

Preferences in a Group of Patients with Cancer: A Grounded Theory

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Purpose: This study was conducted to understand the preferences of patients with cancer in Medellín, Colombia.

Methods: A qualitative approach based on the theoretical and methodological resources of the grounded theory was conducted. Between June 2020 and March 2021, patients over 18 years old with a confirmed diagnosis of cancer within the past 2 years treated in Medellín, Colombia, were selected. Theoretical saturation sampling was performed. Each participant was interviewed between 2 and 3 times in accordance with the open, axial, and selective coding of the grounded theory.

Results: A common preference set emerged in all patients related to the attributes of healthcare professionals and is a category that unites their scientific and humanistic aspects. On the other hand, very heterogeneous preferences were presented that were associated with the doctor–patient relationship and the therapeutic objectives. In the doctor–patient relationship, there are those who adhere to a paternalistic model and those who opt for an informative model. In therapeutic objectives, two subcategories emerged: those who are inclined to preserve life and those who accord more value to the quality of life.

Conclusion: The categories that emerged illustrate the complexity and challenges of the preferences of patients with cancer in theoretical and experiential terms for social studies of medicine, philosophy, and bioethics. From medical social studies, it's emphasized that the experiences of dehumanization are constant, which generates shared preferences in the patients related to the ideal of the medical professional. From the philosophical perspective, the care received by patients coincides with what was called medicine for slaves in ancient Greece, insofar as patients are not assumed to be free subjects. With respect to bioethics, some ideas are raised contrary to the support of individual autonomy; relational autonomy and the respect for the person above the autonomy itself are advocated.

Keywords: preferences, cancer, grounded theory, social studies of medicine, bioethics

Introduction

A fundamental ethical principle in current clinical practice is to consider patients' preferences in decisions related to the care, diagnosis, treatment, and prognosis of their diseases.¹ In this context, patients' preferences are part of the bioethical principle of autonomy;² they are one of the pillars of evidence-based medicine^{3,4} and are considered the core idea of healthcare practice by relevant government institutions such as the Food and Drug Administration.⁵ In addition, patients' preferences are considered in the development of medicines and medical devices. The evaluation of healthcare technologies and the development of clinical practice guidelines determine the quality of healthcare service delivery systems;⁶ patients'

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preferences have even led to measurements important for healthcare management (administration), such as cost-utility or cost-benefit studies or “Patient-Reports Outcome”.⁷

Despite the importance of patient preferences, there is no single or universally accepted definition of the concept of preferences; however, some stakeholders in the field agree that this concept refers to patients’ statements regarding the convenience of a variety of experiences, treatment options or health status.^{1,8,9}

In this regard, the concept of preferences has been applied in several investigations to describe, for example, the choice between a group of treatment options,¹⁰ the involvement of patients in shared decision-making processes,¹¹ and patients’ access to information and communication with healthcare professionals.¹² In addition, research has linked patient preferences to health outcomes. Some studies suggest that the physician’s adaptation to the patient’s treatment preferences promotes therapeutic adherence¹³ and improves the quality of life,¹⁴ other investigations postulate that treatments generate benefits regardless of whether patients’ preferences match those of physicians in the case of diseases such as the infectious diseases or diabetes or experiences of pain.¹⁵

Studies on this topic have revealed that patients’ preferences are quite complex. Thus, patients’ preferences can be very stable for chronic and mild conditions;¹⁶ nevertheless, patients’ preferences in severe life-threatening diseases such as cancer can vary as patients receive new information, experience stress, or experience deterioration of health.¹⁷ On the other hand, preferences may simply not exist, be unclear, or not well defined in unknown and emotionally difficult situations such as choosing between invasive treatment and other treatments. In such cases, patients may experience conflict regarding what they want in terms of healthcare.¹⁶

Because of the complexity of this matter and criticisms of clinical practice characterized by scientific and economic aspects,¹⁸ it has been suggested that the incorporation of patients’ preferences in the decision-making process is limited to a statement of good intentions, a rhetorical resource, or a topic of interest in biomedical publications.¹⁹ There is a gap in the literature regarding patients’ preferences and their adherence in clinical practice. In addition, the topic of patients’ preferences has not been equally addressed in all clinical conditions; they are affected by structural issues of the healthcare system.

Cancer is among the clinical entities in which patients’ preferences are more difficult to evaluate as those who with cancer go through distinctive characteristics that are not applicable in other diseases. Patients with cancer face a life-threatening sickness. Their healthcare involves numerous physicians and multiple treatment modalities (medication, surgery, and radiation). Patients with cancer have late physical problems such as fatigue, aches, edema. After treatment, there is a long period of insecurity about the possibility of metastasis or relapse. Patients make decisions with high levels of stress and uncertainty, and they must deal with complex medical information, communicate with multiple healthcare professionals, and select treatments that have an impact on their survival and quality of life.²⁰

The incorporation of patients’ preferences varies for many reasons, including structural issues such as the type of healthcare system, which determines the relationship between the specialist supply and the service demand and limits consultation time; this in turn makes it difficult to establish an appropriate doctor-patient relationship and standardize the type of treatment or benefit plans for certain diseases. In this sense, the healthcare system in Colombia assigns a double role to the physician: one related to healthcare and the other to optimize the system resources. According to a previous study,²¹ this design has important implications for doctor-patient relationships. Previous studies conducted in Colombia indicated that 23% of patients were not satisfied with the treatment they received from healthcare personnel.²² Physicians and patients realize that the duration of consultations is insufficient to have access to good service; moreover, insurance companies restrict the quantity and quality of what physicians can prescribe,²¹ and the number of specialists in Colombia is one of the lowest in Latin America.²³ In addition, the Colombian healthcare system has been permeated by what some authors have called the McDonaldization of Medicine. This includes a reduction in the time of contact with the patient, the predominance of quantity over quality, the over-standardization of treatments for certain types of diseases regardless of the distinctiveness of each patient, and the control of healthcare professionals by technological devices, which is demonstrated by the fact that physicians spend more time during consultations interacting with computers than with patients.²⁴

The integration of patient values and preferences into clinical decision-making has become increasingly relevant

in the fields of practice, education, and health research^{25–27} over the past 20 years. Researchers who have questioned this concept from a medical perspective agree that it is a confusing notion that is poorly unified.^{8,28} Approaches about the topic denote quite diverse meanings and uses, presented especially in systematic reviews, theoretical reviews, empirical studies, and measurement scales.²⁹ Many disciplinary approaches have delimited the concept, ranging from healthcare economics and decision and cognitive psychology sciences to social psychology and medical education.^{8,30} This is particularly important in patients with cancer in Colombia because of the specific characteristics of the sickness and the healthcare system of the country. Approaches that directly ask patients about their preferences and values in terms of decision-making and other clinical considerations in their encounters with healthcare professionals are still limited.²⁸ This study was conducted to understand the preferences of patients with cancer in Medellín, Colombia, from a qualitative approach based on the theoretical and methodological resources of the grounded theory.

The choice of this methodological strategy is based on the fact that, since its genesis according to Barney Glaser and Anselm Strauss (book *The Discovery of grounded theory*), it was structured with particular and differentiated features compared to other qualitative options, among which it is worth highlighting the following: provide theorization options different from those of functionalism and structuralism; consolidate the applied rationality in a theorization grounded, generated and developed from the data collected during the investigative process; close the gap between theory and empirical research, legitimize a qualitative research style in which theory is defined as a group of concepts formulated and related in a logical and systematic scheme, which allows describing, explaining or predicting social, psychological, educational or other phenomena; in this case, it is a theory that emanates from the narratives of the study subjects, which are collected, analyzed and theorized by the researchers in an iterative way.³¹

Finally, the understanding of the preferences of patients with cancer by means of a qualitative study allows further exploration of the experiences, perceptions, patterns of behavior, acceptance, and rejection of current healthcare actions. In addition, it transcends the biological dimensions of sicknesses and accounts for human interactions and human interpretations of such interactions; this is a relevant situation because healthcare involves people and this dimension is more complex than the biological dimension. Furthermore,

the understanding of the preferences of patients with cancer allows guidance of the responses of healthcare institutions on the basis of the knowledge that is socially structured in the voice of the affected people.³²

Methodology

Type of study: grounded theory, defined by Corbin and Strauss as

a theory derived from data collected systematically and through a research process [in which] data collection and the analysis and theory that will arise from them are closely related to each other. (p 13)

The grounded theory is conceived as a methodological strategy for developing theories, concepts, hypotheses, and propositions based on direct data from participants.³¹

Context: Between June 2020 and March 2021, patients with cancer treated in Medellín, Colombia, were selected. In Colombia, patients access healthcare services through an insurance that provides an equal benefit package for all, but it is divided into two regimes: the contributory regime, designed for people able to pay a contribution financed by the affiliate or the affiliate and its employer, and the subsidized regime, designed for people without access to formal jobs. In the contributory regime, affiliates contribute money according to their financial potential to access healthcare services. In the subsidized regime, the contribution is covered by the State with the help of the contributions by those affiliated to the contributory regime. The insurance is managed by private companies called healthcare service promoters, who guarantee access to healthcare services and their quality by hiring public and private companies to assist their affiliates.

Selection and eligibility criteria: Patients over 18 years old with a confirmed diagnosis of cancer within the past 2 years were included. Patients in the terminal stage, which hindered the interview, and those whose mental faculties were affected by the sickness or comorbidities (as determined by a professional psychologist) were excluded. The participant selection technique was established using the maximum variation criterion to capture a wide range of different preferences among patients.³² The criteria of maximum variation that were considered were age (22–71 years), socioeconomic housing status (one to six level), educational level (primary to postgraduate), and type of cancer (stomach, prostate, cervix, leukemia, thyroid, and breast cancer). Although there are a wide variety of cancer types, stages of sickness, and treatments, there are also

structural aspects (cultural, social, political, and aspects related to the type of healthcare insurance system) that justify a unified account of their preferences.

Sample: Theoretical saturation sampling was performed, ie, patient selection was stopped when the information became monotonous, redundant, and nothing new emerged in the categories of analysis between one patient and another. This saturation of the pre-established and emerging categories was achieved with 15 participants, who were interviewed 2 or 3 times (40 interviews in total, duration 24 h and 48 min).

Information collection: Two professional psychologists conducted semi-structured interviews following a script provided by the principal investigator. The interviews followed this scheme: (i) introduction and informed consent explaining the purpose of the interview, in which the informed consent is read and the anonymous nature of the information is explained; (ii) questions about the background and socio-demographic factors of the participant, such as age, sex, socioeconomic status, monthly income, education, and occupation; (iii) history of symptom onset and the evolution of the diagnostic and therapeutic process; (iv) first encounter of the participant with their healthcare provider; (v) relationship with the treating physicians and positive and negative aspects in the meetings with the healthcare personnel; and (vi) treatment decisions that include differences of opinion between the participants and physicians, as well as the aspects they usually think about when making decisions about the therapies they received. This interview scheme did not serve as a checklist that needed to be followed in that order; it was intended to guide interviewers so that the topics could be mentioned according to flow of the conversation with each patient. Each participant was interviewed between 2 and 3 times in accordance with the open, axial, and selective coding of the grounded theory.³¹ The data were analyzed between interviews to address and reinforce aspects that were not clear in the previous interview. The original protocol required in-person interviews; however, this was difficult to implement because of the new conditions imposed by COVID-19 pandemic and because some patients had unforeseen health conditions and often needed to cancel meetings. Thus, remote interviews (without a face-to-face meeting, where the interview is conducted over the telephone, computer, or video conferencing software) were conducted. All interviews were recorded in audio and/or video and transcribed.

Methodological rigor criteria: The criteria of credibility, auditability, and transferability were applied in the study.³³ Credibility was achieved by the interviewers' extended discussions with the participants as they were constantly asked to confirm whether the findings were a true approximation of their cases. Auditability was assured by the fact that interviews were conducted by two psychology professionals who were trained together with the purpose of ensuring a similar speech with patients. In addition, an independent coding was performed by two researchers; it was determined a priori that the final coding would be the product of a consensus between them and, in cases where consensus was not achieved, they would be referred to the third researcher. In terms of transferability, a detailed description of the demographic and contextual characteristics of the patients was prepared.

Analysis of the collected information: The interviews were analyzed following the open, axial, and selective coding stages.³¹ During open coding, the interviews were broken down into simpler text fragments and were given a name, code, or label to represent them. All text fragments were compared for similarities, and the same code was assigned to those who were considered to share some common characteristics. The coding was performed based on the words of the interviewees (in vivo coding) or from concepts established by the researchers. When the codes were abundant and began to accumulate, similar or related events were collected in a more abstract common classificatory heading or categories; this allowed the researchers to reduce the number of codes. In turn, the categories were developed in terms of properties and dimensions to differentiate between categories and confer greater accuracy. Axial coding regrouped the data fragmented during the open coding in a process that involved the relationship between categories and subcategories following their properties, dimensions, and how they intersected. This procedure was not always sequential to open coding but sometimes simultaneous. During selective coding, a core category representing the central topic of the research (preferences) was selected, and the data around it were integrated. The following criteria were taken into account in the selection of the central category: i) to be an abstract term or phrase under which all categories could be grouped; ii) to reflect the range of variability within each category, and iii) to reach an explanatory whole by connecting each category.³¹ The information was reflected into a significance matrix and reviewed for internal

consistency. Categories with little development were completed, and the surplus categories were eliminated. Finally, the theoretical scheme was validated in a two-stage procedure. In the first stage, a constant comparative process was conducted between the emerging theory and the data, with the purpose of verifying if the researchers' abstraction could explain most of the cases. In the second stage, participants were presented with the significance matrix and asked to discuss whether it constituted a reasonable explanation of what happens in their cases.

Ethical aspects: Informed consent was obtained from all participants in audio and/or video, and the participants consent included publication of anonymized responses. The procedures were presented and approved by the ethics committee of the Universidad Cooperativa de Colombia, Act No. 027-2020, following the principles of the Declaration of Helsinki, the Resolution 8430 of the Ministry of Healthcare of Colombia, and the policy of ethics, bioethics, and scientific integrity for Colombia by Colciencias (now the Ministry of Science, Technology, and Innovation).

Results

Fifteen patients with cancer aged between 22 and 71 years, from all socioeconomic status (one to six level) and varying educational levels including five healthcare professionals (three physicians, a bacteriologist, and a dentist) were interviewed. The types of cancer varied: they included one patient with stomach cancer, one with prostate cancer, one with cervical cancer, two with leukemia,

two with lymphoma, three with thyroid cancer, and five with breast cancer (Table 1).

In the interviews, a common preference set emerged in all patients regardless of the diversity in their social status, type of cancer, age, sex, or spiritual and cultural aspects. This set of stable preferences is related to the attributes of healthcare professionals and is a category that unites their scientific and humanistic aspects. On the other hand, very heterogeneous preferences were presented (adaptive according to some characteristics of the participants) that were associated with the doctor–patient relationship and the therapeutic objectives. In terms of the doctor–patient relationship, there are those who adhere to a paternalistic model and those who opt for an informative model. In terms of therapeutic objectives, two subcategories emerged: those who are inclined to preserve life and those who accord more value to the quality of life (Figure 1).

Attributes of Healthcare Professionals: To Be a Person First, Rather Than a Diagnosis

As mentioned above, the participants stated a set of preferences related to the attributes of healthcare professionals. These attributes are divided into scientific and humanistic aspects. In terms of scientific aspects, the patients commonly mentioned their respect for the technical knowledge that physicians have about the sickness, the confidence inspired by the education that physicians have received and the multiple specializations they have, as

Table 1 Characteristics of the Participants

Code	Sex	Age (Years)	Type of Cancer	Education	Occupation	Economic Stratum	Monthly Income COP
E01	Male	22	Stomach	Undergraduate	Univ. student	4	\$700,000
E02	Male	23	Lymphoma	Secondary	Unemployed	1	\$0
E03	Female	26	Thyroid	Postgraduate	Physician	5	\$2,700,000
E04	Female	27	Leukemia	Postgraduate	Physician	4	\$8,000,000
E05	Female	29	Lymphoma	Undergraduate	Physician	3	\$3,900,000
E06	Female	33	Thyroid	Technical	Secretary	2	\$1,100,000
E07	Female	51	Breast	Technical	Dental assistant	2	\$1,800,000
E08	Female	52	Breast	Secondary	Housewife	2	\$850,000
E09	Female	53	Cervix	Secondary	Businesswoman	3	\$0
E10	Female	53	Breast	Primary	Housewife	1	\$500,000
E11	Female	55	Breast	Secondary	Housewife	5	\$2,500,000
E12	Female	58	Thyroid	Undergraduate	Bacteriologist	5	\$0
E13	Female	61	Leukemia	Undergraduate	Retired	3	\$2,000,000
E14	Male	61	Prostate	Undergraduate	Odontologist	6	\$3,000,000
E15	Female	71	Breast	Technical	Secretary	3	\$1,500,000

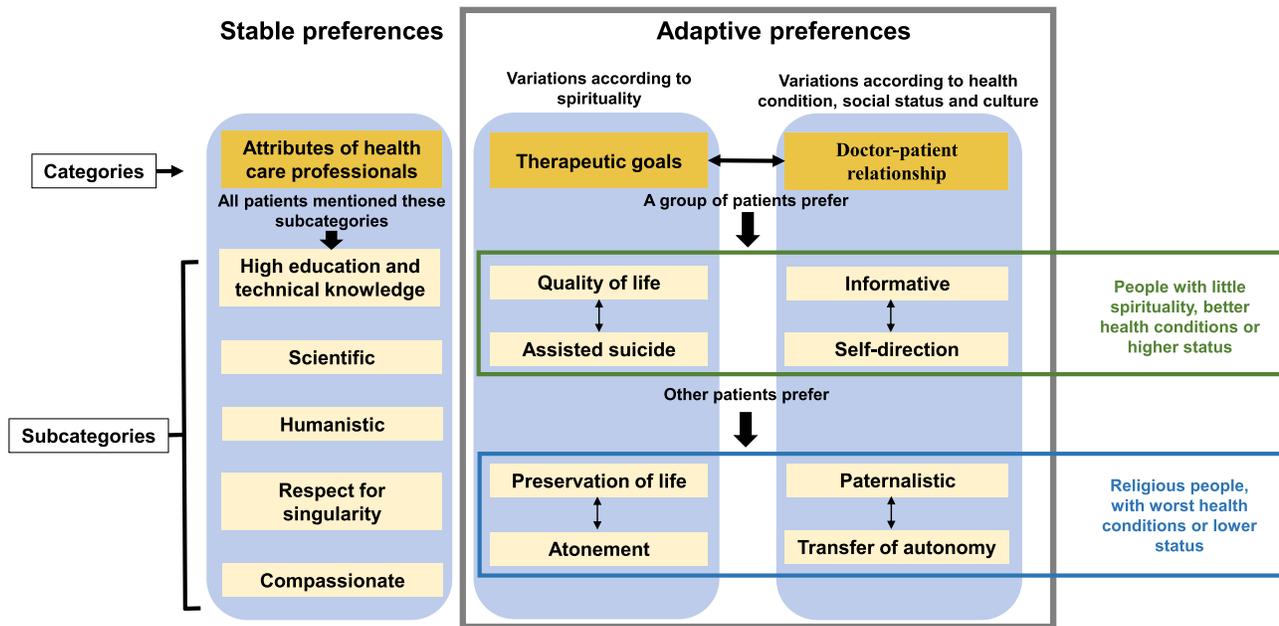


Figure 1 Significance matrix of therapeutic preferences in patients with cancer.

well as the formal treatment they received in outpatient consultations and in the episodes in which they required to be hospitalized. Words such as “eminence,” “trust,” and “excellence” emerged.

In terms of humanistic attributes, all patients emphasized, in addition to technical excellence, the importance and time that their physicians dedicated to care; that they were interested in the patient’s daily lives; including their job situations, their family members, and their relationship with friends.

To be a person first, rather than a diagnosis. **E12**

Consultation time is considered essential to establish good communication channels and develop empathy and compassion. Professionals who have the ability to listen are well-valued as they give the patient a chance to share their tensions, problems, concerns, and doubts about the sickness since

Many times, what one looks for and needs in a doctor is someone who listens to you; many times, one can feel relieved with a well-given explanation. **E12**

To support these preferences, some patients reported situations related to the dehumanization of medicine, which consisted of indifference and coldness in interactions, in the medical look reduced to the functional aspects, taking care of the biochemistry, tumor markers, and radiology but overlooking the patient. In the participants’ perspective,

some of the reasons contributing to this phenomenon include the high demand for healthcare services relative to the supply of specialists in the field and the lack of time to establish an adequate doctor–patient relationship. These two aspects are linked in a type of deindividuation of the patient and a reduction in the compassion of healthcare professionals.

The human part and the human accompaniment that you never have. That part is very hard because, for example, appointments with the doctor were so fleeting that I didn’t have the right to ask ... you couldn’t ask questions beyond ... because you were asked to “talk to my assistant.” The doctor had an assistant who was almost always the only one who cleared up your doubts because the doctor only had time to examine you, see you, and say goodbye. And the next, and the next, and next ... Appointments were one minute long, but you had to wait for two or three hours. **E12**

There was a time when I had a horrible abdominal pain; they had to suspend the oral medication. It was a horrible pain that only morphine could take away; when I started experiencing that pain, I had to call [the medical staff]. Many times, they came about an hour or half an hour later. I don’t know if it’s like they get used to the pain or like “Oh yes, he’s calling again” or “again with the morphine” ... One also understands that you are not the only patient and that they are busy with other things, but they should not get used to the suffering of others, as “Oh, he has been

complaining for a week and he is complaining again.” The easiest pain is the one of the other and, of course, since they aren’t feeling it, then they remain calm. **E04**

Similarly, they reported situations in which they perceived that they were being objectified. They reported that some healthcare professionals consider them as an object or a subject lacking agency, a passive individual who is given orders to follow. They reported that patients’ perspective on sickness and healthcare is overlooked. When feeling ignored or objectified, their perception of autonomy is reduced, and feelings of impotence begin to emerge.

I remember a feeling that I had at the beginning of not being able to control what I did, then they came in and said: Put on these pajamas. It’s time to urinate into this bottle. Let’s go and do this test, then remove the blouse ... Literally one doesn’t feel like a person. I was never treated badly, but you didn’t have control of yourself. This is how all patients should feel. **E04**

In accordance with these experiences, the participants accorded more value to humanistic aspects than to scientists regarding their preferences about the attributes of healthcare professionals, because

finally, it ends up not being very important in the professional life if you are the one who knows the most or the number one in what you do. What matters is whether you are a good person and you treat patients well. For sure, one prefers that as a patient. **E03**

Preferences About the Doctor–Patient Relationship

It Gives Me More Confidence That the Doctor is Above the Patient

In this category, there is a group of patients who prefer that all treatment decisions are made by healthcare professionals. These patients fall within the subcategory of the paternalistic model, with the particularity that they themselves relinquished their autonomy, so that the choice of the options that affect their life lies entirely with the physician. They emphasize the principle of trust in that process and assume that physicians know and choose what is best for them.

It gives me more confidence that the doctor is above the patient. **E12**

In my case, my doctor made the decisions about my treatment, but this matches with the option that I would

prefer, (...) I remember something I told the hematologist the day she explained the whole treatment to me, I remember that I looked at her and said: Well Doc, the most important thing is that I get out of this, I trust you and I know that you are going to make the best decision for me. That was what I wanted, for them to do everything within their reach that she deemed necessary, because I trusted her knowledge. I knew that she was doing things well. **E05**

This group of patients opts for a paternalistic model because they consider that healthcare professionals have a technical knowledge of the situation far superior to their own; they have turned to healthcare services precisely in search of the advice and judgment of experts that they lack, and their health situation has led them to a state of weakness and vulnerability that does not place them in a good position to make decisions, a fact that could prevent them from acting with the autonomy they exercise in other scenarios.

I think I wasn’t prepared to decide. I was out of my wits to be able to decide. I only came and went as ordered and dictated in the medical part; I just followed orders and that’s it. It seems to me that it was appropriate in my case because it worked. **E01**

A common theme in this group of patients (those who opt for a paternalistic perspective) revolved around not inquiring about their sickness and wanting nothing to do with what is related to their diagnosis, even in the physicians involved in this research, either voluntarily or by physical inability to do so.

No, I didn’t want to, I didn’t read absolutely anything. I wanted nothing to do with it as a doctor (...). I said, I’m just another patient and I am completely relaxed. **E05**. My reaction was: I’m not going to look for anything. I didn’t look for treatment and never thought about asking the doctor if there was another option. He inspired so much confidence that he told me: “This is it, this is what we have to do.” **E04**

I had no approach or interest in investigating my sickness because when I arrived at the hospital, I was in such a critical state that any kind of interaction or search was physically impossible for me. I completely detached myself from the informative part and from my case. I got to a point where I was so bad that I didn’t even pay attention to the diagnosis (...). The last thing I wanted to hear was about the sickness. In another situation, the lucid self, the first thing I would have done is to ask,

inquire, and consult, but at that time it was the last thing that interested me. **E01**

They Have More Knowledge Than I Do, They are the Counselors, but the Decision is Mine

To participate in treatment decisions, the first step is to access information about the sickness. In this respect, another group of participants opts to investigate diagnostic, therapeutic, and prognostic alternatives; to do so, they refer to three sources of information: healthcare professionals, previous experiences of friends or family, and searching on the Internet. Regarding the information they obtain through healthcare professionals, they relate situations in which physicians illustrate them in relation to the diagnosis; each stage of the process that they are going to initiate in the treatment and the way in which some of them bind them in decisions; however, in several cases, the information on risks and benefits, the explanation of treatments, and the incorporation of their values and preferences in decision-making are reduced to the signing of the informed consent form:

At first, what they put you on is to fill out a form about what they are going to do to you, what they are going to do it for, and why they are going to do it. But I never got any explanation about the risks and benefits. Zero explanations. **E12**

These patients are characterized by an interest in deciding and solving problems related to their sickness, taking control over their health, asking for second opinions, and adopting critical thinking over medical judgment because they consider that

The title of a physician doesn't imply that a person knows everything they should know. **E03**

In this manner, they conceive the physician as a counselor, an advisor, and one who provides technical reasons for each treatment, but each patient assumes the responsibility for the decisions about their health.

I prefer to make the final decision about the treatment I should receive, but after considering my doctor's opinion. Obviously, they have more knowledge than me, they are the counselors, but the decision is mine because in the end I am the one who has to live if they operate on me, it's me who has to go through the surgery, not them. So, the final decision is mine. **E03**

Preferences for Treatment Goals Suffering is Part of Vindicating with Nature, with the Environment, and with God

In the category regarding preferences for treatment goals, two subcategories emerged: those who focus on the quality of life and those who focus on the preservation of life. In this respect, patients report that the primary goal of their cancer treatment is to increase the chances of survival and restore their health. Chemotherapies, radiotherapies, iodotherapies, and/or surgical interventions have been performed for this purpose. They describe experiences about how their condition improves, and some define therapeutic success as miraculous.

All participants in this group expressed a strong belief in God and the influence of the mastery of spirituality or transcendence in their decisions. They indicated that their anxiety was reduced by practicing spiritual disciplines or rituals and that they attained calmness by addressing their concerns to God, particularly during stressful situations such as receiving chemotherapy, prior to invasive interventions, or when they simply felt overwhelmed by thoughts related to their sickness. Daily life is conceived as an opportunity to correct mistakes and sickness, pain, and suffering are taken as an opportunity to atone for bad habits or behaviors of the past. In accordance with this, they refer to God as the sole determinant of the moment of their death.

Then I think that suffering is part of vindicating with nature, with the environment, and with God and suddenly becoming aware that one did wrong. **E13**

God gave me life, then God is in charge of taking me. I would simply ask him for a lot of courage and endurance to resist until he wants to take me. **E09**

I Prefer It Short, but Good

For another group of patients, the main therapeutic objective was the disappearance of pain as it was unbearable, incapacitating, and led them to heteronomy. Pain management is even above life preferences.

By the time I received the first chemotherapy, I wasn't a person, I remember that the only thing I asked for at that time was for a bed, because I had no strength to be there. I was lying in that chair, that image I have is the reflection that I couldn't decide anything. The only thing I asked was that the pain stop. It wasn't a matter of going against death or being saved, it was that I couldn't live with that pain. **E01**

In this context, a new category emerges, which is related to the quality of life. In this context, this group of patients agrees that their preferences in therapeutic objectives are that healthcare professionals help them live a quality life, rather than extending their life.

I think that if I have quality of life, I would love it, but if I don't have quality of life it would be different. I wouldn't think the same. When I lose my faculties or if there is pain, it would be very different. I think that everyone thinks the same, living with quality of life is rich, but when you don't have it, I wouldn't like life to be extended. No, if I am suffering, I would like to end it. I prefer it short, but good. **E12**

In this order of ideas, some patients report that they would rather end their lives in situations of extreme pain, situations of inability to feed themselves, situations requiring invasive medical devices, situations of loss of mental faculties or suffering, and when their medical condition is irreversible. For this purpose, they mention two options: i) assistance by healthcare professionals claiming their right to a dignified death, or ii) asking a family member or friend to help them die.

I recently had a few bad days and I thought exactly about that. I had a conversation with my brother, I even warned him: don't be afraid (...) but please, if at some point I see myself again in the same way I saw myself last year, look for a way to help me because I don't want to see myself as I saw myself for a long time, I feel I wouldn't bear it. There arises the controversial issue of having a dignified death and helping patients die. How nice it would be that someone could help when there is no longer a medical solution for such a distressing and complex process, so that this won't be a torture. An agony; just to help people rest. I think that this is what we all want, all of us. **E01**

Discussion

This qualitative study is oriented by the premises of cognitive psychology, symbolic interactionism, social studies of health-focused sciences, and bioethical studies. It provides experiential contributions to the theoretical debate regarding the place of preferences in decision-making within the scope of evidence-based medicine and person-centered medicine. Considerations are also made regarding the inclusion of patients in the research agenda, especially on the values and preferences of patients with cancer.

The first outcome to be discussed is regarding the group of common preferences among interviewees

regarding the ideals of the medical professional. We have categorized them as stable preferences because despite the variability of participants that ensured with the theoretical sampling for maximum variation, some narrations about how healthcare professional should be have been identified, and they are constant in the discourse of the interviewees. In this respect, the theory of classical utility argues that preferences always express underlying values; moreover, these are always stable and complete,³⁴ so that preferences remain independent of contextual variations.³⁵ On the other hand, literature in the field of behavioral decision theories states that preferences are always context-sensitive;³⁵ along the same lines, some social psychologists and theorists of social constructionism consider that preferences are the result of the individuals' perceptions, which consolidate through interactive processes.^{36,37} In this study, as opposed to the utilitarian perspective, preferences are considered a "social construction" rather than the manifestation of an inherent value, so the term stable should not be understood as underlying. Based on this, the participants built a meaning around certain preferences that arise from experiences in the interaction with dehumanized social environments, "objectifying" institutions and disciplinary speeches from experts. Thus, it is the experience of the dehumanization and the medical super-specialization, while constant in the context, that has generated shared or common preferences that are called "stable."

The issue of dehumanization is core within the results to the extent that it does not only represent a situation of malaise added to the own burdens of the sickness; it is also useful to question and reject "coldness" in the interactions with the assistance institutions. This finding coincides with two similar studies that address dehumanization in patients with cancer using a qualitative approach: one in Medellín, Colombia,³⁸ and the other in the United Kingdom.³⁹ Moreover, the objectification and reification of the body within the medical instance is linked to dehumanization because it leads to "professional neutralization of the patient's agency," "an erasure of authenticity," an "alienation of identity," and a "displacement of the self from the social world".⁴⁰ In this sense, some authors of epistemological history and social studies of medicine point out that these forms of dehumanization cannot only be identified and placed historically but are also essential within modern scientific medicine.⁴¹ This practice began to gain traction at the beginning of the 19th century with the development of new methods of clinical inspection,

together with the anatomopathological breakthroughs that led to physicians focusing on “the sick body” and “the injury”.⁴² This trend was reinforced by Claude Bernard’s proposals, radicalized with the breakthroughs of immunology in the early 20th century and currently with molecular biology and body visualization technologies. These facts have medicalized people’s identities,⁴³ thereby deepening “objectification” and “reification.” Therefore, the subjective experience of the patient, not being totally excluded from the medical act, is considered part of a nonscientific environment that does not need to be studied; in this respect, the experience of being treated as an object by the participants in this study is one of the distinguishing features of modern medical institutions, inherited from the 19th and 20th centuries.⁴⁴

The choice made by the participants in this study of a technically and scientifically trained physician who is at the same time endowed with humanistic values bring to mind old ideals about the type of physician that has been set at different historical moments: the connoisseur of an art that allows them to understand the singularities of their patients.⁴⁵ The philosophers of Anglo-American medicine of the 20th century highlighted the importance of a training in humanity for doctors as an antidote to the objectifying forces of modern technical–scientific rationality.⁴⁶ Patients’ expressions such as “one is a person first” bring to mind Paul Ramsey’s book, *The Patient As Person*, and the efforts of personalist bioethics to address the moral content gaps posed by principled and liberal currents of bioethics, which placed the person’s figure as a source of dignity⁴⁷ and regulatory moral mandate above the idea of the respect for autonomy. Proposals such as those of Laurence McCullough are also valuable in this case as they emphasize the importance of rescuing an ethics of virtues centered on the development of classic values such as integrity, prudence and honesty.⁴⁸

The results of this study emphasize that participants highlight the idea of a physician who is concerned about the truth, aware of their limits, and opportune in communication and decision-making; they also ask for more time to be allocated for the medical attention and more interest in their daily life. These attributes are similar to those reported in a study conducted with patients with cancer in Ohio, United States.⁴⁹ The consistency of these findings coincides with several constructivist perspectives which deem necessary to review and modify the provisions that lead to overvaluing the physician’s perspective and underestimating that of the patient’s, which is an important

obstacle in the development of a humanist physician oriented toward virtues. To this end, it is vital to train physicians in communicative competences that allow them to focus on the patient and to reveal their world.⁵⁰ It is suggested that the identification of the sickness is established through a biomedical exercise; however, special attention should be paid to: i) the ideas that patients have about what happens to them; (ii) consider feelings and emotions in the face of the experience of being sick; (iii) considering the effects of functional problems in social terms, and; (iv) consider the expectations of patients. This “heuristic” is important, as it helps physicians not only to understand the patient in a complete way, but to find agreements, especially regarding the choice of treatments.⁵¹

With regard to preferences for the doctor–patient relationship, two very strong trends were identified. The first relates to the few experiences with healthcare professionals who are interested in making shared decisions with their patients; the second refers to the abundance of physicians who do not listen to their patients. This typology coincides with Plato’s classification in ancient Greece: the doctors of slaves and those of free people.⁵² With the former a tyrannical praxis was applied; with the latter, a medicine more attentive to the origin and disease progression was implemented: the treatment was socialized with the patient and their relatives, physicians learned from the experiences of the patients, and training and persuasion about medical actions were given before providing prescriptions, with a real worry about reassuring the patient in the face of decisions. This suggests that, in the case of the participants’ experiences, the oncology care they receive is classified, in terms of ancient philosophy, as a “slave medicine”; ie, a medical praxis that does not respect or assume patients as “free” subjects (as these terms implied in ancient Greece).

Another result to be highlighted is the preference of a group of participants for a paternalistic model in the doctor–patient relationship. These preferences for a paternalistic model have also been documented in previous studies with family members, who report that they are not interested in participating in clinical decisions and choose to delegate that responsibility to healthcare professionals.⁵³ The option for the subcategory of paternalistic preferences is well explained from the functionalist models of social theory.⁵⁰ This subcategory describes an ideal model of 19th century medicine: the doctor plays an important social role, which is to identify the pathological,

the abnormal, the deviated, with the purpose of correcting or orienting individual norms that deviate from an expected state of social normality.⁵⁴ For their part, the patient passively assumes the role of surrendering to medical power in the hope of being able to integrate with the demands of normality and functionality that are typical of the society and its institutions. This is clarified by the paternalistic position that some of the participants in this study take on the issue of therapeutic “decision-making.” This position is contrary to the support given in the past 50 years to patient empowerment, autonomy, and “shared decision-making” within the scope of ethics and medical education,⁵⁵ given that participants prefer to see themselves as “agency-free” entities, thus giving the doctor the greater responsibility for making decisions. This question shows a predominance of positions that accentuates the ever larger gaps between the biomedical conceptions and the conceptions of the sickness inherent in the “world of life.”

In the same vein, the relativization of the informed consent and its reduction to a purely procedural issue, without considering the importance of informing and explaining scientific evidence around risks and therapeutic benefits, constitutes an element that contributes to the establishment of hierarchies within the relationship between physicians and patients. This accounts for a problematic issue, insofar as it produces, as highlighted by several research subjects, a position of ignorance or detachment in the face of one’s own sickness, which reinforces the confinement in a subjective experience that does not dialog with the biomedical perspective. Nevertheless, these preferences that favor a paternalistic option also make important claims that should not be dismissed. They show that the respect for their autonomy is not so important for this type of patients. What comes first is the confidence they have in their doctors and the fact that they treat them as people. This question is important because it is part of the arguments expressed from the personalistic approaches; in this sense, Eric Cassell states that the problem of autonomy in decision-making lies in how difficult it is to think of an autonomous subject in a serious condition of sickness and pain.⁵⁶ Hence, the importance of physicians being guided by their respect for the person, a much more decisive and stable attribute than the idea of autonomy.

With regard to the preferences alluding to an informative model in the doctor–patient relationship, some preferences are linked to values from popular culture, such as

autonomy, empowerment, and the responsibility for one’s life.⁵⁷ These expressions match the utilitarian approaches of the doctor–patient relationship, especially those that were recently developed, such as evidence-based medicine, which is oriented toward the idea of the “shared decision-making”.⁵⁰ In this respect, the physician is regarded as a technical professional who presents scientific evidence to their patients, details the specificities of each option in terms of the risks and benefits, and seeks to offer advice on the option that best “fits” the patients’ values and preferences.⁵⁸ Epstein et al developed the concept of “shared mind” to construct an effective communication strategy that includes sharing feelings, thoughts, perceptions and meanings between two or more people.⁵⁹ This approach focuses on relational autonomy and not on the classical idea of individual autonomy. From this perspective, agreements and decisions are not reached from a transaction between doctors and patients but are “built” in their interactions. It is important not to disregard this idea, insofar as it is shown as a way of bridging the gaps between biomedical approaches and patients’ perspectives on their sickness.

When addressing the preferences for treatment goals other lines of discussion are displayed. Those who have focused on treating their cancer for the purpose of increasing survival and recovering health, highlight the positive effects of the objectification of their body. As Timmermans and Almeling suggest,⁶⁰ the notion of objectification was associated with the evils of modern medicine, such as iatrogenesis or bureaucratic control. However, it is important to remember that the objectification and the critical reading of it tend to overshadow the improvements in the pathological condition or the beneficial effects of the objectification itself. As shown in this study, there are a group of patients who point out that the different technologies and procedures in which they have become organic entities subject to scientific intervention, such as chemotherapies, radiotherapies, etc., produce important changes in their biological status. However, this biomedical discourse seems to be insufficient in the face of legitimate demands for a life with a better quality. In this sense, studies around the dilemma between quality of life and extension of life have found that people of advanced age with a greater deterioration of physical condition prefer a quality life rather than its extension. On the other hand, young patients prefer aggressive treatments that allow them to increase their survival years. In general, these studies emphasize that preferences for quality of life

or extension of life are not influenced by gender, education, having children, marital status, cancer type or religion.⁶¹ As opposed to these studies, the delimitation of this category in the participants of this study was strongly influenced by the sphere of spirituality or transcendence.

The notion of spirituality is a frequently mentioned in studies of patients with cancer and is associated with inner peace, search for forgiveness, hope, acceptance of reality, search for meaning, change in the meaning of life, spiritual strengthening, and detachment from life.⁶² In accordance with this, the spiritual needs of patients with cancer should be recognized and considered by the medical team and the policy makers of the healthcare system. This notion, as shown in the interviews, relates to the preferences oriented toward the objective of survival as long as there is an assessment of life as a supernatural entity over which humans have no power. This brings to mind deep-rooted ideas and beliefs of the Judaeo-Christian tradition in which the body is conceived as a substance integrated into a wider totality, and not as an object possessed by the subject, which is a typical ideal of the modern tradition and the individualistic liberalism.⁶³ This is an important idea that questions the autonomist support. Here individuals “are not masters of their own life,” an issue that is very legible in this group of interviewees but that is contrary to the other considerations that disregard pain and heteronomy.

This study has some limitations. The interpretation of the participants’ experiences and perspectives was performed in a limited geographical area and time period; therefore, contextual information has been provided in the light of which the transferability of the results should be assessed. In addition, there is limited research in Colombia in this field; therefore, the findings contrasted with the international literature. Despite these limitations, this research found and furthered elements of contemporary medicine that act as structural problems for healthcare in general and for patients with cancer in particular. These problems must be compensated for by actions such as improving training programs in medical humanities from the undergraduate level; introducing patients’ preferences in health quality markers beyond their traditional and rhetorical use; assuming critical positions against the economism and organicism of medicine; assuming the therapeutic preferences of patients as a consubstantial part of healthcare; encouraging the development of research with relational approaches to autonomy and structure–agency connections in health; and incorporating the assessment of patients’ preferences in the guidelines for care and clinical practice.

Conclusion

The categories that emerged in this study illustrate the complexity and challenges of the preferences of patients with cancer in theoretical and experiential terms for social studies of medicine, philosophy, and bioethics. From medical social studies and social constructionism theories, it is emphasized that the experiences of dehumanization are constant in this context, which generates shared preferences in the patients related to the ideal of the medical professional; that is how the preferences that were called stable and the categories related to the attributes of healthcare professionals in their scientific and humanistic dimension emerged. From the philosophical perspective, the results of this study show that the care received by patients coincides with what was called medicine for slaves in ancient Greece, insofar as patients are not assumed to be free subjects. This is evident in the category that addresses the doctor–patient relationship. With respect to bioethics, some ideas are raised contrary to the support of individual autonomy; relational autonomy and the respect for the person above the autonomy itself are advocated. This was particularly important in the participants’ experiences that led to the category related to therapeutic goals and the subcategories on the extension of life and the quality of life.

Disclosure

The authors report no conflicts of interest for this work.

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