with this problem they will have to live up to 18 years' (Informant 3). 'They lack sympathy ...' (Informant 1). At the same time, doctors demonstrate a care for the family, understand their problems and the desire to help parents choose an acceptable way of treatment, for example, to reduce the cost of money that the family is

spending on the treatment of the child or their willingness to spend money more rationally, 'if I see that the financial status of the family is low, I try to prescribe another medicine, although less effective. Sometimes parents themselves spend their money ineffectively, i.e., instead of getting all necessary medical services at a local hospital, they pay money to come here, and vice versa" (Informant 4). 'There are expensive medicines and cheap medicines. And if you need to buy expensive ones, it's best to let the doctor explain why they are so, why they are needed and why parents should buy them. No one will explain it better than the doctor' (Informant 5).

During the study, we revealed characteristics that indicate the trend among professionals to the partner type of communication. Trust as a condition of this type of communication is based on the recognition of equal rights and responsibilities of each participant, observance of certain ethical requirements. Describing the process of communicating with the parents of children with disabilities, the doctors said that they were trying to explain to parents as much as possible the aspects of the pathology of the child. To discuss the possible consequences of the pathology for his health and the way to solve the problems with the child's health. But this type of communication contains a certain disparity between professionals and parents, who do not have special knowledge, which limits the partnership. In this regard, doctors try to avoid complex medical terms, explain all the questions to parents in a simple language, 'She (the mother of the child—the author) after all, came to my office and, maybe, she will come to me in 3 months, or in a year, and all these 3 months she will be somewhere left upon to her own resources, if she lives somewhere far away in the region and does not see narrowly focused specialists; then, I need to bring her to understanding of the problem. so that she recognises it and understands what to do in this specific situation …' (Informant 1). Some doctors supplement verbal communication with the support of brochures and photo albums. They offer parents electronic communication in between treatment periods of the child's rehabilitation through a forum on the official website of the medical institution or other possibilities that the Internet provides.

Parents' understanding and an adequate view of the problem that affects the child's health creates favourable conditions for restoring his health, as parents become participants of his rehabilitation. The active behaviour of parents, according to the doctors, acts as a factor ensuring the accessibility of medical care to a child, as it contributes to timely and complete assistance to the child. Most of our informants expressed the opinion that parents are not always, but often enough help the doctor in the process of treatment and rehabilitation of the child. This is because the value of the child's health and the need to restore it are among the priority values of most parents. 'Yes, there are different people … interested 'insofar as', 'some parents, who are interested as they should, and still others for whom the health of their child is the idea fixe. Well, asocial type. Initially, everyone is still worried about health' (Informant 2). Only one of the doctors expressed the opinion that parents are more likely to interfere with treatment, 'There are few parents who follow recommendations from A to Z, and a healthy lifestyle depends only on them. … If there is no correspondence between the behaviour of the patient's parents and the recommendations of the doctor, the effectiveness of rehabilitation is reduced' (Informant 4). None of the doctors expressed their opinions on the engineering type of communication.

Among the factors influencing doctors' choice of the type of communication, management and organisational conditions in which communication occurs are of primary importance for them, i.e., the institution's requirements for performing professional activities, the number of patients recorded for consultation, the amount of time that they have in establishing communication, '… We have a definite plan—the amount of work that must be fulfilled, and if we have already exceeded it, I try to talk with my parents in a different way, maybe even sometimes I can refuse' (Informant 4). When building communication, doctors consider the willingness of parents to follow their recommendations as well as parents' experience of communicating with medical professionals. Among other important factors is parents' ability to adequately perceive and understand the importance of the doctor's recommendations, parents' idea for restoring the child's health, the severity of the pathology

diagnosed in the child. Personal settings of doctors, professional value orientations and professional experience of interaction with patients also influence the choice of the type of communication by doctors. We managed to record that doctors, at their starting point of work in a medical institution, initially sought a partnership type of communication with the parents of their patients. However, under the influence of the organisational conditions of their professional activity, the doctors developed their interaction with parents who have children with serious health problems into the authoritarian type, 'Well, there was a time when I discussed all the methods of treatment, what and how I could do, and now I'm just saying, 'Do so, full stop'. This strategy saves the time; the line of patients does not get longer …' (Informant 6). Our finding is that authoritarian and paternalistic types of communication turned out to be the most common types among doctors when interacting with parents of their patients.

What stand out from the interview with parents of patients and adults who were patients of healthcare institutions in childhood are the fact that they mentioned authoritarian, paternalistic, partner and engineering types of communication. Interestingly, patients also mostly preferred authoritarian and paternalistic types of communication.

The current study found that the parents could explain their preferences for the authoritarian type of communication with doctors the following way, 'Medical care and the doctor … I put an 'equal sign' between them. But ... we are not doctors, if a doctor gives clear recommendations, you need to follow them. I like better the authoritarian type of communication. There should be no right for the patient to choose whether you want to get medical care, or you don't ... the patient … he does not know how it should be' (Mother of a teenage girl, 43). 'Most likely, it does not depend on the doctor. Of course, I prefer a friendlier type, because it's easier to interact with a doctor somehow. But my orthodontist, she is authoritarian enough, but she ... says everything calmly, what needs to be done, so, please, do so. I do not see anything wrong with this. All right. If they are good doctors, they cannot say anything wrong' (Girl patient, 15 years old).

The paternalistic type of communication is characterised by the fatherly, caring attitude of doctors to parents and children, 'Most likely, these doctors, understand our situation when they come to a meeting with us ... This attitude in hospitals, as here, will be everywhere. We feel like home here' (Mother of a one-year-old child, 34 years old).

The partner type of communication with doctors was formulated by a woman who has an adult son who had a congenital pathology as a child and was a patient of a medical institution, 'I need to be more balanced, so that we, and them ... It is better when doctors give advice, not instructions!' (Mother, 67 years old).

In this study, two adult young people, who were patients of the healthcare institution—a man and a woman—, formulated the engineering type of communication quite clearly. This type of communication is characterised by the expectations of patients or their parents of the high professionalism of doctors and does not imply a personal component in the relationship between them. The interaction between the doctor and the patient, in their opinion, should be limited only by eliminating any functional disorders that affect health, and no more, 'I think that it is not the type (communication—the author) of the doctor that is important here, but his competence, that's all' (Woman, 38 years old); 'Well, every doctor has his own procedure ... and why should he do it (he speaks quietly) … in a kind or evil way … This is just a procedure, I believe. I think that they all had their own procedure … nothing else' (Man, 40 years old).

The results of the study show that the doctors' competence is of much importance for parents while communicating. Above all, the doctors' experience of practical work with children with pathology is considered as most important factor by the parents while communicating with them All parents in their remarks stressed the fact that the doctor in the communication process should be credible. 'Healthcare is important and trust is important. If you trust a doctor, then, basically, it is irrelevant whatever type of communication he sticks to ..., you trust him, I, for one, have something to

compare. … Here, as I said, I trust doctors, I know that they are experts of a narrow type, and they know it ... here you trust professionals and you know that they have had the same cases. They have studied this; they have already seen many children. A lot of such stuff has passed through their eyes and hands'.

4. Discussion

The analysis of the interviews showed that the type of professional communication is built by the doctor, and the parents of patients rather accept the proposed types of communication. They expect a certain type of communication about their child's health when interacting with different doctors from healthcare institutions. The basis of their preferences is the trust in the doctor. Their behaviour forms in accordance with the roles that this or that type of communication assumes, and can in various ways ensure the completeness of medical care for the child and the achievement of its result (Starshinova & Gogoleva, 2016). Another important finding is that parents and doctors prefer the same types of communication, because communication depends on the conditions of a children's rehabilitation hospital, which is determined by the prevailing organisational culture. The results of our previous research showed that in this medical institution, the bureaucratic top-heavy type of organisational culture prevailed, it is based on the high regulation of activity (Starshinova, Pankova, Blokhina, Gogoleva & Tkachenko, 2015). This type of culture is more focused on the internal environment and not on the external (Schein, 2002). In the value system of a bureaucratic type of culture, professionalism refers to priority values. But the primary purpose of the medical institution's activities is to meet the needs of children with disabilities in restoring health. This goal is achieved through formal communication mechanisms and the regulation of the process of activity. The created conditions of activity within the framework of such a culture lead to a kind of 'loss' of this goal. Here, we observe the process of goal's transformation into formal mechanisms during its implementation. This is confirmed by the doctors' statements that the implementation of the 'plan' for the reception of the number of patients was a factor which determined how communication with the parents of their patients would be built. Values of authoritarian and paternalistic type of communication correspond to the bureaucratic top-heavy type of organisational culture of a medical institution. Authoritative type of professional communication is based on recognition of the authority of the profession of a doctor, his knowledge, experience, subordination of parents to his requirements for the treatment of a child. Paternalism presupposes a caring, paternal attitude of the doctor to his patients and their families. There is a body of literature describing Russian public health system, especially paediatrics, which shows that 'this model of relations remains the most preferable among both doctors and patients' (Kuz'min, Semenova, Petrova & Zakroeva, 2016). Authoritarian and paternalistic types of communication, with certain differences, form a mixture of high self-esteem of doctors and their confidence in their professional competencies and the assumption that professionals should rely only on themselves, and parents must follow their recommendations. Parents, getting into conditions established in a medical institution, are forced to accept the existing patterns of communication. The study showed that the dominant types of professional communication dictate to parents the role of executors of those recommendations that are prescribed by the doctor. Authoritarian and paternalistic types of communication allow medical experts to mobilise parents experiencing a crisis psychological state regarding the birth of a child with a pathology, because of which the child becomes disabled. During this period, parents are confused, they do not understand what they can and should do in the situation of the birth of a sick child. Strict, formal relationship with doctors or the relationship of paternalistic type allows them to cope with the crisis. But the position of the diligent executor of medical prescriptions, as a reaction to the proposed professional communication, may result in passivity or detachment, since parents think that the doctor is responsible for the result of restorative treatment. In this respect, the partner type of communication has a considerable potential. Such relationships include the possibility of sharing responsibility between professionals and parents and lead to positive results of restorative treatment and further maintaining the health of a disabled child. None of the doctors indicated that they could make their choice of communicative

type by recognising the equal rights of both sides. Doctors could not accept the equal role of parents in decision making regarding the diagnosis and treatment of a child's disease. But doctors expressed opinions pointing to the recognition of parents' importance and the appreciation of partnership communication. This type of communication not only motivates parents to become a participant in the rehabilitation of the child, but also able to develop their activity. This model has a great potential in providing access to medical care for children. The contractual type of communication, close to the partner type, focuses on the conclusion of a contract between its participants, but is limited in domestic practice due to the relatively short period of its development within Russian healthcare system. The possibilities of this type of communication in Russian medical institutions need further study. The engineering type of communication, excluding the personal component in interaction with parents, does not contribute to their motivation for inclusion in the child's rehabilitation process. This type of relationship is characterised by a technological approach and provides only 'correction' of impaired functions in the child's body. The possibilities of this approach in achieving access to medical care for disabled children as the formation of a certain pattern of parents' behaviour regarding their child's health are limited in comparison with others. But this type of communication has the right to exist, because there are always parents who cannot and do not aspire to participate in the rehabilitation of their child for various reasons. They trust professionals completely. In our study, such a model was preferred by adults who were born with maxillofacial pathology and were patients of the medical institution during their childhood Their opinions are based on a retrospective view of the relationship between the doctor and parents. This view is of interest, and can be the subject of a further study.

5. Conclusions

The analysis of the obtained results of communication study indicates the potential of each communicative type and the possibilities it contains for a medical care of a disabled child to make the rehabilitation accessible and of high quality. We revealed the opportunities in certain patterns of parents' behaviour aimed at restoring and maintaining the health of the disabled child. These opportunities can be formed in the process of professional communication, depending on its type. This paper has discussed that the behaviour of parents may be passive, but may be characterised by high activity aimed at achieving positive changes in the health status of the disabled child. At the heart of this behaviour, there are the parents' value orientations and their attitudes. The study of the dynamics of communication types in accordance with the type of organisational culture is of direct importance for the management of a medical institution. Changes in the organisational culture of the institution should be oriented towards the immediate goal of its functioning — i.e., meeting the needs of disabled children to improve their health.

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