

# Communication in situations requiring unusual support in audiological practice

## Znaczenie komunikacji w sytuacjach wymagających nietypowego wsparcia w praktyce audiologiczno-terapeutycznej

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**SUMMARY:** The article discusses the importance of effective communication and informational support for parents of children with hearing impairment who are in difficult situations. I present three cases: a young parent of a child with hearing impairment; parents and children with genetic deafness (the “Deaf” family); and a child with multiple disabilities, including hearing impairment. Based on these cases, I discuss general guidelines of how to give effective help to patients in difficult situations, which can occur in the practice of physicians and speech therapists. In the last part of the article, I show a roadmap for effective communication between healthcare professionals and patients with hearing impairment. The roadmap was developed based on the classic Jacob's theory of speech acts.

**KEYWORDS:** hearing impairment in children, support, young parents, parents of deaf children, multiple disability, communication with patients

**STRESZCZENIE:** W artykule zostanie omówione znaczenie skutecznej komunikacji i wsparcia informacyjnego dla –będących w trudnej sytuacji – rodziców dzieci z wadą słuchu. Na przykładzie trzech przypadków: młodego rodzicielstwa, głuchoty genetycznej (rodziny Głuchych) oraz zaburzeń sprzężonych występujących u dziecka, zostaną opisane ogólne zasady postępowania, dzięki którym udzielanie skutecznej pomocy w nietypowych sytuacjach, będących udziałem lekarzy i terapeutów w praktyce audiologicznej, staje się łatwiejsze. Ostatnim elementem pracy jest opracowanie ścieżki komunikacji personelu z pacjentem z wadą słuchu. Ścieżka ta oparta jest na klasycznej teorii aktów mowy Jacobsona.

**SŁOWA KLUCZOWE:** niedosłuch u dzieci, wsparcie, wczesne rodzicielstwo, rodzicielstwo głuchych, wady sprzężone, komunikacja z pacjentem

### INTRODUCTION

Parents of children with hearing impairment have multiple problems, which tend to change with time. In Poland, doctors treat young children with hearing impairment according to treatment standards, which include education of children and parents alike [Zaborniak – Sobczak, 2015]. Acquisition of language by children with hearing impairment depends on the quality of treatment and on the age in which the children

receive it [Geers et al., 2009]. Giving support to parents of children with hearing impairment may improve the development of these children [Moeller et al., 2013; Sarant and Garrard, 2013; Razafigamahefa-Raelina, 2016]. This support includes helping parents choose the best treatment and teaching them how to communicate with their children, which improves the quality of life of both parents and children [Bruin, Nevo 2013, Kumar et al. 2014]. In children with hearing impairment, early diagnosis, adequate treatment, and hearing prostheses improve language

acquisition. However, non-medical factors, on the part of parents of these children, are also important; these factors include an ability to concentrate on the child's disability, depression, amount of support, and satisfaction with support (Geers et al, 2009, Kobosko 2011, 2016, Woźniak, Bieńkowska, 2016).

Prof. Alexandra Quitter (1991, 206:207) said: "Parents who bring up children with hearing impairment experience immense, chronic stress, which is caused by frequent meetings with doctors and speech therapists, controversies related to whether the phonic or manual communication is better, and decisions affecting their children's education (...). This situation, as well as the chronic, persistent stress caused by it, can deprive the parents of energy, time, money, and lead to strong emotional reactions, frustration, depression, and social isolation". In Poland, based on the data from the Universal Program of Hearing Screening in Neonates, 110-120 children with substantial or deep hearing loss are born each year [Szyfter et al. 2016]. Most of these children undergo a standardized diagnostic-therapeutic workup [Bieńkowska 2016], which includes therapeutic-informational-organizational support given to parents by physicians, audiologists, and speech therapists [Day, 2012, Woźniak et al., 2016, 2017]. In difficult situations caused by health problems or by family problems, children and their carers need help that goes beyond standard schemes. Thus, in such cases, doctors, nurses, audiologists, and speech therapists should go beyond the standard informational-therapeutic approach (Park et al. 2016).

In this article, I present three families of children with hearing impairment who were my patients: (1) family in which children and parents had hearing impairment and used sign language (the "Deaf" family); (2) children with hearing impairment born to a young parent; (3) a family of children with multiple disabilities, including hearing impairment. I describe both the ways in which I helped these families and the effects of my interventions. In each family, I show the importance of giving support at diagnosis and during treatment. Based on these cases, I discuss the following questions: "what is communication with the patient?", "what are the conditions for communication with the patient?", and "what is the importance of communication with the patient?"

## THE "DEAF" FAMILY

The parents, aged about 30 years, have severe hearing impairment and had been raised among siblings who did not have hearing impairment. The parents graduated from schools for deaf children. They communicate with one another with the Signed Polish (pol. System Językowo-Migowy) and use the Pol-

ish Sign Language (pol. Polski Język Migowy) to communicate with friends. To communicate with other people, they use unclear speech (father) and writing, including electronic communicators and applications (phone, text). The parents live with a grandmother in a one-family house. The grandmother understands the sign language but, in active communication, she tends to spell only. The mother's sister helps in getting things done in different offices, hospitals, and schools. The parents have three sons who have hearing prostheses because of severe hearing impairment. None of the sons has a cochlear implant. The sons regularly attend routine hearing assessments and take part in speech therapy.

Piotr. Piotr is an 8-year-old boy with bilateral, severe sensorineural hearing loss, which was diagnosed by auditory brain responses (ABR) at the age of 5 months. Since then, he has had a hearing prosthesis; the hearing field improvement is about 80 dB to 90 dB (outside the field of speech). The boy hears loud instruments and musical vibrations. Since the age of 11 months, for 3 years, twice weekly, he had had home-based rehabilitation (rehabilitation scheme called "Sounds of Dreams") [see Radziszewska, Gałkowski 2012]. He took part in two 2-week rehabilitation camps [see Bieńkowska and Zaborniak 2015] and in individual and group therapy (logorhythmics) in a specialized center (twice monthly). The therapy included hearing-verbal lessons, including early reading lessons. Up to the age of 3 years, Piotr had not received a cochlear implant because his parents did not agree to that form of treatment. Speech therapists and doctors, with the help of professional sign-language translators, informed the parents that the treatment was indeed indicated. Moreover, members of the extended family (aunts, grandparents) asked us to convince the parents about the implantation; however, our attempts resulted in Piotr's missing auditive therapy sessions. We even asked the parents to confirm in writing that they did not agree to cochlear implantation, although the implantation could help Piotr's hearing. Instead of cochlear implantation, the parents asked for lessons of sign language, which were given to Piotr by a therapist who lived in the same town as Piotr and his parents. All therapists engaged in Piotr's treatment stayed in touch with each other and exchanged information on the progress made by Piotr so that the treatment could be modified. The parents stressed that they trusted their speech therapist because he did not insist on cochlear implantation. A therapist who gave Piotr home lessons is now fluent in sign language, and he worked with Piotr in pre-school and school for 5 hours weekly. This support was encouraged by Piotr's main speech therapist and was enabled financially by the local town council. Piotr's language skills, including reading and writing, have improved. Although Piotr does not use phonetic language, he is a first-grade student of a local elementary

Tab. I. Communication with deaf carers of children

DIFFICULTIES	THREATS	THINGS TO AVOID	HOW TO HELP?
<ul style="list-style-type: none"> <li>◆ Two-sided communication barrier</li> <li>◆ Down-playing the role of the deaf parent; the interpreter makes the decisions</li> <li>◆ Differences in understanding deafness and language concepts</li> </ul>	<ul style="list-style-type: none"> <li>◆ Lack of common ground for communication, which may lead to a lack of diagnosis, treatment, and/or rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>◆ Do not preach or judge</li> <li>◆ Do not communicate with “non-parents” (interpreters, family friends, non-deaf children, in particular with underage CODA)</li> </ul>	<ul style="list-style-type: none"> <li>◆ Communicate in writing or with the help of a professional interpreter</li> <li>◆ Give information directly to the deaf patient, or his or her parents when the patient is underage</li> <li>◆ Give short, straight verbal or written messages (key-word technique).</li> <li>◆ Help with registering</li> </ul>

school, which complies with the Polish law and the parents' wishes. One of Piotr's teachers said: "Piotr's colleagues learn basic signs of sign language to communicate with Piotr, help him, and play with him. Teachers who work with Piotr and his brothers have completed a basic course of sign language. Piotr's mother communicates with the teachers in sign language or in writing. Oftentimes, the mother asks about her sons' progress and usual preschool affairs by text or email".

Jaś. Jaś is a 5-year-old boy with hearing loss of about 70 dB. With hearing prostheses, the hearing field improvement is about 45 dB to 50 dB, but the boy does not wear the prostheses at all times. Jaś is bilingual. He uses sign language, which is the main language at home, and spoken Polish (much below the age norm), which he uses during therapy and in pre-school. Jaś uses the same methods of therapy as Piotr does, including hearing-verbal lessons, as asked by the parents. During his first years in preschool, Jaś attended the same classes as his older brother, because of the mother's request. However, Jaś did not talk to teachers or colleagues because his brother translated for him. Thus, in his second year in preschool, Jaś attended other classes than his brother did. Jaś speaks and plays with his colleagues more and more. He is fluent in sign language, which he uses to communicate with his parents and the older brother.

Marek. Marek is a 1-year-old boy with severe hearing impairment (> 90 dB), who uses hearing prostheses since the 6<sup>th</sup> month of life. To date, he has not received any institutionalized therapy.

Conclusion: Effective communication with parents who used sign language allowed respecting the parents' treatment preferences and enabling other forms of treatment and education, which helped prevent symbolic institutionalized violence (Sobkowiak 2012, Sak 2014).

**UWAGA:** According to the current bill on sign language, deaf people are entitled to a free interpreter of sign language when dealing with public institutions. The public institutions have to pay for the services of the interpreter. However, deaf people willing to use that help need to indicate such a need

in advance. Moreover, the bill specifies other forms of communication such as email, text messages, internet communicators, and websites.

## YOUNG PARENT

Ola is now 26 years old, and their deaf sons are 8 and 9. Her grandparents are deaf. After giving birth to her first son, Ola was a high school student, and her mother helped her nurse her newborn son. After a break, Ola returned to school. Ola had new parental duties, which were even more demanding because her son had hearing impairment. Before graduating from high school, which in Poland required her to pass an examination called "matura", Ola gave birth to her another son. Neither Ola nor the father of her two sons have problems with hearing or with health in general. They married several years ago. Ola takes care of the sons and the house, and her husband works to earn a living.

Filip. – Filip was born in the 41<sup>st</sup> gestational week in a natural delivery (Apgar scale, 10 points). He underwent hearing screening late, in the 3<sup>rd</sup> month of life, which was due to technical difficulties in the hospital where he was born. The screening revealed bilateral, severe sensorineural hearing loss (> 100 dB). At the age of 8 months, Filip received hearing prostheses and has undergone auditive-verbal therapy ever since. His family has supported him throughout the process. When wearing the hearing prostheses, Filip reacted to only loud sounds of instruments (drum, tambourine, flute) or the "a" sound that was produced close to his ear. At 18 months, Filip was qualified for cochlear implantation but, because of organizational reasons, received a right-sided cochlear implant only at the age of 25 months. Next, to a good effect, he continued individual rehabilitation and auditive-verbal group therapy, which took place in a specialized center. He took part in about 200 hours of home-based rehabilitation and in 8 courses of rehabilitation. Because of failure of an implant electrode, he had about a 1-year break in hearing, but received another cochlear implant. When Filip was 7, a

cochlear implant was fitted in his other ear. To date, Filip's language development is below the age norm. Filip attends the third grade of an elementary school.

Feliks. Feliks is younger than Filip but also has severe hearing impairment. His mother says that the pregnancy with Feliks was normal. Feliks was diagnosed at the age of 2 weeks and received hearing prostheses before he was 3 months old. Just as his brother Filip, Feliks received all the available therapies for a maximum possible time. He now attends the second grade of an elementary school and is a good student; he even won a singing and reciting competition.

## BELOW I SHOW AN EXCERPT FROM AN INTERVIEW WITH THE MOTHER OF FILIP AND FELIKS:

**K.B.** – *How important was the help you received as a young mother?*

**M.K.** – *Right. When the boys were born, I was very young and I didn't know absolutely anything about rehabilitation of deaf children. I didn't even know what a cochlear implant was (laughs). It would've been very tough if I hadn't got the guidance from the people at the Clinic. At the Clinic, the boys were diagnosed, got their hearing aids, and we got to know about cochlear implants and were referred to the Clinic in the Banacha Hospital (in Warsaw). Since the very beginning, we took part in many therapies that the Clinic offered. Although at first the boys were reluctant to participate and I remember that I had to force them. The therapy lasts until now. Up to summer 2016, they took part in therapy every day. They benefited a lot from the therapy. However, at the beginning, I didn't see any immediate change; still, we would go the Clinic regularly. We just didn't see any improvement. Perhaps they were too young and I expected miracles.*

**K.B.** – *How did you feel with all that?*

**M.K.** – *I was tired, but the therapy became such an important part of our daily routine that we rarely called it off even when the boys had a cold. In our calendar, we had the whole week planned beforehand; we knew where we would go when, and when the therapist would visit us at home. Every day. Sometimes, when the boys did not have any therapy sessions, we felt that something was awkward. When I see that the boys are tired with all that additional work they have to do, I sometimes let them go, before holiday or after therapy camps; but I always make sure that such breaks are not too long. All in all, the boys are used to continuous rehabilitation and constant travel. Sometimes they complain, but I see the effects of therapy. For example, at*

*school, in Filip's grade, there is another boy with an implant; the teacher says that only Filip and M. never resist making an effort when given a new task. They never give up because they had learnt to try hard until the task is solved.*

## Conclusions:

Systematic and effective support given to a young mother made her independent in taking care of her children with hearing impairment.

## PARENTS OF A CHILD WITH MULTIPLE DISABILITIES

Parents brought Maciej to a diagnostic center because of suspected deafness. The boy, now 6 years old, did not speak and had four-limb paralysis because of cerebral palsy. The boy was born from a twin pregnancy in the 35<sup>th</sup> gestational week (Apgar score, 6 points). Since his birth, Maciej received physical therapy and, since the age of 3 years, had pedagogical and speech therapy. Because Maciej did not improve, his speech therapist suggested to test Maciej's hearing. During the next 2 months, Maciej was diagnosed with severe hearing impairment (> 90 dB on ABR) in three different centers. Moreover, as ordered by an audiologist, an experienced team of speech therapists carried out behavioral assessments, which showed functional impairment of 50 dB to 60 dB (Maciej's responses to sounds of some musical instruments and very loud speech sounds were inconsistent at the beginning of testing). The parents were instructed how to do hearing exercises with Maciej, which they did 3 times daily for the next several weeks, using musical instruments and recording Maciej's responses on observational maps (free field audiometry was not feasible). Six weeks after the first visit, a physician-audiologist, based on psychological tests, speech tests, and subjective and objective audiology tests, set Maciej's hearing prostheses at 50 dB, which was then slightly modified after careful observation of Maciej's progress. Regular speech and language therapy was then started (2-3 sessions a week with a speech therapist; plus, everyday home-based exercises). After two years, Maciej communicates solely with phonic speech. He communicates with other people, including his colleagues at an integration school, with simple sentences. With regard to speech, Maciej differentiates only between third-row sounds.

## PRACTICE—CONCLUSIONS

In the three cases described above, we were able to find effective ways of helping children and their families, although there were difficulties in communicating with specialists. It seems that this

**Tab. II.** Support given to an underage parent.

DIFFICULTIES	THREATS	THINGS TO AVOID	HOW TO HELP?
<ul style="list-style-type: none"> <li>◆ Lack of support or taking on the role by the mother; lack of an opportunity to decide, foster family</li> <li>◆ Taking on the responsibility of the child or leaving the child without help</li> <li>◆ Lack of responsibility</li> <li>◆ Overburdening</li> <li>◆ Not taking on the role of the parent</li> <li>◆ Being unprepared for the role</li> </ul>	<ul style="list-style-type: none"> <li>◆ Delaying decisions related to treatment and rehabilitation of the child</li> <li>◆ The parent wants other family members to take responsibility for the child</li> </ul>	<ul style="list-style-type: none"> <li>◆ Do not preach or judge</li> <li>◆ Understand the difficulties of the parent and the child (sometimes in three generations: grandparents – parents – children)</li> <li>◆ Do not give insufficient information</li> </ul>	<ul style="list-style-type: none"> <li>◆ Informational support – where to get help?</li> <li>◆ Give concrete information (best in writing) to the legal guardian and the underage parent</li> <li>◆ Give reliable information on the child's health status</li> <li>◆ Do not delay giving information</li> <li>◆ Give social help – supporting therapist</li> </ul>

**Tab. III.** Changes in communication with a family that had a child with multiple disabilities, including hearing impairment.

DIFFICULTIES	THREATS	THINGS TO AVOID	HOW TO HELP?
<ul style="list-style-type: none"> <li>◆ Acceptance by the parent of multiple disabilities</li> <li>◆ Deafness/ hearing impairment is not the most severe disability and is often underestimated, which delays the child's receiving hearing aids</li> <li>◆ Multi-stage diagnosis</li> <li>◆ Diagnostic results are unclear – particularly in patients with cerebral palsy or autism</li> </ul>	<ul style="list-style-type: none"> <li>◆ Not making the diagnosis of hearing impairment</li> <li>◆ Misdiagnosis</li> </ul>	<ul style="list-style-type: none"> <li>◆ Do not underestimate symptoms reported by the parents, which can undermine the objective audiological diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>◆ Establish a detailed diagnostic work-up for children with multiple disabilities</li> <li>◆ Establish MAPS for behavioral observation carried out by therapists and parents to verify objective results</li> <li>◆ Work in multidisciplinary teams</li> </ul>

**Tab. IV.** Jacobson's model of communication in audiological-therapeutic practice.

	WHO	INFORMATION	QUESTION	PROBLEM SOLVING
Sender	Physician, nurse, therapist, audiologist	Diagnosis of hearing impairment	Do I speak clearly?	Look at your interlocutor's face. Shave your beard and mustache. Move your lips.
Context	Specialist personnel, parents of the child	Hearing impairment of the child	Does the talk stick to the subject? Where does the talk take place?	Talk in the office, not in the corridor next to other people.
Message	Specialist personnel, parents of the child	Treatment	Do I speak clearly? In what way would I like to be informed about the problem?	Give information in writing. Write down key information. Speak about important things.
Contact	Specialist – patient – parents – family	We listen to each other	Do both sides take part in the talk?	Time, eye contact.
Code	Specialists – patient – parent/ carer	Common language	Does the patient understand what I say? Does the patient understand and/or hear the Polish phonic language?	Speak with simple words. Write down key information. Ask a sign language interpreter for help.
Receiver	Patient, parent/carers	An understandable message that takes into account the receiver's abilities (e.g., level or type of education)	Does the situation-related stress interferes with the conversation at the moment?	Additional person might listen to the conversation. Provide care for the child or speak when the child is asleep.

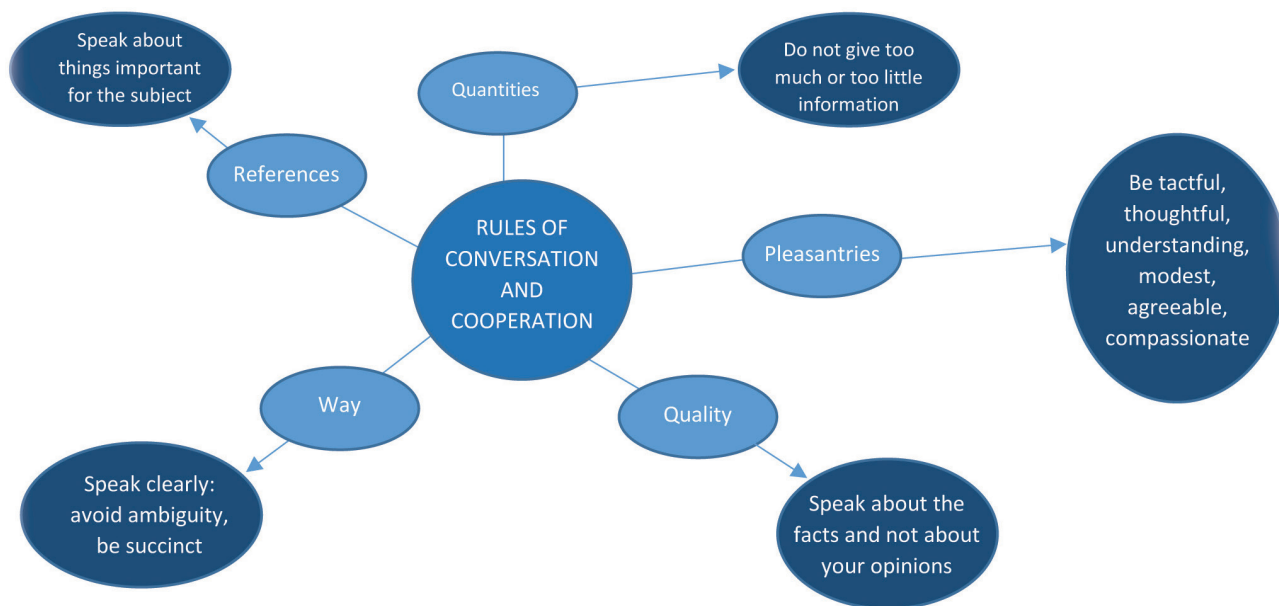


Fig. 1. Rules of conversation and cooperation (Grice, 1977).

success was enabled by long direct contacts, communication ways that suited the needs of the children's carers, and intense therapy and external support. Usually, parents expected from the audiologist that he or she informs them well on the diagnosis and available treatments and gives them support during the treatment. Below I describe the available ways of institutional support for children with hearing impairment and their parents.

Reimbursement from the National Health Fund: Free audiology examinations, hearing prostheses: earplugs, hearing aids, FM systems, implants, referral from the family physician or from the audiologist/laryngologist to a speech therapy clinic; referral from the audiologist or laryngologist to a Day Rehabilitation Center for People with Hearing Loss

Teaching help: Early developmental support from the moment of diagnosing a disability to starting education at school. Special education since the third year of age to completion of education. Local Psychological-Pedagogical Clinics decide on the way of support.

PFRON: Reimbursement of hearing aids, Fm systems, rehabilitation camps, and other equipment used to overcome communication barriers.

Other funds: Families can receive 1% of income tax from individual taxpayers. Charitable foundations (Polsat, WOŚP, TVN). Non-governmental organizations for children with hearing aids.

## COMMUNICATION – GENERAL CONCLUSIONS

Current treatment barriers faced by children with hearing impairment and their parents can be overcome when one takes advantage of the available knowledge and chooses adequate hearing prostheses for patients. In addition to institutional reasons, these barriers can be created by poor communication between health care professionals and patients and their families. Thus, it is important that health-care professionals have good communication skills, which can help understand patients' problems and expectations. When communicating with patients, it is always useful to set the aim of dialog and use conversational phrases and rules of cooperation put forward by Paul Grice (Fig. 1).

Cases presented herein and my long-term experience with patients and their families allowed me to create a communication roadmap based on the classic theory of Jacobson's speech acts (Jacobson, 1989). There are six factors that are responsible for effective communication with the parents of children with hearing impairment; it is particularly important to inform patients and their families well on their diagnoses and treatment from the start (Tab.). When one respects the rules of the communication set out by the communication roadmap, one can communicate better with patients. This strategy complies with the Bill of Patient Rights (Dz. U. z 2009 r. Nr 52, poz. 417).

Moreover, it is very important to give sufficient time to patients to improve the patient-doctor relationship, which can lead to better treatment outcomes.

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