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Quality of life in Nephrology and peritoneal dialysis: bringing the person back to the center of the prescription.

Marilena Cara

Nephrologist Psychotherapist Psychoanalyst Analyst at the Italian Center for Analytical Psychology (CIPA-Milan) and International Association for Analytical Psychology (IAAP).

***Corresponding Author:** Marilena Cara**,** Nephrologist Psychotherapist Psychoanalyst Analyst at the Italian Center for Analytical Psychology (CIPA-Milan) and International Association for Analytical Psychology (IAAP).

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The term "Quality", in its various definitions and meanings, refers to a subjective concept and contrasts with that of quantity, in fact indicating a specific characteristic, a merit, a distinctive quality of someone or something.

The time of globalization, enabled by technological innovations and fundamentally by the birth of the web (fifty years have now passed since its birth), through the unification of markets, has pushed towards the need to cling to standardized categories that are measurable and understandable to everyone equally, regardless of the socio-cultural substratum and consequently sacrificed the concept of quality in favor of quantity.

However, in the healthcare sector, being characterized by a dimension of suffering, it is very important to always keep in mind the care of the individual person and the subjective needs of that individual.

Nephrology, a branch of internal medicine, deals with the treatment of a complex chronic disease that is absolutely unique and not comparable to other chronic conditions due to the vastness of the refined medical topics (acid-base balance, calcium-phosphorus metabolism, hydro-saline balance, endocrinology, immunology, pathology cardiovascular).

When facing the end stage renal disease phase, the patient must choose the life-saving dialysis method that most closely matches personal needs. This objective can only be achieved if the subject is not only informed, but trained, in relation to the theoretical, practical, social and individual process that he will have to face.

Peritoneal dialysis, unlike hemodialysis, deals with a chronic condition in which the patient is an integral part of the therapeutic

process: the patient performs dialysis on himself while he lives. The patient does not TAKE the therapy, he DOES the therapy through his own body: the abdomen.

It is a logical deduction to be aware of how fundamental and essential it is to place the patient at the center of care. In this dimension of pathology, accompanying the patient in the choice of dialysis method takes on even more importance, with primary attention to quality of life as a fundamental aspect of the dialysis prescription, being the subject responsible for his own treatment. This accompanying process requires necessary communication and relationship skills that distinguish the neurologist from other specialists.

Since quality of life is a subjective concept, as we have said, the starting point of any therapy that is offered to the patient and for the reasons just mentioned, in a decisive way in peritoneal dialysis, can only be the individual, the Person.

So the point is: how can doctors or nurses evaluate the patient's level of quality of life?

Can the tools needed by clinicians, who experience patients first-hand, for assessing quality of life be the same as those used by the healthcare institution?

The institution needs tools capable of measuring a service, both in terms of efficiency and quality, a necessary and indispensable measurement to evaluate the functioning of a service or the capacity of an operating team, therefore a control tool.

The term quality of life in fact indicates the well-being of one or more individuals or of a habitat or a work environment, a community, city or nation.

The debate on quality of life is an ancient one.

Aristotle (Nicomachean Ethics) used the concept of Eudaimonia: happiness: Good success of your "demon". Your demon is your ability-quality, your specific one, your vocation, your art. Achieving happiness occurred through the realization of yourself, qualities.

Before him, Plato had dedicated several years of his life to the organization of the perfect city.

The term quality of life began to be used in its modern sense starting from the 70s, when we began to talk about Welfare. Mainly in the United States, QoL (quality of life) was an indicator to describe the progress of society not only in terms of economic wealth achieved

but in terms of well-being achieved in a given socio-cultural context.

In 1948 the World Health Organization defined the concept of quality of life and health as follows: "A state of complete physical, mental, and social well-being - and not the mere absence of disease". A measurement of health not only in terms of frequency of illness.

In 1995, the proposed definition of the WHO Quality of Life Working Group defines quality of life as “individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their objectives, expectations, standards and concerns”. A SUBJECTIVE perception.

Monitoring health status with measures of this type provides GOVERNMENTS with INFORMATION useful for planning, improvement and evaluation, helping to identify disparities between population groups and evaluate progress in achieving health objectives.

We are talking about information useful for planning for governments.

In clinical research, quality of life measures are widely used to evaluate the outcome of medical surgical treatments.

In the medical and healthcare field, a patient's quality of life can be "measured" either through a clinical assessment of the state of health that takes into account mental and physical well-being or through a subjective evaluation, based on the perception that the subject reports of his own quality of life.

There are numerous tests for evaluating the quality of life in healthcare and various generic questionnaires (aimed at measuring the well-being and overall functionality of the subject without reference to a specific disease) or specific ones (which include specific questions oriented towards the pathology the subject suffers from). affection) in which I was losing myself.The questionnaires have a reproducibility requirement, among the most used are the SF-36, WHOQoL, EuroQoLL5D.

These definitions and questionnaires can certainly be useful in clinical research, but the question is how misleading they can be in understanding the needs of the person being cared for. I speak of needs because I believe a state of well-being cannot exist without at least partial satisfaction of the indispensable needs of that individual.

If a widely used test, such as the SF-36, allows us to evaluate a subject's quality of life through 36 items compiled in a short time (5-10 minutes), how could we develop our understanding of how that person functions? subject?

After various reflections I have chosen not to delve further into the field of texts and the numerous and complex definitions because I believe that they do nothing but distance us from the person.

So how to do it?

I believe that the tool, for those involved in clinical medicine, through which it is possible to "measure" the patient's quality of life, is the empathetic relationship between the person who treats and the person who needs care.

It is knowledge of the patient that often directs us as nephrologists to suggest one method rather than another, regardless of the technical feasibility data

It is my conviction to believe that a peritoneal dialysis doctor or nurse with developed relational skills (albeit unconsciously) during each visit, each therapeutic adjustment, each acute problem,each confrontation of the change in the patient's family structure is evaluating and sharing his quality of life.

The relational contact that develops during the approach to a patient in the peritoneal dialysis clinic is also the tool for observing her quality of life.

Common sense and literature inform us of how a better quality of life is associated with better survival of the patient and consequently of the dialysis technique.

I believe it is important to convey the message to young doctors and nephrologists: beyond standardized tests and tools for measuring the quality of life, the person who treats has within himself as a person and an individual the quality, that is, the gift, to evaluate the quality of their patients' lives.

I consider knowledge of oneself (Eudaimonia) and of one's identity, both personal and professional, to be fundamental as the first fundamental tool for treating and evaluating the patient first as a person and then as an illness.

Personal care originates from the ability to take care of oneself.

Furthermore, psychoanalysis teaches how the ability to evaluate one's quality of life, and to be sufficiently aware of the degree of one's well-being (which for each of us will be based on subjective requirements) are fundamental requirements in order to develop the ability to evaluate quality of the other's life. We cannot take care of what we do not first know within each of us.

Do you need a test right now to answer the question: "from zero to 10, how would you rate your quality of life today"?

How can we deal with the interference of the patient's state of mind in the treatment process if we are often unaware of our state of mind during the relationship with the patient?

It has been clear for some time that healthcare workers have to deal with limited staff resources. Adding tests and evaluation forms could on the one hand be reassuring and on the other take away precious time from the care of the operator-patient relationship and communication considered increasingly important in the treatment process today.

Despite the extraordinary rapid development of medical technology, clinical medicine remains a human science based on the relationship with the patient. Instrumental diagnosis alone is not sufficient to reach the diagnosis but only the care of the person as a whole can lead to a correct diagnosis and therapy.

I conclude with this phrase by Tiziano Terzani taken from the book "Unaltro giro di giostra": "doctors can be good advisors, but the final decision on what to do or not to do touches the patient because that decision, in the final analysis, is not neither scientific nor practical. It's existential. And it is up to everyone to decide how he still wants to live.”

Evaluating and measuring the patient's quality of life can then be the only tool to accompany the patient along the path that he himself chooses to follow while respecting his own existential nature, and therefore quality of life becomes the tip of the scales of therapeutic decisions .