ORIGINAL ARTICLE

DOI: https://doi.org/10.20453/renh.v17i.2024.5958

Adherence to indications and outpatient medical care from the perspective of caregivers of children

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ABSTRACT

Objective: To describe adherence to treatment and outpatient medical care from the perspective of caregivers of children. **Materials and methods:** Qualitative research, with a descriptive case study approach. Fourteen caregivers of children who attended outpatient consultation in a pediatric health institution of high-resolution complexity participated as informants. They were selected by saturation or redundancy and inclusion criteria. A semi-structured interview guide was used for data collection, and then the data was subjected to thematic analysis. **Results:** Five categories and seven subcategories emerged, highlighting positive and negative aspects, such as sociocultural conflict mediated by verbal and nonverbal communication barriers, pathology-focused medical care, lack of support and difficulties in the delivery of medical appointments at admission. Regarding the positive aspects, a high level of adherence to medical treatment by the caregiver was found. The negative aspects identified were related to the need to humanize health care in institutions, as this trend has currently become more relevant and has been endorsed by many authors. **Conclusions:** In the narratives it was possible to identify negative and positive aspects during outpatient medical care. The negative aspects are related to the relationship between the physician and the caregiver, and the positive aspects promote adherence to medical indications by the caregiver.

Keywords: perception; medical care; communication; doctor-patient relationship; adherence.

Received: November 1, 2024
Accepted: December 5, 2024
Online: December 12, 2024

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INTRODUCTION

Adherence to medical instructions involves the patient's acceptance of the diagnosis and its impact on the prognosis. Non-adherence worsens the prognosis, and the outcomes may be unfavorable (1). Multiple factors contribute to non-adherence, including the patient's lack of knowledge about the disease, treatment and the consequences of non-compliance, a poor patient-physician relationship, the complexity and long duration of treatment, asymptomatic illness, lack of

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follow-up or an established plan for discontinuing medication, presence of adverse effects, medication costs and/or copayments, failure to attend medical appointments, psychological issues such as depression or anxiety, patient beliefs and perceptions about medication, and cognitive difficulties (2, 3).

The World Health Organization (WHO) defines adherence to medical instructions as the extent to which a person's behavior—taking medication, following a diet and implementing lifestyle changes—corresponds to the agreed recommendations of a healthcare provider. The World Health Organization considers it a global health issue of significant magnitude (4).

In children, adherence to medical instructions depends on their caregivers; however, it is partially influenced by good verbal or gestural communication and the interaction between the physician and the caregiver. It is of utmost importance to take this aspect into account during medical care (5, 6).

Communication between the physician and the caregiver involves an exchange of information, where the message is expected to be clear and precise. When the informational, emotional and relational content is in harmony, the outcome is positive (7, 8). If medical indications are not understood, an accident may occur due to improper administration of the prescribed medication dosage (9). Poor treatment in infection cases can lead to drug resistance, becoming a public health issue, as seen in tuberculosis, HIV and other infectious and infectious diseases (10).

In the physician-patient relationship, it is important to understand the health-disease process, which involves the patient, the family and healthcare professionals (11). The physician plays the fundamental role in patient care by gathering the necessary information for diagnosis, providing reassurance and security, and facilitating the patient's disclosure of symptoms, as well as their cooperation during the physical examination (12).

Consequently, it is essential to maintain a close, familiarized physician-caregiver relationship that fosters mutual trust. This, in turn, strengthens knowledge, acceptance and adherence to medical guidelines while preventing rejection (13).

In order to investigate adherence to medical instructions and outpatient care from the perspective of caregivers of children in a high-complexity referral institution, certain gaps or shortcomings were identified in the physician-caregiver relationship. Additionally, there is a distorted perception of the quality of care received or a "misinterpretation", which leads many people to opt for non-adherence to treatment.

According to some research studies, the causes of non-adherence to treatment are linked to the belief of not having been treated properly, difficulties in understanding medical explanations related to treatment, lack of time for communication, and an inadequate physician-patient relationship (14), as well as the patient's perceptions of medication and the presence of cognitive difficulties, among others (3). Adherence rates in developed countries are around 50%, whereas in developing countries, they are significantly lower. This leads to disease aggravation, an increase in hospitalizations, and high costs for the patient, the family and the healthcare system (15). A study was needed to provide a clear and realistic description from the perspective of the protagonists regarding outpatient medical care in a high-complexity pediatric healthcare institution. The problem is particularly important because it involves children, as therapeutic regimens are crucial, especially in the case of infectious diseases. Pediatric physician-patient relationships are more complex than in other medical fields. A pediatrician must interact with multiple individuals—the mother, the father, the grandmother, the aunt—and if he ignores them, treatment failure is evident, especially in managing chronic or prolonged conditions (16).

In this context, researchers aimed to describe treatment adherence and outpatient medical care from the perspective of child caregivers in a high-complexity referral institution in Lima, Peru.

MATERIALS AND METHODS

There are three types of case studies: explanatory, descriptive and exploratory. This study is qualitative research with a descriptive approach, aimed at addressing a problematic situation in terms of a logic centered on a primary analysis of the subject/object of study (17).

The case study investigates a phenomenon in depth within its real-world context, especially when the boundaries between the phenomenon and the context are not clearly defined. It is applied as both a pedagogical tool and as a research instrument in different disciplines, including nursing. This type of study emphasizes the understanding of a particular phenomenon, the subjective acceptance of individuals,

whose interpretation is based on observations and testimonies (18-20).

The study population consisted of 14 caregivers, the vast majority of whom were women, with only one male participant. It is assumed that mothers, most of whom are single mothers, know their children much better. The children's ages range from 0 to 17 years, 11 months and 29 days, as it is a pediatric institution to which they are referred from different parts of the country. The institution offers 57 specialties, with pediatric medicine being the most in-demand. The most prevalent conditions are chronic diseases, including cardiovascular, renal, neurological, genetic, and respiratory malformations, as well as rare diseases. Some children attend for preoperative evaluation while others have their first consultation.

The sample was selected by saturation or redundancy technique, along with inclusion and exclusion criteria. The inclusion criteria considered were the voluntary willingness to participate and the acceptance of being recorded through the signing of an informed consent form, the ability to understand and speak Spanish, being of legal age, and being responsible for the child's care to ensure the administration of medical instructions. Individuals who were illiterate or did not understand Spanish, those with hearing impairments, cognitive deficits, or mental disorders were excluded.

The project was approved by the Institutional Ethics Committee at the end of 2019; however, due to the pandemic, it was postponed, and the interviews were conducted during the first quarter of 2023, at the exit of the consultation. The interview was recorded on an electronic device in a private area of the hospital in a conversational and personalized manner, ensuring cordiality, tranquility, confidence and confidentiality. Identification was assigned by interview number: I1, I2, …, I14.

First, sociodemographic data were collected, followed by the actual interview with an approximate duration of 30-40 minutes. A preliminary trial interview was conducted for validation purposes.

The interviews were transcribed verbatim in Word and sent via email or WhatsApp to the informants for their review. It was verified whether any terms or phrases needed to be added or removed; all informants gave their approval.

To determine adherence to medical indications, the caregiver's concept and knowledge of health, illness and care were considered, as well as attendance at three consecutive follow-up medical appointments scheduled by the physician and coordinated with the principal investigator, who was responsible for reminding the caregiver of the date and time of the appointment through phone calls. The interview served as the starting point for the respective check-ups (January to June 2023).

The data collected were systematically organized to differentiate the units of meaning, categories and subcategories, using the chromatization technique. The analysis and interpretation were carried out by expanding the units of meaning based on the stated objective and the proposed criteria within the thematic analysis (21).

It is worth noting that ethical principles and scientific rigor are considered throughout the entire process. Furthermore, the results were approved by the Institutional Ethics Committee.

RESULTS

92.86% of respondents were women (n = 13) with only one male participant. The ages ranged from 19 to 40. 57.14% had completed secondary education (n = 8); 28.57% had completed university studies (n = 4); and a smaller proportion had incomplete secondary education (n = 2). 42.85% received medical attention for the first time, while 57.15% were returning patients.

Then, the following presents the results of the analysis, outlining five categories and seven subcategories. The first two subcategories refer to the physician-child caregiver relationship. The following three subcategories are important factors as they promote adherence to medical instructions. The sixth subcategory highlights an institutional issue that needs to be addressed by authorities. And the last subcategory denotes an important aspect in solving the problem (Table 1).

Table 1. Data analysis and interpretation using thematic analysis.

Category	Subcategories
Perception of the physician-caregiver relationship	Sociocultural conflict (communication barriers)
Hegemony of the biologist model in medical practice	Medical care focused on pathology
Adherence to treatment and care	Caregiver's perception of health and illness Knowledge about the child's illness, care, and adherence to medical instructions
Team: Supportive relationship	Planned follow-up
Humanizing medical practice	Lack of support and unavailability, obstacles and difficulties in medical appointments Integral and holistic health care

Sociocultural conflict (communication barriers)

In the physician-caregiver relationship, a multicultural encounter takes place, where diverse beliefs and values regarding health, can positively or negatively influence treatment. This generates the need to know the other person's culture to redirect decision-making in an accurate and timely manner. Let us consider the following speech:

> **I3:** *I do not really trust medications [...], I am here because of SIS* (Integral Health System) *[...], I believe in cleansing rituals, I prefer herbs like eucalyptus with honey, garlic, and ginger, and that helps alleviate my cough; pills don't do anything. I give my child what the doctor prescribes, but I also supplement it with herbs from the countryside.*

Regarding the initial communicative act, we find ambivalent responses. On the one hand, the expressions of caregivers of children who have received medical care for the first time are accompanied by positive feelings and emotions, such as feeling well, safe, confident, thankful and calm. This is evident in the following statements:

> **I3:** *I did not expect good treatment.*
>
> **I4:** *I am happy with the attention and the doctor's kindness [...], I feel happy and glad; my children are in good hands.*
>
> **I2, I8, and I10:** *I received a kind greeting [...], I feel calm and grateful.*

However, caregivers, especially returning patients, express feelings of rejection and dissatisfaction with the treatment received. In fact, when asked how they would like to be treated, they respond as follows:

> **I1 and I13:** *That they have more patience, know how to listen to us, give us support, do not throw us out.*
>
> **I5:** *That they help me, not yell at me [...]. That they provide information patiently, allow me to ask questions if I don't understand [...], and explain more about the illness.*
>
> **I6 and I14:** *That they greet me or respond to my greeting. It is uncomfortable when they do not respond, I do not know how to act, and I feel embarrassed to ask questions, they do not make us feel confident.*
>
> **I9 and I12:** *I would like them to change the way they treat us.*
>
> **I10:** *They do not treat us well; they make us wait for a long time.*

As for the written communication on medical instructions, all informants unanimously agree that they are illegible, so the pharmacist is their primary source of assistance. Let's see some statements:

> **I1, I3, I4, I5, and I9:** *I don't understand the handwriting on the prescription, but the pharmacist does and helps.*
>
> **I6 and I14:** *They write so fast that instructions are unreadable.*

Medical care focused on pathology

Child caregivers think and complain that physicians do not conduct physical examinations as thoroughly as they believe your child requires. Criticism increases

if they are not taken into account during the medical interview. This is evident in the following statements:

I5: *My child was seen very quickly, I didn't feel good about the way we were treated.*

I9: *The doctor speaks very little; she does not answer when we ask questions.*

I11 and I13: *I would like more dedication during my son's examination. I would like to be asked, to be explained; I don't want them to focus only on the pathology—I want a complete examination.*

Caregiver's perception of health and illness

Respondents understand health as "the most valuable thing." They conceptualize it as being well and feeling well in all aspects—physiobiological, psychological, environmental, sociocultural and economic. Additionally, they define health as a source of happiness that must be preserved through care and protection. This can be seen in the following statements:

I3 and I7: *Health is the most valuable thing.*

I4: *Health is very important; it is kept through a good diet.*

I5 and I8: *Health is about care and protection.*

I9 and I12: *Health is very important; it is everything.*

I13: *Health [...] comes first. Illness is worrisome; I want to see my daughter happy, healthy, and enjoying life.*

I14: *Health means being well and feeling good in all aspects of life.*

Knowledge about the child's illness, care, and adherence to medical instructions

Child caregivers demonstrate an acceptable level of knowledge regarding the illness and the necessary care measures. Additionally, they express concern and fear of death or worsening of the condition if medical instructions are not followed. This is evident in the following statements:

I4: *I have two sick children [...], one has a broken tooth, it hurts a lot; the other has an inguinal hernia [...]; I've been told that both cases are serious [...]. If I don't follow the medical treatment, my children's conditions could worsen.*

I5: *His testicles have not descended; I do not know what care measures to take; there are things that I just don't know.*

I6: *My son was born with a clubfoot. I must take care of my casted leg, ensuring it does not move too much to prevent a hip fracture due to the cast's weight [...]. I will follow the doctor's instructions, otherwise the foot would return inward again as it was at birth.*

I7: *They're going to rule out heart disease. I don't know the care I should have [...]. If I don't follow the instructions, my child could die.*

I8: *He has kidney problems, losing calcium and protein in the urine. Food should be low in salt, not sweets [...]. I want to see him healthy, eating normally. If I don't follow instructions, his health will worsen.*

I9: *My son has a cough, I thought it was tuberculosis, but PPD test was negative [...]. Among the necessary care measures: no pets, maintaining cleanliness, no stuffed toys on the bed, and a clean environment [...]. A year ago, he had meningitis and epilepsy [...], now he has bronchial issues, along with diarrhea and vomiting [...]. I must continue using the inhaler and give him oral rehydration solution for each episode of diarrhea or vomiting [...]. I follow his therapies for seizures, otherwise, he could die.*

I11: *He has a cough; I thought it was COVID-19 [...]. I must take care of his diet and hygiene.*

I12: *He urinates blood, it can be due to his kidneys [...]. He should stay in bed until he gets better—no jumping, no running [...], soft foods, no fats, no seasonings, no artificial coloring, and no spicy food.*

I13: *She has pain in her knees. [...] I must watch for swelling or redness in the knee area to bring her immediately, [...] she should not walk too much or hit in that area [...]. I must give her paracetamol and bring her to the hospital for some tests.*

Planned follow-up

Follow-up is a fundamental aspect, as patients (child caregivers) feel important and grateful to the doctor and nursing staff for their concern about their child's health. This is evident in the following statements:

I9: *I am grateful; it seems strange that you call to remind me of the appointment—no one has ever called me before.*

I12: *Yes, I'm keeping track of the appointment, thank you. Tomorrow I'll be at the hospital first thing in the morning; I hope to be attended quickly in Admissions—that's where the problem is.*

I13: *Thank you very much for getting me the appointment, Miss, otherwise, my son would miss the*

scheduling for his heart surgery. Thank you, thank you for calling me.

Lack of support and unavailability: obstacles and difficulties in medical appointments

Almost all caregivers have a negative perception of the admissions and security staff due to criticism, mistreatment of family members, and a lack of support in the process. These issues are evident in the following statements:

I1, I2, I4, and I9: *I would like them to answer the phone to schedule an appointment [...];* we spend *days calling and they don't answer. I come in person, and they say the appointments are by phone. The staff from Admissions do not understand us, we live far away.*

I5: *They should improve the appointments scheduling process [...]; the lines are too long, and young children get bored and stressed. They should give priority to small children.*

I12: *They need to change the way they treat people, from the security staff to Admissions. They should treat us like human beings—greet us, not ignore us.*

Integral and holistic health care

Health professionals should provide comprehensive and holistic care to patients and their families. Sometimes what a person needs and appreciates even more than medication is the loving presence, someone genuinely concerned about them, a helping hand to count on, and someone who knows how to listen. Today, it is necessary to restore the human aspect of medical care. Let's see the following case:

I9, I11, and I14: *I would like them to be more human.*

I10: *My son hasn't had bowel movements in seven days. He cries and is afraid to go to the bathroom—I don't know what to do. At the health post I was given this syrup (lactulose), but it's not working. I came to the emergency service; they told me to call at the end of the month for an appointment; it's March 10; they don't listen to me, there's no humanity* [she cries].

DISCUSSION

Sociocultural conflict (communication barriers)

This occurs within a multicultural setting. The healthcare institution in this study serves as a national referral center with high-complexity case solution. It brings together individuals from the coast, the highlands and the jungle, each carrying their own cultural identity and a unique perception of health and illness.

Culture influences people's behaviors, beliefs, and language, shaping the way they act according to their culture. Understanding a patient's culture is essential to strengthen, restore or negotiate care based on their beliefs, particularly when cultural differences may interfere with adherence to medical instructions (22).

Communication plays a fundamental role in human relationships, encompassing the way of speaking, informing, communicating, transmitting emotions and attributing intentions. Therefore, communication must be clear, precise and appropriate for the intended recipient (23), otherwise, it may lead to misunderstandings and conceptual deficiencies (24).

In this study, some caregivers reported receiving good initial treatment expressed through greetings, friendly attention, and order of arrival, which translates into a sense of calm and trust. However, most of them expressed dissatisfaction and a lack of understanding of the physician's verbal and non-verbal communication. In this regard, studies suggest that the communicative process is related to effectiveness; that is, if the physician, during patient care, manages verbal and non-verbal communication in an assertive and supportive manner, based on the principle of solidarity, adherence to instructions and treatment success would be ensured (25). On the other hand, both parties would benefit: caregivers would feel better attended, and the physician would experience reduced stress and avoid potential legal proceedings (26).

Pathology-centered medical care

In the biologistic model, the person is seen as a purely biological being, without considering their social, cultural or family essence in the health-disease process (27). Caregivers request comprehensive medical care for their children, arguing that physicians focus solely on the pathology of the child. They feel discomfort because they are not asked any questions, they are not heard, their doubts are not clarified, and they feel distant and distrustful. It is important to involve the family in the care of the patient, as the information they provide contributes to a more accurate diagnosis and better treatment (28). In the case of children, parents or caregivers serve as their spokespersons; if they understand the situation, they will assume responsibility and ensure compliance with their duties. Special attention must be given to the family, providing a clear and precise explanation of the necessary care and verifying their understanding of the message—without offending if any improper attitudes are observed during the interaction (29).

Caregiver's perception of health and disease

Most child caregivers are familiar with the basic aspects of maintaining their children's health; however, they have a great need for emotional support and assertive communication from the physician. However, a caregiver's knowledge of the child's health and disease largely depends on their educational level, cultural beliefs, guidance, diagnosis, treatment, and care, as well as appropriate follow-up by the physician and all healthcare professionals who have direct contact with the patient (6).

Knowledge about the child's illness, care, and adherence to medical instructions

Knowledge of an illness refers to the set of information that a caregiver must possess to positively approach the disease and the patient's treatment, fostering a sense of self-sufficiency (30). The interviewed caregivers are aware of the diagnosis, treatment, and consequences of non-compliance. They state that they received this information from the physician and other healthcare professionals, and supplemented it with online search.

Non-adherence to medical indications is a multifactorial problem (31). The World Health Organization (WHO) classifies it as a "global problem of great magnitude" (4), highlighting the importance of addressing the issue and seeking effective solution strategies. Upon further investigation, it was found that caregivers feel deeply committed to their children's recovery or, in some cases, to improving their quality of life, which is why they express significant concern. Noncompliance, on the other hand, is associated with treatment failure and even death.

Planned follow-up

In addition to the caregiver's knowledge of the child's illness, care, and the health-disease process, it is also vital to mention the physician's planned follow-up through necessary check-up appointments during the course of treatment. Medical follow-up is a strategy that allows for the assessment of adherence to the instructions, the impact during treatment, and the difficulties faced by the caregiver. Furthermore, it provides key elements that facilitate decision-making for both parties. Both the physician and the child's caregiver share responsibilities; however, it is the physician who must establish effective communication (1). It is part of care humanization for individuals, families and communities.

Lack of support and unavailability, obstacles and difficulties in medical appointments

The interviewed caregivers express their frustration with the appointment scheduling system for outpatient consultations: "the Admissions staff does not answer the phone." They may spend days trying to get an appointment without success. It is a very cumbersome process, which they consider a form of mistreatment.

Integral and holistic health care

Child caregivers request comprehensive medical care for their children. Discussing the "holistic model is not just about seeing the patient as a whole, but it involves recognizing the complexity of the human being and the world, linking factors that may either facilitate or hinder health processes (32).

In this case, not only are the physician's professionalism or scientific and technical knowledge valued, but also their communication skills and, most importantly, their human warmth (33, 34). Apart from that, the process of dehumanization was worsened with the pandemic, making it necessary to adopt a comprehensive approach with humanizing practices, such as a therapeutic touch, words of encouragement and comfort—gestures that are often the most appreciated by patients (35, 36). All healthcare workers should demonstrate an attitude of self-transcendence, placing the "other" at the center of their concerns (36-38).

Limitations

This study has limitations associated with the data collection technique, as in other qualitative studies. During the interview process, there is a possibility that respondents may not fully express their feelings due to the fear of being judged for their statements. Despite the explanations of researchers, many individuals do not wish to participate for this reason.

CONCLUSIONS

In the narratives of child caregivers, both positive and negative aspects were identified in the outpatient medical care provided by a high-complexity pediatric healthcare institution. Verbal and nonverbal communication barriers were noted in the physician-caregiver relationship, due to ignorance of each other's culture, a medical approach focused solely on biological aspects, and the lack of support and unavailability of the admissions staff.

Similarly, a high level of adherence to medical instructions was observed, which are based on three very important factors: the caregiver's knowledge of the child's illness, a clear understanding of the health-disease process, and the physician's planned follow-up, as evidenced by attendance at three consecutive medical check-ups. These three factors, as demonstrated in this study, play a crucial role in strengthening adherence to medical instructions. If a strong physician-caregiver relationship and humanized care are established, it is assumed that adherence to medical indications could be achieved almost entirely.

Conflict of interest: The authors declare no conflict of interest.

Funding: Self-funded.

Ethics approval: Study protocol approved by the Ethics Committee of the National Institute of Child Health, with code PI-80/19, reg. CIEI-392-2023.

Authorship contribution:

MPTD: conceptualization, data curation, formal analysis, research, methodology, monitoring, validation, visualization, writing of original draft, writing - review & editing.

GUA: data curation, formal analysis, research, visualization, writing of original draft, writing - review & editing.

JMP: formal analysis, research, resources, visualization, writing of original draft, writing - review & editing.

MERV: data curation, formal analysis, research, resources, validation, writing of original draft, writing - review & editing.

Acknowledgments: To the participating parents for their valuable information, which made this study possible.

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