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Review Article

The Birth of a Child with Down Syndrome: The Impact of the First News

Sergio E Manosalva Mena*

Teacher of the Differential Education career, School of Education, Bernardo O'Higgins University, Spain

***Corresponding Author:** Sergio E Manosalva Mena, Teacher of the Differential Education career, School of Education, Bernardo O'Higgins University, Spain.

Received: December 18, 2020; **Published:** April 30, 2021

Abstract

The purpose of this investigation has been identified adjectives employed by the medical team of public attention in announcing the birth of a child with Down Syndrome, to contribute, subsequently, with assertive communicative recommendations and a less negative emotional impact. A study of Discourse Analysis was conducted through a semi-structured interview to 9 mothers, who gave birth children with Down Syndrome, in hospitals of the Metropolitan Region of Santiago de Chile.

Keywords: *Down Syndrome; Birth; Communication; Discourse Analysis*

Introduction

It is not easy to accept the birth of a child with a disability, and it becomes even more complex when socially the diagnosis is plagued with negative beliefs and myths about it.

Often the professionals who give the first news do not know how to act or do not know how to communicate the type of diagnosis in the best possible way. This may be due to multiple factors where the center of these errors is anchored in the ignorance of handling assertively or the words are tinged with the prejudice of those who emit them.

Many times a miscommunication or misinformation can cause a wound that is difficult to heal or condition a type of negative relationship that can lead to irreversible consequences in the psycho-emotional balance of those who make up the social system.

In order to contribute with a minimum of knowledge in this regard, it is that we deliver some communicational elements necessary to know according to the purpose of the information that we want the other to handle.

Purposes of the communication and its dimensions

We can define the purposes of communication based on the following criteria:

- It must not be logically contradictory or logically inconsistent in itself.
- Must be focused on behavior; that is, expressed in terms of human behavior.

- It must be specific enough to allow us to relate it to actual communicative behavior.
- It must be compatible with the ways in which people from a given socio-cultural group communicate.

Our basic objective in communication is to become effective agents; that is, to influence others, the physical world that surrounds us and ourselves, in such a way that we can become determining agents and feel capable of making decisions, if necessary. In short, we communicate to influence and to affect intentionally.

When analyzing communication, and trying to make it as effective as possible, the first thing we should ask ourselves is what is the purpose it pursues and what result does the issuer expect when issuing its message. What is he trying to accomplish in terms of influencing the surrounding environment? What do you want people to believe as a result of your communication, and what do you want it to be able to say or do? In psychological terms, what is the answer you are trying to get?

When we learn to use the appropriate words to express our purposes in terms of specific responses from those to whom our messages are directed, we have taken the first step towards efficient and effective communication.

We have already said that the purpose of communication is to affect and influence. However, these considerations are showing us that the human being, in most cases, "does not know well what his purpose is" or "forgets it". This does not mean that there is only one proper purpose and that the issuer should be aware of it. What it implies is that there is a purpose in communicating, but that we are often not fully aware when we act, when we perform a communicative action.

We can hardly stop communicating, whether or not we are aware of the purpose that led us to it. Since childhood we have learned and practiced verbal and non-verbal techniques to be able to affect or manipulate the environment that surrounds us. These patterns of behavior become so fixed, so habitual, that we often do not realize how frequently we try to handle things. In reality, our value system can develop in such a way that we do not like to admit that we are manipulative, even in the sense that we have been using the term. All that is suggested here is that we need to focus our attention on analyzing the purpose of our communication so that we can monitor our behavior to determine if we are behaving effectively.

The dimensions of the purpose of communication

The "who" of purpose. Any human situation in which communication intervenes implies the emission of a message by someone and, in turn, the reception of that message by another. When someone writes, another must read what he has written; if someone paints, someone else has to look at what is painted, and if someone speaks, there must also be someone who listens to what he says. Any analysis of a communicative purpose or of the success obtained in achieving the expected response, needs to pose and answer the following question: Who was this intended for?

It can happen that the message is received by the one to whom it was intended or that it is received by people to whom it was not addressed, both cases can also occur.

This distinction between "intentional" and "unintended" recipients in communication is important, in at least two ways. First, the communicator can affect people differently than he intended if he forgets that his message can be received by those for whom he was not intended.

The second reason for making this distinction between intentional and unintentional recipients is that it enables us to critique communication.

One of the dimensions that must be considered in any analysis of the communicative purpose is that of determining the intended recipient of the message. The communicator may want his message to be addressed to him, or to other people. And those who receive it may or may not be the ones who were meant to receive it.

When producing, receiving or criticizing any type of communication, the determination of the communicator's purpose must be formulated in the following terms: who the communicator tried to affect and in what way. The purpose and the audience are not separable. All communication behavior is intended to produce a certain response from a certain person (or group of people).

We have been talking about the purpose, more than the entire privileged point of view of the person initiating the communication. But we have only done it for coexistence reasons. In every communication situation there are at least two groups of "expected responses": the response demanded by the person issuing the message and the response required by the person receiving it.

The analysis of any communication situation must take into account the following premises: the way in which the source of communication tried to affect the person receiving the message, and the way in which the receiver tried to affect himself or others (including source).

We cannot claim that the effects and outcome of all communication are consistent with the intended intention; receivers do not always serve the purpose of the source.

When there is incompatibility between the purposes of this and those of the receiver, communication is interrupted. When these purposes are independent or complementary, communication can continue.

In summary, we have described one of the dimensions of the purpose of communication, that is, the specification made by the source of the intended recipient, deciding whether or not a given recipient is an intentional recipient, and finally, the analysis of the purposes of the intended recipient. receiver when taking part in a communication.

Assuming that communication occurs because someone wants to influence behavior, we have to ask ourselves:

- Who was the intended recipient?
- What is the purpose of the recipient, intentional or not, when engaging in a communication?

The "how" of purpose. Once the decision has been made regarding the object of communication - the "who" of the purpose - the question remains of how the intended source or recipient manages to affect the behavior, and what kind of effect they want to produce. This question needs to be analyzed in itself, starting from at least two points of view.

We can locate or place the purpose of communication somewhere, along a limited continuum in one of its extremities for what can be defined as "consummatory purpose" and in the other for an "instrumental purpose. The position along this continuum is determined by the answer to the question of to what extent the purpose of this message is fully fulfilled at the moment of its consummation, or to what extent does this consummation become only "instrumental" in provoking and allow further conduct.

We have talked about two dimensions in the purpose of communication. First it is necessary to determine the true "subject" of the purpose. We have to distinguish between the communication, its intended recipient and the unintended recipients who receive the message. With respect to each of them, it is necessary to ask whether their intention when participating in the communication is, above all, to affect themselves or others, or both at the same time. Before any kind of purpose analysis can proceed, this question requires a specific answer as to the behavior that the message is intended to produce.

Second, we have referred to the need to place purposes on a consummatory-instrumental continuum. Both source and receiver purposes can be located along this continuum. Is the purpose satisfied with the consummation of the message, or is there a need for the behavior produced by it to be used later as a provoking instrument for subsequent behavior? [1].

Fidelity in communication

The word fidelity is used to indicate that the communication objective has been achieved.

There are different factors that increase the fidelity of communication. Some have to do with who emits or receives the message, others have to do with the message itself and others with the communication channel used.

Regarding the issuer and the receiver

Among the factors that influence an increase in loyalty on the part of whoever sends or receives a message is:

- Your communication skills,
- Their attitudes,
- Your level of knowledge and
- The socio-cultural position it occupies.

Communication skills: They refer to those where the person issuing the message uses the most appropriate and clear words to mean. This requires a linguistic facility that allows us to express ideas, what we think, exactly. In the same way, the person who receives the message must have the skills to listen (or to read) and to think properly.

The attitudes: Three forms of attitudes affect communication: attitudes towards oneself, attitudes towards the subject at hand and attitudes towards the recipient of the message.

Attitudes towards oneself can be one of security or insecurity of one's own abilities, which affects the fidelity of communication.

The second of the attitudes is related to conviction, to believing in the value of the message. If you do not believe in what is being communicated, the fidelity of the communication goes down, and on the contrary, if you believe in what is said, the communication is more effective (the fidelity of the communication goes up).

Finally, attitudes towards the recipient of the message can increase or decrease the effectiveness of communication. That is, if the recipient of the message feels appreciated, taken into account as a person, their availability to understand what is being transmitted will increase.

Knowledge level: The greater the knowledge of what is being communicated, the greater the fidelity of the communication. You cannot properly give or receive a message if you don't understand what it is about.

Socio-cultural system: "People do not communicate the same when they belong to different social classes, and those with different cultural backgrounds do not communicate in the same way either. Social and cultural systems determine in part the choice of words that people use, the purposes they have to communicate, the meaning they give to certain words, their choice of recipients, the channels they use for one or another type of message, and so on" [1].

It is important to consider that, to increase the fidelity of the communication, the most important thing is to focus on who will receive the message. That is, if we do not do our best to make the recipient understand, we are not communicating or, in other words, the communication is not effective.

Regarding the message

Among the message factors that affect fidelity, we have:

- The code,
- The content and
- how to handle the message.

Regarding the message code, we can say that it is any group of symbols that can be structured in a way that has some meaning for someone. Once the code has been chosen (verbal, gestural, written, etc.), we have to know the content of the message to be transmitted, that is, the material of the message that is selected by someone to express their purpose, what they want. Once the code and content have been chosen, it must be given a treatment that allows the code and content to be given a treatment that allows the message to be communicated in the best possible way... "We can define the treatment of a message as the decisions made by the communication source when selecting and structuring the codes and content" [1].

"What determines the treatment of the message? On what basis are decisions made by the source regarding treatment operated? Above all, the personality and other individual characteristics of the source are what determine the treatment of the message. Each of us has encoding standards that are characteristic of us; each one selects a certain code, content and treatment of the elements and rejects others. Each of us structures the elements of his message in a certain way and not in others. Our communicative possibilities, attitudes, knowledge, culture and the position we occupy within social systems, dictate some of our choices" [1].

Regarding the channel

The selection of the type of channel to use to transmit the message depends on the message itself and the purposes of the source. There is no single channel to convey the message. This should be considered when communicating, as the fidelity of the message can be altered when using an inappropriate channel. The question that must always be present is what kind of messages should be transmitted on which channel?

Objectives of human communication

One of the indispensable conditions for human communication is that there is an interdependent relationship between the source and the receiver. Each of these affects the other. At a certain level of analysis, communication involves only physical interdependence; that is, the source and the receiver are dyadic concepts; each one needs the other for its definition and existence.

At a second level of complexity, interdependence can be analyzed as an action-reaction sequence. An initial message influences the response that is made, and this, in turn, the subsequent, and so on. Responses influence subsequent responses because they are used as feedback by communicators, as information that helps them determine if they are achieving the desired effect.

At a third level of complexity, communication analysis refers to empathy skills, to the interdependence produced by expectations about the way in which others will respond to a message. Empathy designates the process in which we project ourselves into the internal states

or personalities of others, in order to be able to foresee the way in which they will behave. We infer the internal states of others by comparing them with our own predispositions and attitudes.

At the same time we entered to play a role. We try to put ourselves in the place of the other person, to perceive the world in the same way as that person. In doing so we develop the concept of "self" that we use to make inferences about others. By communicating with each other, we stop making inferences about others. By communicating with each other, we stop making inferences to assume a role as the basis for our predictions. The expectations of the source and the receiver are interdependent. Each affects the other, each develops, in part, through the other.

The last level of interdependent complexity is interaction. The term interaction designates the process of reciprocal role assumption, of mutual performance of empathic behaviors. If two individuals make inferences about their own roles and assume the role of the other at the same time and if their communicative behavior depends on the reciprocal assumption of roles, in this case they are communicating through mutual interaction.

Interaction differs from action-reaction in that the actions of each of the communication participants have been interrelated, in that they influence each other through the development of hypotheses about what will be the result of those acts, how they fit to the purposes of the source and the receiver and so on.

The concept of interaction is essential for an understanding of the concept of process in communication. Communication represents the attempt to unify two organisms, to fill the gap between two individuals through the emission and reception of messages that have meaning for both. At best, this is an impossible task. Interactive communication approaches this ideal.

When two people interact, they place themselves in the other's place, they try to perceive the world in the same way that the other does, they try to foresee how the other will respond. Interaction implies the reciprocal assumption of a role, the mutual use of empathic skills. The object of the interaction is to obtain a perfect combination of oneself and the other, a total capacity to know how to anticipate, predict and behave according to the mutual needs of oneself and the other.

We can say that interaction is the ideal of communication, the end towards which human communication tends. This communication is not entirely interactional, or at least it does not emphasize this level of interdependence. As we can see, an important part of our social behavior is made up of attempts to find substitutes for interaction and bases that consume less energy for communication.

We can communicate without reaching an appreciable point of interaction. However, while we are in an interactional situation our effectiveness, our ability to affect and be affected by others will increase. As the interaction grows, the expectations become perfectly interdependent. The concepts of source and receiver as separate entities lose meaning, while the concept of process becomes clear.

Theories of empathy

All human communication involves predictions on the part of the source and the receiver regarding how others will respond to the message.

Every communicator carries with him an image of his receiver. It takes this into account (as you imagine it to be) when issuing a message. Anticipate possible responses from your receiver and try to predict them ahead of time. These images affect the behaviors of your own message.

The recipients of the communication select and attend the messages, in part, due to the images that have been formed of the sources and to their expectations regarding the type of message that these sources will have to emit.

As sources and receivers, we have expectations in relation to each other that influence our communication behaviors. Behavior is also affected by the images we have of ourselves. Our self-images influence the type of messages we create and the treatment we give them. Our expectations regarding our own behavior influence, for their part, the choice of the messages that we have to attend to.

As sources and receivers we carry with us our own images and a set of expectations about others. We use these expectations to encode, decode, and respond to messages. We take others into account when framing them; We construct them to influence a receiver, but our expectations of him influence us and our messages.

When we develop expectations, when we make predictions, we are assuming that we possess skill in what psychologists call empathy: the ease of projecting ourselves onto the personality of others.

There are basically two theories about the basis of empathy: Theory of empathy based on inference and the theory of empathy based on role performance.

Theory of empathy based on inference: This theory maintains that the human being can observe his own physical behavior directly and relate it symbolically to his own internal psychological states: feelings, thoughts, emotions, and so on. In other words, he reasons with himself that if, for his part, his behavior represented this or that feeling, a similar behavior performed by another person must represent the same feeling.

Theory of empathy based on role performance: Role-assumption theorists argue that the newborn cannot distinguish between himself and others, or between one person and another. To develop the concept of himself, the child first needs to see himself as an object; he has to act towards himself in the same way that he acts towards other objects, towards other people. In other words, the concept of 'self' does not precede communication, but develops through it.

As the child develops, he acts more and more toward himself, in the same way that others act toward him. At the same time, he learns to produce and manipulate symbols that have meaning both for him and for others. Provided with a set of signifying symbols, the child can now begin to understand the roles that he assumes. He can also understand the way other people behave towards him.

When we empathize by making inferences and we are not rewarded, we have only two things to do. Either deform the behaviors that we perceive from others and make them correspond to our expectations, or else take a look at the images we have of ourselves, redefine the "self", return to the assumption of the role.

If we take the first solution, deforming the world we perceive, we become mentally ill, we suffer "hallucinations" and we end up going to a sanatorium, which is not desirable. However, we can anticipate that a large part of the mental health problem has been related to the inability or resignation of the person to modify the image that he has formed of himself when he discovers that he is not rewarded in his social environment.

For the second alternative, we have to return to role performance, we have to assume the role of others again, develop a new concept of the generalized other, a new set of expectations for our own behavior. By doing this, we redefine ourselves, modify our behaviors accordingly, and begin again to interfere with other people.

In the first situation mentioned there is a large group of people who later we distinguish as misfits. Among them we have, for example, the unwanted child with whom double bonds are established that can lead to schizophrenia.

The family is the first frame of reference for all human beings within our culture and, therefore, it will be the first area affected by the disability of one of its members.

Therefore, it should be considered that the moment the diagnosis of Down syndrome is confirmed and communicated there is a very harsh emotional impact and it is essential - to cope with it - good information and the affective support that each and everyone requires of the members of the family nucleus.

One of the first reactions that parents have when they are diagnosed with their son or daughter's condition is to ask "why us?

Each family, as a unique system, has its own characteristics that will determine particular and individual reactions within the family group to the birth of a child with Down syndrome.

Although the reactions are diverse, the different studies carried out in this regard show common responses and general characteristics determined by factors that determine the attitudes and behavior of the family.

Some of the factors that influence the type of responses that the family manifests are the following:

- How parents find out about their children's diagnosis.
- The quality of the information and psychological support that they have received since the child's birth.
- The moment when the diagnosis was communicated.
- The socioeconomic and cultural level of the parents.
- The affective climate of the couple before and during the confirmation of the diagnosis.
- The resources, support and advice that society offers.

Regarding the acceptance of the diagnosis of the child's condition, there is no fixed time, this may vary depending on:

- The experience of parents with people with disabilities.
- Personal feelings of the children.
- Family feelings about children.
- Parents' ability to cope with critical situations.

Depending on how these factors occur, the adaptation and initial and later development of the child with a disability will be facilitated or difficult, which is why it is very important to know and help parents in the process of acceptance of their child with Down Syndrome.

Inevitably there are emotional imbalances in parents and in the family group, which can vary from family to family and within the couple itself.

Generally, a strong emotional tension arises, before which the couple needs to maintain their frankness to ensure respect and consideration of the feelings of each one.

Later the parents go through a process of knowing and understanding what their child is like, either by learning about Down Syndrome, the implications for development and/or taking time to get to know it and come to love it as it is.

This process of acceptance of the son or daughter with a disability will be directly determined by subjective factors, objective factors and social factors.

Subjective acceptance factors

They are defined as defense mechanisms of the I; among these are:

- **Guilt:** It can provoke atonement reactions: caring for the "child-victim", who despite everything is fundamentally rejected. The action is carried out as a desperate attempt to make himself forgive his own faults and even existence.
- **Frustration:** There is a loss of expectations. Since he is not the child they expected, they begin to live a "duel"; the duel of expectations.
- **Lack of expectations:** The future of the child appears blocked for the parents. They will not have offspring, they will not be able to meet their own needs and they will not provide the expected satisfactions. They will house the idea of the child's death.
- **Indifference:** Parents neglect the situation. This reaction can occur, when knowing the diagnosis or later when seeing a medical, therapeutic or educational failure.

Indifference can arise after a feeling of social loneliness created by one parent when the other has created an overly symbolic relationship with the child.

Negativity: Difficulty in the son is denied. This reaction is common in parents who belong to depressed socio-economic strata, where they ignore the concept of disability. They place their trust in the doctors for a speedy healing of their child's disability.

Hetero aggressiveness: A first reaction of parents is to be aggressive towards whoever gives them the news, towards their social environment or towards their concept of God. Later, aggressiveness is liable to be sublimated as an impulse that leads parents to organize and demand understanding for themselves and their children.

Self-aggression: Aggression turns against themselves. Parents frequently develop overprotective behaviors, refusing any separation from their child, no matter how short it may be. In addition, they reject the help of third parties.

Objective acceptance factors

Within what has been concluded through experience and research, we have:

- **Etiology of disability**: Parents are more attached to the child who has contracted a disability after an illness, since there was a time when normal emotional relationships were established.
- **Morphology**: It refers to the child and her physical appearance, which can cause sympathy or rejection, internalizing these feelings from the birth of the child.
- **Associated disorders**: They influence parental tolerance, undermining the possibility of overprotection or deep detachment.

Social acceptance factors

The following factors influence:

- **Socioeconomic level:** The environmental climate from the social and from the economic point of view seems to exert a direct influence on the family. Communication and free expression among the members of the family unit are closely linked to the stability of the system and to the type of interactions that are maintained in it, which makes it possible in a better or worse way to face the situation of a child with a disability. Likewise, the ease or difficulty of obtaining and maintaining resources to access more information and advice influences the way of relating to the new member with a disability.

- **Social prejudices:** They influence the way of facing the situation, leading the family to distance themselves from their son or to accept him with his condition as it is.

- **Attitudes of family members:** Problems begin when only one member considers the child "abnormal". It usually arises as a result of the diagnosis, which eventually labels the child. The behavior of the member who shows a negative attitude obviously influences the rest of the family, arising different reactions within the group.

Stages through the family

Different authors have defined a number of stages that the family goes through and which have been named in different ways. For Shea and Bauer (2000), after the diagnosis, and once the parents are aware, they go through different psycho-emotional stages: shock, denial, haggling, anger, depression and acceptance.

These stages correspond to the multiple range of feelings, emotions and/or defense mechanisms that arise from the family. However, the presence of these three elements is not uniform in all families since some may not be present or may be diminished while others may be exalted or amplified. As emotions are transitory and variable, the sequence is not fixed. The movement and duration of each of the stages will also vary depending on the personality characteristics of each member.

It is important to note that frequently, feelings and/or emotions overlap or coexist; For this reason, it is more appropriate to refer to the different feelings and emotions that appear in the parents, taking into account that what happens in conjugal interactions will directly influence the other family subsystems.

They are distinguished:

- **Surprise:** It is caused when parents perceive or receive the news that their newborn child presents some alteration, which produces in them a state of shock; that is, an emotional blockage is manifested whose state is very intense without becoming too long.

- **Disbelief:** Refers to the denial of the facts, which is the first defense mechanism to which parents resort. It is intended to reduce the level of distress without altering the reason that produces it. A very frequent attitude in parents is to review the past looking for the possible causes of the anomaly of their son or daughter. With this they try to justify the facts, giving them a character of family inheritance, which implies a "normalization" of the difficulty.

- **Guilt:** From the causal point of view, the feeling of guilt frequently appears in the parents due to the possible responsibility that falls to each of the parents in the face of the problem of disability in the couple. They accuse each other without justification of being the culprits of their child's condition. Sometimes this leads to a marital breakdown. Guilt, in some situations, is related to the responsibilities of others, such as the professionals who participated in monitoring the pregnancy or at the time of delivery.

- **Fear and frustration:** These feelings are expressed as the fear of not being able to overcome the situation; to the prejudices of relatives and friends, to the uncertainty of the child's future, to the therapeutic possibilities and to the possibility that the situa-

tion will repeat itself in the family. Frustration, on the other hand, is related to the idealized image that parents have conceived while waiting for their child.

- **Sadness:** It is a state where disorientation, confusion, social isolation, lack of initiative and continuous and permanent crying occur. The parents, in addition to feeling sadness in a sense of "mourning" (for the idealized son who did not arrive), and for the situation itself, cry out of self-pity. The feeling of sadness experienced in a long and exaggerated way, in some cases, can have serious mental health implications, such as depression.

- **Anger:** It is usually the negative social reaction to frustration and sadness. It is usually directed at the reason that caused the pain. This contrary response allows the balance of emotions to be maintained, however, it has a high cost since most of the time the origin is in the child himself. Sometimes the feeling is expressed in terms of aggressiveness towards the treating physician, such as when there is guilt towards the professional.

- **Acceptance:** If the aforementioned feelings were experienced and expressed, the attitude of acceptance towards the child with a disability will be facilitated. An important positive consequence of the parental crisis is -often- the rethinking of values and the importance of affection. Some parents find that by accepting their son or daughter's condition, their unique differences, can help them much more. They realize that they cannot change the condition of the child, but they can change his attitude towards him, which leads to the generation of bonding behaviors, feedback for parents and for the rest of the family group. However, this is only possible when the parents manage to overcome their own pain, understanding and loving the child as he is and not as he could have been.

By virtue of the different stages and reactions that the family presents, it will be the type of psychological and pedagogical intervention for the parents, the child and the rest of the members that compose it.

Parental perceptions and attitudes when receiving the news

Research and accumulated experience show us the importance for parents of how and when the news of the birth of a child with Down syndrome is communicated. Depending on this, among other factors, will be the attitude assumed by the parents. Depending on the emotional response of the mother, father or caregiver, this will positively or negatively influence the type of attachment that occurs between the two during the first years of the new member's life.

Perhaps due to ignorance and existing myths regarding disability in general and mental impairment in particular, health professionals are, for the most part, not prepared to communicate and receive responses from parents regarding the birth of a child or girl with Down Syndrome.

We want, just to become aware of this, graph with some testimonies from parents, the moment when they are given the news of the genetic condition of the son or daughter. For this, nine cases will be witnessed where the adjectives given to the baby with Down syndrome were analyzed with the techniques of critical discourse analysis.

Testimony N° 1

"I didn't know anything and nobody told me what to do. I only knew that I had Down Syndrome because the midwife told my husband that something was wrong, after neither the doctor nor the nurses told me anything... they only said: "his baby is under observation". After a day of not knowing why they didn't show it to me, and because I started complaining about my chest, Jaime asked the assistant in the piece. She said to him in an I don't know what voice: 'And they still haven't told you what's wrong!?'... He said no and she told him that 'it seems they don't bring it to him because he has Down Syndrome'.

The matron came… I wouldn't stop crying; I wanted to die, she told me: "Mommy, I am contacting a group of parents", and she left.

Testimony N° 2

"When I got to the room, a Bible was open on the nightstand and I didn't understand. When a nurse came, my husband asked her. She told him if she had already been referred to the geneticist. He asked her why and she said, "The boy may have something". I asked my husband to ask again and they confirmed it".

Testimony N° 3

"A nurse came, she asked me how I was feeling and she suggested that I read the Bible. She marked a page for me and left it for me in the drawer… I didn't understand, but they never brought my son to me. She asked and they told me that they would bring it, but they did not bring it.

After a long time or hours I opened the nightstand -because I'm still a believer- and I started reading and I knew that something was happening… I don't know why they didn't give me their face".

Testimony N° 4

"It is that anyone tells you, because they believe that one is ignorant. They tell you that your son was born like this and that everything will cost him. So, a she believes that she had a "thing" and not a child, because nobody tells you something good. They come to take us".

Testimony N° 5

"Those from the hospital, the doctors, the nurses, all those who know and don't want to tell you because they think you are less than them. That in addition to being ignorant, your daughter came out like this. And to console you, they tell you that they are contacting I know who. And when one she said that she wants to see someone if she one all she wants is to die and not hear from anyone! I just wanted to see my husband... because I didn't even remember my other children".

Testimony N° 6

"… I have to admit that it is still difficult. I did not love my son, I felt rejection for everything they told me. I wanted to leave him at the hospital.

… It has cost me and I think I regret what I thought".

Testimony N° 7

"Nobody wants to say. Everyone throws the ball, until the parents themselves start asking questions and there is nothing else left to tell them how to do it".

Testimony N° 8

"I got up to see where they had the buses. The lady asked me who was coming to see. I told her that I was a mother, that she hadn't seen my baby and that it was so weird because they always deliver her to the shot. When I asked her where she (the baby) was, she told me they couldn't pass it to me yet. I asked why and she told me how "monga" was born. They had to do some tests to make sure of her and that later they were going to tell me. So I knew, and I was sorry and I went to cry".

Testimony N° 9

"As they did not show me my son, I asked what was happening and a nurse told me: Have they not told you yet what he has? I asked what was happening, if he was sick, and another told me if he didn't know that he had genopathy. I thought he was a little dwarf, and then I said I didn't care and wanted to see him. I got angry. It didn't matter to me if he was a dwarf or blind or whatever because he was my son, but since my wad was a girl, I was sure that he was only a dwarf. I got up and went to see it, and where I wanted to see it, the nurse just showed it to me.

They sent me to a geneticist. She picked him up and looked at him from all sides, and she stopped and told me: 'Yes, he's one Down', I said 'yes, but he's pretty, he's not ugly'. She replied: 'Mmmm… Now the' mongos, the downcitos are coming out prettier.

There I was very sorry, because my little boy was like a 'thing' and I thought that they would always look at him that way".

Conclusion

When the news of the birth of a child with Down syndrome (or another disability) is going to be given, we must consider some central aspects so that our communication is as positive as possible and can, therefore, be received in the best possible way (even knowing that it is difficult).

We will provide some suggestions for communication strategies, words or terms to use and examples of suitable messages.

The stages that we can consider within the news communication process are the following:

- Communication.
- Emotional assistance.
- Information delivery.
- Meetings with parents who lived the experience.

Communication

Before communicating the news, the health team must establish a procedure that specifies who will give the news, when they will give the news and how they will give the news. This procedure requires a commitment and a positive attitude from the team for putting the agreements into practice.

It is suggested that to determine:

- The who is done according to personal conditions.
- The when is done within the first minutes or hours and once the mother has been in contact with the child.
- The how, be done in private, with direct and appropriate messages, be aware of the essentials of mental deficiency and use functional communication, that is, it is not necessary to elaborate more than necessary.

Emotional assistance

The basic principle to consider in emotional assistance is "discover what the person needs and act accordingly".

We will understand by "attending", having the ability to listen, accompany, comfort, share, guide, encourage, leave alone...

We must bear in mind that emotional assistance is put into practice with:

- Touch
- Wisdom (intuition, guidance of the heart)
- Empathy and congruence.
- Exploring what the person needs and how they receive what is delivered (ask, offer, check).

Information delivery

One of the fundamental requirements in the delivery of information is to be well informed; This refers to knowing what you are talking about.

We must bear in mind:

- Answer questions clearly, adequately and congruently.
- Rectify erroneous beliefs.
- Provide updated and truthful information.

Visit of parents who lived or live the experience

When offering parent visitation, it should be done tactfully. For this, it is suggested that one way of communicating is the following:

- "There is an Institution called xx made up of parents of children with disabilities... if you wish, they can visit them to transmit their experience and guide them".

Words that are convenient and not advisable to use

There are multiple ways in which the message can be transmitted, there are more appropriate ways than others. Within our experience there are words that should not be used because of the pejorative of the term or because of the negative connotations that they carry [2-9].

Words not to use	Words that you do want to use
"Nice stay"	Down syndrome
"Illness"	Condition
"Nice place to stay"	Delicate news
"Your child is sick"	Your child is special
"Nice stay"	Disability
"The Boy/Girl"	Your baby
"Nice place to stay"	Your child
"Nice stay"	I inform you

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Volume 10 Issue 5 May2021