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NICOLA

Aldo ZAnon

This case concerns a medical counselling intervention based on the principles of Person-centered medicine, making use of Kairological counseling to support a couple of parents whose son was born with Down syndrome. The intervention was deemed necessary because the parents had reacted by leaving their son after receiving the diagnosis.

The main elements on which the subsequent medical intervention was based were:

– its preparatory and meticulous planning – researching and securing formal employment – drawing up a structured program – involving medical and paramedical staff – establishing a rigorous space-time framework – the strict application of counseling methodology, including welcoming the parents, helping them overcome feelings of guilt, promoting their resources, creating new spaces and opportunities, fostering empathy, and reinforcing the fundamental principles of human dignity – the personal (and ethical) responsibilities of the parents, as well as those of the physician, who is directly involved through the evocation of his own suffering and experiences as a parent

The parents' decision to resume care of their son represents a clearly positive outcome. And indeed, the sense of gratitude expressed through their smiles is truly priceless.

Key Words: Person centered medicine, Down Syndrome, Kairologcal Counselling.

Correspondence to: Aldo Zanon MD- MA-LD E-mail: zanonaldo@unambro.it.

Nicola, a newborn, was just 20 hours old when I returned from my vacation. He was born at 34 weeks of gestation and weighed only 1700 grams. His Apgar score was 8 at the 1st minute of life and 10 at the 5th minute.

His young 24-year-old mother had been hospitalized several times during pregnancy: at the 10th week of gestation (for a threatened miscarriage) and again at the 32nd and 34th weeks due to the baby's minimal growth rate. Concerned about the risks of premature birth, she underwent pulmonary prematurity therapy, including surfactant and corticosteroids.

The baby was diagnosed as breech, so the doctors—considering both the risk of complications and the mother's physical stature—opted for delivery by Caesarean section.

Immediately after birth, the premature infant was transferred to the neonatal pathology unit. The newborn's father, who accompanied him during the transfer, was a relatively young 27-year-old who showed ambivalent emotions and, like many new fathers, seemed unable to fully grasp the events unfolding around him. He smiled at his baby, yet remained distant.

In the initial stages of life, Nicola did not present significant pulmonary disease. Thermoregulation was adequate, so on the 3rd day he was removed from the thermal cradle and placed in a regular bed. However, he suffered from hypotonia and fed very poorly. Bottle-feeding was impossible, as was feeding through a nasogastric tube. The baby continued to lose weight.

The mother came to see him as soon as she regained her strength and found him in that condition on the 4th day of life. Slowly but resolutely, she held him in her arms and observed him carefully while smiling. We sensed that she could hardly speak to him.

Through the glass window, we also noticed her communicating something to the baby's father, after which both smiled.

In the days that followed, both parents visited the child frequently; they were always together, as the mother still needed assistance to move around.

From the beginning, the baby showed signs of hypotonia and features of Down syndrome—very straight hair and a receding occiput. These identifiable traits were noticed particularly by the more technically trained nurses. In contrast, other nurses associated his appearance with that of the mother, who indeed had large, well-defined almond-shaped eyes.

On the 5th day of life, the doctors decided to analyze his chromosomal profile.

No doctor found the courage to face the parents and communicate the suspected diagnosis. It was not until the 8th day that the chief physician finally did so.

The two young parents left the physician's office looking very sad and almost disheartened; the mother was crying, and the chief physician—who had been forced to deliver the painful news—was equally distressed.

On the 10th day, the chromosomal analysis arrived: male karyotype, 46 chromosomes with a Robertsonian translocation between two chromosome 21s; the result was trisomy 21. A genetics consultation and parental karyotyping were required.

After spending approximately half an hour in the chief physician's office, the two young parents left looking helpless and crestfallen, appearing even younger than their age. Signs of strain and sadness were visible on both their faces as they walked, dragging their feet. The husband held his wife in a gesture of comfort. They left the surgical department without saying a word and without giving even a glance at their baby.

"They don't want their son anymore," said the clearly exhausted chief physician. "Why?"

Questions, doubts, suppositions, and comments circulated throughout the department in the days that followed. Everyone felt a sense of guilt and concern at the thought of a nursing infant being left without care or affection.

The chief informed the *Procura della Repubblica di Venezia*, as required by protocol, and soon the decision was made to place Nicola in the care of an orphanage.

The parents left and showed no further interest.

The baby did not eat, remained hypotonic, and soon showed significant signs of heart disease (a common A-V canal). His condition did not improve, and digitalis and diuretic therapy became necessary to support early cardiac insufficiency. Bottle-feeding remained nearly impossible.

The nurses, who felt the emotional burden most intensely, urged that the parents be contacted.

For this reason, I informed the chief physician of my availability and volunteered to use my medical counseling expertise to manage this stage of the parent–child relationship. The chief physician, who was about to leave on vacation, gave his consent.

Given the difficult and delicate situation, and the novelty of this type of intervention in our hospital, I decided to structure the counseling process with particular attention to every detail.

My first step was to speak with the nurses, inform them of my intentions, and explain my plan to meet with both parents and the baby's relatives. I explained why this waiting period was crucial and why we should not attempt to "fill the time" for the parents, as this interval served as a period of reflection, growth, and understanding for them. I also reassured the staff by saying: **"**Expect to see the parents come back!"

That mother is resourceful! She is sweet, very feminine; she loves life, she is caring, maternal, has a sincere smile, and is intelligent. Even though she is very young, she is extremely close to both her husband and her son. During her time here, she showed a strong interest in receiving information and in learning how to do the things that would eventually help her care for and nurture her child.

The father, on the other hand, although he has shown little visible concern for the baby, possesses many paternal qualities and is capable of assuming responsibility despite his young age. He has remained very close to both his son and his wife throughout. I am certain they will come back. We must respect their dignity and give them the freedom to reflect and think. This does not mean we are neglecting them or leaving the matter unattended; rather, it means we are developing a plan of support and assistance.

The relief shown by the nurses was a clear sign that they had reflected on the reasoning presented to them, and each of them was hopeful about contributing to the project.

The parents' return was announced by the maternal grandfather who, after fifteen days of silence, came to our department as their forerunner. Some nurses directed him to me, and he pleaded: "Please do something, doctor! Those two poor young people cannot go on like this anymore. Help them! They are wearing themselves out, constantly thinking and crying. I don't even recognize my own daughter anymore. They just need to accept the baby… I'll take care of the rest. I'll pay for their domestic help!"

Encouraging him to trust me, I emphasized the importance of his closeness, his concrete support, his wisdom, and the ethical value of his intervention. I asked him to remind the young parents not to hesitate to reach out to me for help during this very critical moment in their lives.

Soon afterward, Nicola's parents called to schedule an appointment for the following day. They arrived together and on time, after visiting Nicola.

On a calm morning, away from the daily chaos of the surgical department, I met with them for half an hour. Although still somewhat sad, they now appeared more lively and almost hopeful.

We discussed their strengths and their considerable capabilities. I offered them an interpretation of their behavior as soon as possible. At first, it had seemed like a provocation, but beneath that façade lay a request for help. This was the help I truly wanted to give them.

They expressed their fears, spoke of their hopes and doubts, and explained how they had come to make such a sudden decision.

I responded by telling them how I had noticed and appreciated their mutual closeness and their love for their child during the initial stages of this very difficult period. As they listened, they seemed relieved, and smiles returned to their faces.

Together, we analyzed the steps needed to ensure their own well-being. We also spoke about Nicola's worth. But after a while, my reasoning gave way to personal involvement; I wanted to approach the conversation from my own perspective, drawing on my emotional experience as a parent. I told them what had happened during my wife's last pregnancy: how her age had been considered a risk factor by geneticists; how oppressed I had felt, how I had gone through denial, how I never found a real solution, how frightened I was as the day of childbirth approached, and how, in that situation, words had been useless to me. Throughout this, I felt they were with me. I scheduled a second appointment for the following week.

They left feeling hopeful. But concerned about Nicola's heart condition, the first thing they did was visit the cardiologist for information. I saw them walk decisively toward the neonatal pathology department, holding the baby in their arms, briefly speaking with some nurses.

From that moment on, their visits became frequent. Both parents were as attentive as before and continued to come regularly, even several times a day, despite the long distance from their home to the hospital.

Thanks to this change, Nicola resumed bottle-feeding—difficult at first, but something he gradually learned to accept.

The parents came to the appointment seven days later. We met in front of the *Cittadella*, the Youth Health Center. When I arrived, they were already there. They had visited Nicola earlier and were now serene.

“We’ll take care of him, doctor… we’ll do it! Yes, absolutely!” As the father made this declaration, the mother looked at me and agreed, smiling: “Yes… we’ll do it!”

We spoke about the importance of seizing this crucial moment, about the apparent and mysterious fortuity that surrounds our health, about Nicola’s birth, and about our meeting.

We reflected on the importance of seizing the opportunities life offers us—moments in which we can make personal contributions to the promotion of our own health. The birth of this baby was certainly one of these fundamental moments, and thus an occasion to work for both his dignity and our own.

Furthermore, we discussed the relevance of taking concrete steps, one at a time; together, they set some simple goals.

In reality, the commitment they undertook with their son was immense yet deeply meaningful, as facing it also meant improving the quality of life of the entire family.

Once again, I emphasized the parents’ strengths. I explained how clearly they had expressed their roles in this difficult moment of refusal. The father was practical and demanded clarity. He had provocatively distanced himself from the situation, thereby preventing closeness with the baby. The mother, instead, used all her resources to keep her husband and son connected, as they were drifting apart. She never abandoned the struggle and always stood ready, waiting for the moment to rebuild the bond.

They chose health together.

We worked to accelerate the bureaucratic procedures in order to grant custody of the baby to his parents, who now wished to bring him home as soon as possible.

When that day finally arrived, the father came to thank me and said**:** “We’ve been thinking, doctor, that the least we can do is offer our experience to help others. If you come across parents who need support, let us know.”

Riassunto

Questo è un caso di intervento di Counseling medico secondo la teoria della medicina centrata sulla persona e utilizza lo strumento del counseling kairologico rivolto a una coppia di genitori con un figlio affetto da Sindrome di Down. L'intervento è stato ritenuto necessario per questi genitori, che avevano reagito abbandonando il loro bambino dopo aver ricevuto la notizia della diagnosi.

I punti principali su cui si è basato il successivo intervento medico sono stati:

– la preparazione propedeutica e meticolosa – la ricerca e l'ottenimento di un lavoro formale – la stesura di un programma – il coinvolgimento del personale medico e paramedico – la rigorosa strutturazione spazio-temporale – l'applicazione rigorosa della metodologia del counseling, riguardante l'accoglienza, il superamento dei sensi di colpa, la promozione delle risorse, la creazione di nuovi spazi e opportunità, la ricerca dell'empatia e le basi fondamentali della dignità umana – le responsabilità personali (ed etiche?) dei genitori, senza dimenticare quelle del medico, direttamente coinvolto dall'evocazione delle proprie sofferenze nelle esperienze vissute come genitore egli stesso

La decisione dei genitori di riprendere in carico il proprio figlio ha certamente rappresentato un esito positivo. Del resto, il senso di gratitudine espresso dai loro sorrisi è impagabile.

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L'intervento si è reso necessario perché i genitori, alla comunicazione della sindrome di cui era aGetto il figlio, avevano reagito abbandonandolo.

I punti di forza su cui si è basati nel successivo intervento medico sono stati:

- la sua propedeutica meticolosa preparazione
- con la ricerca e l'ottenimento di un incarico formale,
- la stesura di un programma,
- il coinvolgimento del personale medico e paramedico.
- la sua rigida strutturazione spazio temporale,
- la applicazione rigorosa della metodologia del counselling con
- l'accoglienza, il superamento del senso di colpa, la promozione delle risorse, la crea- zione di possibilità e spazi nuovi, la ricerca dell'empatizzazione, la premessa basilare della dignità della persona.
- la responsabilizzazione personale dei genitori e del medico con il suo giocarsi in prima persona ed il suo coinvolgersi direttamente con l'evocazione delle sue soGerenze in sue esperienze di genitore.

La ripresa in carico del figlio ha sicuramente costituito un risultato positivo. Non calco-

labile invece il senso di gratitudine poi manifestato dai genitori con il

loro sorriso. Parole chiave: Medicina Centrata sulla Persona, Sindrome di

Down, Counselling.

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