The Importance of Empathic Communication with Patients and their Families

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ABSTRACT

Reading personal experiences in situations involving health problems reflects the impact that inadequate communication has on patients and their families. This article reviews texts from the literature with paradigmatic examples, mentions possible reasons for the use of medical jargon and reflects on the importance of adequate communication with patients and their families, emphasizing active listening, personalized approach considering contextual circumstances, habits and skills that must be present in critical situations meetings. The importance of developing training programs that include simulation scenarios is underlined.

Key words: communication, empathy, patient-centered care, body language.

The literature, and specifically, the content of certain books, can help us reflect on such vital issues as communication with our patients. Particularly in healthcare, reading accounts of personal experiences in difficult situations can be very enriching. In this last year, the reading of texts where it is evident the impact on patients and their families of the way we health professionals communicate led me to reflect and to be more aware of what we say, how we say it, and mainly how we listen.

In the book *Breathe, Baby, Breathe!* Annie Janvier says: “I only really realize now –today -- that the way we neonatologists talk to pregnant women is bizarre. I knew it was weird, but not this weird[1].” Annie is a neonatologist and bioethicist, the mother of Violette, an extreme preterm born at 24 weeks gestation. Annie was hospitalized with the threat of premature labor and then lived as a mother through the entire hospitalization of Violette, who had severe complications.

In the book, she recounts her experience as an obstetrics patient and mother of a daughter in the Neonatal Intensive Care Unit (NICU) of the Montreal Hospital where she works and in the department where her partner and Violette’s father, Keith Barrington, is the head of Neonatology. For her, that experience was eye-opening: “It is now strangely obvious to me that the way I have been talking to mothers and fathers for the past few years is SO incomplete, so simple, so *naïve*.”

Natalia Zito, an Argentine writer, describes in *Rara* her experience of the intrauterine death of one of her twin sons: “There were two babies until the tenth week of pregnancy when the ultrasound technician had to explain to us that one of them had stopped. He used that verb: to stop. To stop is a way of dying”[2]. It is not only about verbal language. In another passage of her book, Natalia says: “They put me in a hospital bed. Nurses come in and out. They all do something to my body, but hardly anyone looks me in the eye. Before they walk away, they squeeze my hand too hard”.

Something similar describes Vicki Forman in her book *This Lovely Life: a memoir of premature motherhood*: “...and the neonatologists, passing by, rarely looked us in the

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eye"[3]. In a chilling passage, the author recounts how the NICU staff stopped paying attention to her son when they saw that his condition was becoming chronic without much chance of changing his slow progress: "I had had enough of smug nurses, absent doctors, uncomfortable residents and the parade of medical students passing Evan's incubator on their way to more interesting or successful cases. Vicki tells her story, living in the NICU with her extremely premature twin sons: Ellie, who passed away at four days old, and Evan, who went through severe complications in the NICU and remained with serious sequelae. In that book, Vicki writes how uncomfortable she felt with some of the expressions and attitudes of the healthcare personnel. In a passage of the book, she says that she felt identified with the words of the father of a former premature patient, who remarked in an interview: "I do not know what makes doctors and nurses think they can say anything to us, but they do."

The abandonment that patients can feel makes a remarkable statement in the book *Momma and the Meaning of Life* by Irvin Yalom, who quotes the words of Paula, a terminally ill patient who gets refused an appointment by her oncologist's secretary: "What is it with doctors? -How can they not realize that when they have no more to give is when they are most needed?"[4]

Anna Starobinets recounts her experience with the Russian healthcare system on her pilgrimage after being diagnosed with a severe bilateral fetal kidney problem at a prenatal visit[5]. In *You Have to Look* she relates that the doctor who performed the ultrasound placed the transducer on her abdomen and said: "Well, the kidneys... yes... it does look like polycystic... Possibly bilateral polycystic (...). Dr. Demidov comments something in a low voice with his nurse, and I get an indistinct murmur: 'Of course... who wouldn't be interested?' The nurse leaves the consulting room. The professor inserts the vaginal transducer into me. After a minute, about fifteen people in white coats enter the office, accompanied by the nurse: medical students and young doctors (...). Look what a most typical picture - says Professor Demidov - (...). With this kind of malformation, children do not survive."

In her book *Parte de la Felicidad,* the Argentinean writer Dolores Gil recounts her experience with repeated losses of desired pregnancies.[6] In the fourth pregnancy, she again had metrorrhagia at an early stage. The ultrasound shows that the embryo has no heartbeat and has died. The author writes: "On the ultrasound report, there is a mysterious acronym: D&RE. No one explains it to me. Days go by before I pluck up the courage to google it: *Dead and retained egg*. I explode with anger because of the initials (...). I am offered abortion pills (...). Everyone gives me different advice (...). It is not that bad. Like heavier menstruation, says the doctor. What a jerk, I think. Obviously, he has never had a period and never had to have an abortion".

Sarah DiGregorio, in her book *Early*, recalls the visit from the neonatology fellow when she was admitted with a 28-week gestational pregnancy and severe intrauterine growth restriction: "The doctor leaned over the side of my bed with some awkwardness and spewed at us a litany of potential complications that come with very premature birth: brain bleeding, gaps in the heart, delicate lungs straining to inflate, intestines that die while the baby is still alive, blindness, loss of IQ, attention disorders, all sorts of disabilities, infections, cerebral palsy, death. He said we had about a 50-50 chance of coming out of this without some disability. He ended, 'Do you have any questions?'"[7].

It is inevitable to evoke Dr. Paco Maglio and his crusade to humanize treatment with patients and their families. His proposal to transform "questioning" into "listening" is memorable. In his book *La dignidad del otro/The Dignity of the Other*, he writes that by confusing communication with information in the doctor-patient relationship, we deprive it of its human context, of the personal interrelation that should prevail in our relation with patients8. He warns that we risk overinforming instead of communicating and emphasizes that patients have the right to know (truthfulness) and to choose what they want to know. Regarding veracity, Maglio recommends that the truth be told in a graded and manageable manner, exercising two virtues: caution and hope. Along the same lines, several years ago, in this Hospital Italiano journal, Nicolás Cacchiarelli and Carlos Musso told us that "the opposite of a cruel truth is not a pious lie, but an adequately revealed (dosed) truth"[9].

An article entitled "The Ethics of Semantics in Medicine"[10] appeared in the December 2022 edition of the *Journal of Medical Ethics*. In it, the authors reflect on the use of certain expressions, their clinical and ethical implications, and the possible reasons professionals use them. Thus, a specific word used by a physician may reflect a conscious or unconscious moral or cognitive bias toward the medical situation that may influence communication with patients or their families and the decision-making process. Some physicians use 'medical' language without realizing it, and patients and their families have difficulties understanding it. The authors posit that there are many reasons why physicians use language that patients do not fully understand:

a) the use of medical jargon to reaffirm the physician's position in some way,
b) the reasonable use of semantics to hide some physicians' uneasiness or inadequate training in delivering bad news,
c) the use of euphemisms as a way to protect patients from bad news or developments that nevertheless carries the risk of undermining patient autonomy,
d) to disguise or avoid sensitive ethical issues.

Interdisciplinary work with psychology professionals provides valuable concepts to improve listening skills, the other important element of human communication. Active listening involves paying attention, without judgment, to the questions, reflections, preferences, or comments that may arise in patients after receiving painful and, in many cases, devastating news. Active listening also involves accepting the emotional responses of the other. And with this kind and compassionate listening, all emotions are recognized as valid, mainly those hard to manage, such as sadness, anger, fear, or frustration. Ultimately, this form of listening builds trust and fosters communication by decreasing the feeling of hopelessness[11].

Recognizing a problem in everyday reality is the first step to addressing possible solutions. How we deliver unpleasant news affects how well patients understand the information, their satisfaction with medical care, their level of hope, their subsequent psychological adjustment, and their decision-making process[12]. If we thus agree that what we say (or do) and how we say it can negatively impact our patients or their families, we become compelled to modify behaviors. Awareness is the first step, and coupled with informative readings, it may be a sufficient response on a personal level, but the challenge is to work to propagate its importance in academic and educational settings. Firstly, we must emphasize an attitude of active listening to those who have been patients or relatives of patients and tell us about their experiences. Next comes organizing athenaeums, reflective debates, and reviewing the literature. But this is probably not enough to change behavior in the long term. One of the most impactful modern strategies is the use of simulation. Although studies of procedural simulation are more widely available, simulation practices have also developed to evaluate effective and appropriate communication for families[9,13]. As Chris Feudtner says: “Repetitive training and coaching on specific behaviors should be emphasized, because they are not only the skeleton of an excellent communication; they are also probably the muscles, the heart and even the soul “[14]. Although this requires resources and effort, it is worth remembering the words of Dr. Juan Carlos Vasallo, pediatric intensivist, who said at the last Argentinean Congress of Neonatology: “If simulation sounds expensive to you, try with error.”

Finally, in this aspect of communication, although it is important to know the general guidelines, I wish to emphasize the importance of practicing personalized medicine, moving away from universal prescriptions[15]. It is vital to be assertive, that is, to express thoughts and feelings in an honest, direct, and contextually appropriate manner, respecting the ideas and beliefs of others. This requires significant personal and interpersonal skills. Some skills may be learned and some do not require a cognitive effort but a commitment and a determination to act in different ways without thinking (basic human education, respect for others, and ‘people skills’). Proper communication comes later and must build on the foundation of these behavioral habits[16]. As we have written elsewhere, the helping relationship has to focus on responsiveness and uniqueness[17]. To be responsive means being willing to respond to the person’s needs according to his or her vital rhythm without accelerating or slowing down his or her usual processes. Uniqueness refers to the fact that each person is a unique and unrepeatable being. As Annie Janvier says: “When we genuinely individualize and personalize our approach, we will contribute to the family’s long-term well-being. It is our obligation and privilege to serve our patients and their families this way”[18].

To conclude, I would like to emphasize the importance of silent accompaniment in extremely painful situations, such as the death of a daughter or son. For this, I bring another voice, that of Eduardo Sacheri: “...in the extremes, in some decisive experiences, words are no longer useful. Words are useless at the peak of happiness and the abyss of sadness. I learned it when I was very young, and tried not to forget it.There are situations in which silence is necessary. Language, in front of certain abysses, is almost disrespectful. Human beings are a species built on language, but there are frontiers --where life is mostly life and where life is mostly death-- where we go back to being what we were when our brains had not learned to babble. And the only way to transit these extreme paths is through company and silence”[19].

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