

Healthcare Inequities Experienced by Patients with Cancer: A Qualitative Study in Medellín, Colombia

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Purpose: This study aimed to understand the lived experiences of patients with cancer that facing inequities in oncological care in the city of Medellín.

Patients and Methods: A qualitative study was conducted based on the theoretical and methodological elements of the grounded theory, specifically the description and conceptual ordering of Corbin and Strauss. Sixteen patients with cancer, who belonged to low (n=5), middle (n=4) and high (n=7) social classes, were included by theoretical sampling with category saturation. Data were collected using semi-structured interviews and analyzed in a category system based on the three social classes.

Results: The patients were aged between 23 and 71 years old, and they were diagnosed with different types of cancer such as breast, cervical, prostate, stomach, leukemia and lymphoma. Patients' experiences showed that diagnosis, specialized care, treatment and hospital discharge were different based on their social class.

Conclusion: Patients' lived experiences associated with cancer reflect complex social situations, in which social determinants affect the level of citizens' empowerment and self-management against the risks of get disease and die. Being part of low and middle social classes meant being subjected to a dehumanized, cold, impersonal and discontinuous treatment, in which healthcare was focused on the disease instead of individuals' preferences and values. In contrast, patients belonging to the high class had the resources necessary to face risks, which ensured access to more humanized and individualized healthcare.

Keywords: cancer, health inequities, grounded theory

Introduction

Health inequities are systematic, unfair and avoidable differences among populations in terms of outcomes and health resource distribution. These emerge from differences in opportunities and social conditions in which individuals are born, grow, work and age, which may prevent them from attaining optimal health.^{1,2} The World Health Organization (WHO) describes two key types of causes behind health inequities: the first group includes intrapersonal, interpersonal and institutional mechanisms that result in differences based on race, gender, social class, sexual orientation and other aspects of individual and collective identity, whereas the second group includes social, economic, and environmental conditions that result in differences in terms of power, resources, goods and services distribution, which are referred to as social determinants of health.² WHO states that social determinants account for the structural inequities within a society, which are reflected in health inequities.³

In oncology, seminal studies about health inequities have focused on inequities associated with racial and ethnic factors, with subsequent evidence underscoring the importance that poverty and lack of social and medical infrastructure have for the unequal provision of health-care services, and for the obstacles to equitable care among patients with cancer.⁴ In this sense, a recent review on lung cancer reported that race and socioeconomic level are still two noteworthy factors that account for the different outcomes observed in patients. While monitoring patients based on their disease

stage, these differences are more evident because black patients of low socioeconomic level have worse outcomes.⁵ Moreover, a systematic review on racial and socioeconomic inequities in lung cancer screening tests in the US reported that black and low-income subjects miss out on the potential benefits of screening, resulting in more severe disease stages, and an increase in their mortality rates.⁶

The medical services network and healthcare quality have also been described as significant determinants of unequal access to oncological services.⁴ Other authors have reported inequities in the outcomes of patients with cancer by geographical region, but these are explained by the uneven distribution (or concentration in some areas) of radiotherapy centers.⁷ A systematic review of Canadian evidence showed the persistence of multiple inequities associated with oncological service access; the most relevant ones were the income, the age and the geography for accessing detection tests and end-of-life treatment and care.⁸

Overall, the scientific literature on health inequities, particularly in oncology, has a statistical or quantitative approach, applying different metrics to measure inequities in health outcomes. Qualitative or hermeneutic studies are scarce, they are classified by the Medical Subject Headings tool as research using non-numerical data to explore a research topic, as well as the art, theory and philosophy of interpreting the meaning of a text, a social action, other speaker's statements or other objects of the social research.

Regarding qualitative studies, a review of scientific literature on inequities in patients with endometrial cancer highlighted the lack of qualitative works to understand the perspective of black women diagnosed with this type of cancer.⁹ A qualitative study on advanced lung cancer reported that patients usually perceived late diagnosis as an inequity; moreover, it highlighted the importance of learning about relatives' perceptions because their care strategies are more pragmatic in terms of daily management and end-of-life care.¹⁰ Despite these and other previous studies, qualitative studies on the inequities in oncological care are rare in the world.

Specifically in Colombia, studies on health inequities in cancer patients have also been carried out from a quantitative approach, highlighting inequities in the survival of cancer patients related to the socioeconomic level and the type of health insurance.^{11–13} This last factor could be explained because the country has two main affiliation and service provision types or regimes: i) the contributory regime, for citizens under formal working conditions who can afford a monthly fee, and ii) the subsidized regime, for people in informal work conditions or unemployed, financed with a subsidy from the state and a proportion of the money paid by those affiliated to the contributory regime. In both regimes, private companies known as health promoting companies (EPS, for its Spanish acronym) act as administrators of healthcare plans. Individuals can access to voluntary plans (in addition to healthcare plans) paying extra money to get better health care, which include supplementary healthcare plans, prepaid medicine plans and policies. These characteristics of the different health regimens influence the experiences of patients in the treatment of their disease; however, there are not qualitative investigations in the country that show it.

This allows the suggestion that worldwide: i) in the study of inequities in patients with cancer predominates the quantitative approaches, ii) it has been focused on race, ethnics and socioeconomic level (mostly using economic income), iii) other studies have highlighted the importance of timely screening, diagnostic and treatment access, and iv) qualitative approaches are scarce. Little is known about the experiences of inequities in the healthcare of patients with cancer in Colombia because this country does not have qualitative studies on this subject.

Lived experience is a concept of phenomenological research that focuses on the interpretation of meanings, including the experiences that the subjects have gone through, but also interpretation, reinterpretation and communication into its enduring form. In this sense, the lived experience is not only something that is experienced but also the special impression that experience produces and that the subjects give it a lasting importance.^{14–17}

Therefore, the objective of this study is to understand the lived experiences of patients with cancer that facing inequities in oncological care services in the city of Medellín. This type of study is highly important because it helps to understand the sociocultural complexity of the process studied and its effects on the daily life of patients. It supports biomedical perspectives by providing studies that describe the importance of subjectivity and intersubjectivity as well as health protection and promotion, among other benefits. Specifically, the grounded theory proposed by Barney Glaser, Anselm Strauss and Juliet Corbin has some advantages as opposed to other qualitative methods, such as breaking with functionalist or structuralist theoretical schemes, following a rational approach in which conceptual orderings are

grounded by data collected during the research process, and articulating empirical research resources with conceptualization and theorization processes that stem from the experiences and lived experiences of social actors.¹⁴

Finally, this study also contributes to research areas that have been traditionally neglected in Colombia, such as medical anthropology and bioethical studies. Analyzing the lived experiences of patients with cancer means deciphering and interpreting subjectivity and its interaction with different social determinants, institutional rules and cultural beliefs, a topic that has been highly recognized by medical humanities as an annex to medical education, but which still occupies a marginal position in the professional practice of physicians.¹⁸ Moreover, focusing on the experiences of patients means being one step closer to providing them with a higher autonomy to confront their diseases, and this also contributes to the development of medicines that are more focused on the needs of patients.

Materials and Methods

Study Approach and Paradigm

A qualitative study was conducted based on the theoretical and methodological elements of Corbin and Strauss's grounded theory, specifically the description and conceptual ordering. The first one is defined as a narrative from the point of view of the affected (in this case, patients with cancer) to describe an event or experience, as well as any feelings and mental representations involved. The second one is the classification of narratives based on a selective and specified group of properties (characteristics that provide meaning to a category) and dimensions (variation scale of the properties that provide specificity and show variations of the study phenomenon). This study did not reach the third phase of the grounded theory (theorization), which is a group of well-developed and related concepts that conform to a conceptual framework used to explain or predict social phenomena,¹⁴ because the purpose of this study was to evidence inequities in the healthcare of patients with cancer (based on their lived experiences and experiences) and not to develop a theory about healthcare inequities in this group.

Context and Strategies to Ensure Reflexivity

During the second semester of 2020 and the first semester of 2021, the work field was approached in five phases: i) initial contact with institutions specialized in the healthcare of patients with cancer; ii) selection of suitable health-care professionals for the initial contact with patients and subsequent interviews (two psychologists were selected in this case); iii) initial contact with potential participants by the medical team; iv) initial conversations between patients and the psychologists in charge of field work to introduce the research project, answer patients' questions and explain the contents of informed consent; v) scheduling of dates and places so that participants are interviewed in a quiet, comfortable, private and safe place. Psychologists with prior experience in oncological patients were considered the best option to carry out the interviews because they ensure the correct application of the beneficence, justice, non-maleficence and autonomy principles from an ethical perspective. Moreover, given their education and professional experience, they would be better at managing different emotional or mental situations that could emerge during interviews.

Study Subjects

Theoretical sampling by category saturation was conducted. Theoretical sampling is defined as the collection of data guided by concepts emerging from participants' narratives, based on constant and iterative comparison, and with the purpose of identifying subjects or events that may maximize the possibilities of obtaining wider variations among those concepts that will conform to the results and obtain a detailed description of the phenomenon in terms of categories, properties and dimensions.¹⁴ The theoretical criteria that were taken into account to ensure variability in responses were: type of cancer, socioeconomic status, monthly income, educational level and occupation. The saturation is defined as the point in coding when no new codes occur in the data. There is a lot of information about the same codes, but no new codes appear. Saturation was reached with 16 patients. Inclusion criteria were: individuals older than 18 years of age, having received a confirmed diagnosis of cancer over the last 2 years and receiving treatment in Medellín. Exclusion criteria were: patients in a terminal disease stage or severe health state (they could not answer the interview).

Data Collection

Semi-structured interviews were conducted based on the following predetermined categories: lived experiences associated with access to oncological care (specialists and diagnostic aids), the ways in which oncological treatment took place, and conditions associated with hospital discharge ([Appendix 1](#)). It is important to clarify that the interviewer asks only a few predefined questions while the rest of the questions are spontaneous, according to the course of the conversation. All interviews were recorded in audio and/or video and written for their subsequent codification.

Interviews were supported by interviewees' sociodemographic and clinical data: gender, age, healthcare affiliation regime, type of cancer, socioeconomic stratum, monthly income, educational level and occupation. Based on the last four variables, subjects were grouped into three social classes: i) vulnerable or low-class population, consisting of subjects from low socioeconomic strata (1 and 2), with no income or a monthly income below the minimum wage (around USD 260), incomplete basic education and unemployed; ii) middle-class population, formed by subjects from middle socioeconomic strata (3 and 4), an income between one and three minimum monthly wages, having completed at least technical education and working in technical and professional middle-level areas; iii) high-class population, formed by individuals from high socioeconomic strata (5 and 6), with an income higher than three minimum monthly wages, complete university studies and whose professions were directors, executives, scientists or scholars. In this study, low-class participants were affiliated to the subsidized regime, middle-class participants were affiliated to the contributive regime and high-class participants had voluntary health-care plans.

Methodological Rigor Criteria

Application of credibility criteria was ensured by prolonged contact with patients; auditing (among researchers and by patients) of researchers' interpretations; transferability by a detailed description of the study context, participants and category system; and theory and research triangulation.¹⁹

Data Analysis

Transcribed interviews were codified independently by each researcher using codes previously determined for the central categories of the study, as well as emergent codes for subcategories, properties and dimensions (which were based on terms used by patients or obtained from the theoretical framework of the study). Subsequently, each codification was compared, and the categorical system to be used for the study results was unified (by consensus). For each category, the most significant narratives were selected to evidence health inequities, based on patients' lived experiences. Finally, the categorical system was plotted based on the three social classes, the three types of affiliation and the contents of each inequity-tracing category.

Results

A total of 16 patients aged between 23 and 71 years were interviewed. Their diseases included breast, cervical, prostate and stomach cancer, leukemia and lymphoma. Four patients were affiliated to the subsidized regime, six to the contributive regime and six had prepaid medical plans, policies or supplementary plans ([Table 1](#)). Based on their income, occupation and educational level, patients were classified into three social classes: low class, middle-class and high-class. The lived experiences of patients in terms of health-care services were divided into three phases: access to the system, treatment and hospital discharge.

Access to Health-Care Services

All patients were affiliated to the General Health Social Security System (SGSSS, for its Spanish acronym); however, their lived experiences with health-care providers reflected wide gaps in the opportunities enabling them to access a diagnosis along with specialized physicians. These gaps are reported by affiliation type and social class. Patients with prepaid medicine plans report having a timely access to basic and specialized services, highlighting short periods among procedures. They consider themselves privileged as opposed to other patients with a similar diagnosis or disease.

Table I Description of Participants' Characteristics

Code	Sex	Age (Years)	Type of Cancer	Social Class
M23LVS	Male	23	Lymphoma	Low
F33TMS	Female	33	Thyroid cancer	Low
F52SVS	Female	52	Breast cancer	Low
F53SVS	Female	53	Breast cancer	Low
F53CVC	Female	53	Cervical cancer	Low
M22EMC	Male	22	Stomach cancer	Middle
F51SMC	Female	51	Breast cancer	Middle
F55SMC	Female	55	Breast cancer	Middle
F71SMP	Female	71	Breast cancer	Middle
F26TAP	Female	26	Thyroid cancer	High
F27LAP	Female	27	Leukemia	High
F29LAC	Female	29	Lymphoma	High
F58TAP	Female	58	Thyroid cancer	High
F61LAP	Female	61	Leukemia	High
M61PAP	Male	61	Prostate cancer	High
M64PAC	Male	64	Prostate cancer	High

I consider myself as privileged not only because I'm a physician but also because I have access to healthcare by means of a policy, which facilitates everything. As a physician, you can see that this is not the case for other patients. I got tested on a Tuesday morning, and on Wednesday morning, I was already in the hospital doing all the other tests. On that same day, I underwent bone marrow aspiration. [F27LAP]

Patients affiliated to the contributive system, without a supplementary healthcare plan, reported heterogeneous narratives. However, the most common answer was associated with the ease of primary care and initial proceedings. Waiting time, both for specialist consultations and specialized tests, was one of the barriers faced by participants. As a strategy to overcome this barrier, patients pay the costs associated with tests and specialist consultations by themselves. Once cancer has been diagnosed, they contact the EPS for a second time; in this case, waiting times are shorter and healthcare is smoother.

I can't complain; the thing is that my daughter decided that, for the sake of time, it would be best to do everything privately, so as to reduce waiting times. My daughter asked for an appointment with the EPS, but the waiting times were extremely long, so we got a private appointment with a breast specialist. He examined me and confirmed that I had cancer. When we got everything, we contacted the EPS and continued with them. They scheduled my surgery and treatment in record time. [F55SMC]

On the other hand, patients affiliated to the subsidized regime belonging to the vulnerable social class agreed that EPS placed multiple barriers to health-care services, which included expiration dates in health service provider institution (IPS for its Spanish acronym) contracts, excessive administrative proceedings (such as authorization management), service fragmentation with different providers, limited availability of specialists and long waiting times between initial diagnosis and defined clinical management, as a consequence. As a result, patients begin legal proceedings and eventually access health-care services through a writ for the protection of their constitutional rights.

Terrible. It was terrible because it took them a year, almost a year, to schedule a surgery since I was first diagnosed with cancer. I had to request a right to petition. The EPS has been terrible; that's my opinion [...]. I even had to go to court and ask for a writ of protection. [F33TMS]

Besides the type of affiliation, the influence of social capital on health-care service access was also noted. This was particularly evident for the physicians included in this research because they knew people working in that field, and this situation created empathy among treating physicians, which made the healthcare process smoother. One of them reported the following:

Yes, since I am a physician the EPS acted quickly; everyone in the hospital did everything they could to ensure I was fine, that I was feeling well, that tests could be done quickly. I remember that the hematologist would say: I won't wait any longer to start chemo, because that's lost time and you're very young. I'm going to start chemo even if the EPS does not authorize it. [F29LAC]

Treatment

Regarding treatment, inequities were also observed with affiliation and social class, especially in the continuity of the patient–physician relationship and chemotherapy interruption. Patients with prepaid medicine can easily pick their doctors from a list sent by the provider; thus, any patient–physician relationship is broken, mainly because of the patient's choice after taking into consideration factors such as consultation opportunity, the perception of the physician's scientific competence, and humanistic attributes associated with the profession. Once patients find a physician that they like, treatment is continuous and uninterrupted.

I asked for an appointment with the physician who diagnosed me; as I had to wait 6 months because he was really busy, I scanned the list for another physician's policy. I found a physician who did the surgery and treated me. [M64PAC]

In patients affiliated to the contributive regime, physicians tend to change over treatment. However, this is not because of the same reasons described above, because constant changes and the subsequent deterioration of the patient–physician relationships are imposed by EPS. This instability and fragility of their relationship with the treating physicians generates uncertainty among patients, as well as anxiety, displeasure, anger and fear, which magnify their feelings caused by the disease, and worsen their mental-emotional health.

No, I haven't had the chance; since we are in a pandemic, this is the second telephonic examination. First, I saw a doctor, then I was told that I wouldn't be able to make an appointment with him so I had to see another one. I kept seeing that one and I was happy with him. Now I'm told that there's no appointments available with him, and that it will be another doctor who I see [...]. I was told that it would be her I would be seeing. Look at all these changes, there's never one permanent doctor. [F55SMC]

Patients affiliated to the subsidized regime reported deterioration in the patient–physician relationship and interruptions in chemotherapy. Chemotherapy interruption is a critical event that causes a risk to their life and worsens their physical and emotional health. The reasons for interruption were expiration of the EPS contract, lack of medications and suspension caused by accumulated EPS debts.

They were like a barrier at first; my chemotherapy was suspended many times because the EPS had not paid because the contract had expired. So I would start to cry and call everyone. Once, I saw the people of Teleantioquia [the main local TV channel in the city] and thought: 'I'll stand in front of them behind a window and make such a scandal that the press will see me, listen to me and pay attention to me.' I was desperate. I would call the superintendency of health and cry so that my treatment wouldn't stop. [F52SVS]

Another essential issue during treatment is the accompaniment by relatives and/or friends. Patients affiliated to the contributive regime, with or without policy, always attended medical consultations, surgical procedures and chemotherapy sessions with companions that helped them manage their feelings and travel from their homes to the hospital, and assisted them in case of body weakness or secondary effects. On the other hand, those affiliated to the subsidized regime and from the low social class could not be accompanied by economic reasons.

I have never been alone, one of my children would always be there for me. My son used to be with me when he was here; if he wasn't able, my daughter was. My wife would be with me when preparing for surgeries and stuff. [M61PAP]

Can you imagine yourself traveling every day to get radiotherapy for a month? I had to pay four tickets so as to get to the center. Every day, I paid four tickets. For this reason, I couldn't afford to go with a companion. [family income is not enough to cover the expenses associated with traveling from home to the hospital]. [F53SVS]

Hospital Discharge

During the period of hospital discharge and post-treatment care, considerable differences were also observed among the three groups. High-class patients affiliated to a prepaid medicine appreciate hospital discharge because their home is perceived as a place where the therapeutic effects are enhanced and is full of peace, quiet and distractions. In contrast, they consider that the hospitalization aggravates their disease. Following discharge, health-care professionals continually attend to these patients.

After 11 days in hospital, I asked all the physicians to let me go home since I'd get sicker locked in there ... they let me go home under the following conditions: I was to be locked in my room, everyone should wear a mask, and no-one could enter my room unless they were delivering food. I was happier just thinking that I'd be in my room, looking out of my window ... In my room, I watched You Tube, wrote and painted. After a week at home, I had to see the physicians again, who were amazed to see how well I felt and how boosted my defenses were. [F61LAP]

Some patients affiliated to the contributive regime felt deprivation and abandonment after hospital discharge. They attributed this situation to the cost-effective rationale that exists in medicine, the need to reduce hospital costs by some administrators, and a lack of compassion by health-care professionals. All this resulted in the ratification of misled ideas about the severity of their disease, whose relevance increased because of lack of communication and poor or no medical support.

After discharge, I felt deprived, I felt as if I had been abandoned. I had a total breakdown, because I'd say: 'mum how can I go home if here, with all the physicians and specialists around me, my pain won't stop. What am I going to do at home? I'll die in pain. Hospital discharge was sudden, it happened overnight, I was highly surprised. We panicked [...]. I think they say [at the hospital]: 'you're wasting money, occupying a bed that someone who can actually be saved can use, so let's discharge you.' In my case, as nothing could be done, hospital discharge was really like: 'go home until you die.' Support was really limited. [M22EMC]

Lastly, low-class patients affiliated to the subsidized regime reported the presence of stressing factors in their homes, interfering with sleep, calm and recovery. In their opinion, hospital is an appropriate place for their recovery, whereas they perceived their homes as a place that worsens the disease and impedes therapy success. As with patients affiliated to the contributive regime, post-treatment support was limited.

When I finished my fourth chemotherapy cycle, I left the clinic because I always had to stay in hospital for a week. I remember leaving the clinic and finding it really hard because that day there was a party next door. When you leave hospital in such a bad state, you need to rest. It was hard getting home and finding a party next door, since when you undergo chemo all you want to do is rest. The party lasted almost 2 days. [M23LVS]

All narratives were summarized in a category matrix showing how the differences in the healthcare of the study patients (specifically those related to access to healthcare and oncological diagnosis, treatment and hospital discharge) configure the health inequities perceived and experienced by patients, according to the type of healthcare affiliation, which is determined by the subjects' social class (Figure 1).

Discussion

Health inequities, particularly in patients with cancer, have been traditionally studied with quantitative methods, demonstrating differences in health outcomes (morbidity, mortality, disability, etc.) among different groups. Such groups are generally formed based on one or several health determinants such as race, ethnics, socioeconomic level, income or residency area.⁴⁻⁷ In spite of the relevance of this type of approach, there are several methodological challenges, which include: the risk of incorrect conceptualization or operativization of the construct that acts as a social determinant;

Structural determinant of social injustice			
Social class	Low class	Middle class	High class
Structural determinant of health injustice			
Healthcare affiliation	Subsidized regime	Contributive regime	Voluntary plans
Inequities perceived and lived by patients			
Access to specialists and diagnosis	Untimely care, segmented services, long waiting times	Timely initial care with associated costs and long waiting times	Timely and rapid initial care, no additional costs
Treatment	Physicians rotation, chemotherapy interruption and no family company	Physicians rotation, physicians appointed by the EPS, continuous treatment, family company	Election of physicians, patient's preferences, continuous treatment, family company
Home-based hospitalization Hospital discharge	Deprivation and abandonment, home worsens the disease, hospital as a quiet place for recovery	Deprivation and abandonment, administrators reducing costs associated with hospitalization	Discharge is cherished, based on patient's preferences, hospital as a stressing place, home as a place promoting recovery

Figure 1 Category system about the lived experiences of patients with cancer in Medellín, which show health inequities during the treatment of their disease.

implementation of epidemiological studies with a high risk of inferential fallacies such as ecological, atomistic, sociological or psychological fallacies; lack of articulation of individual, community or social measurements, etc. Moreover, inequities are a complex construct which can be difficult to describe by the means of reducing variables or statistical and epidemiological measurements.²⁰ For this reason, these classical epidemiology metrics should be transferred to qualitative studies, in order to move from statistical relations toward topics showing sociological, historical, economic, political or cultural determination of inequities in the healthcare of patients with cancer. Moreover, it is important to support quantitative-epidemiological findings with qualitative evidence, since the latter reflects experiences, perceptions and behavior patterns that define the acceptance or rejection of clinical acts; consolidate public policies requiring affected parties' opinion; improve social response toward health protection and care; and identify lines of action in health that are consistent with key actors' perspectives and lived experiences during the morbid process, among other benefits.²¹

Furthermore, traditional metrics do not always show intersectionalities associated with race, ethnics, gender, socio-economic level or other determinants of health inequity, which is somewhat relevant since the most affected groups generally show intersectionality. For example, black poor women living far from oncological centers are the most affected party when it comes to healthcare inequities.^{4–7} This highlights the importance of applying strategies that show the intersectionalities of these inequity determinants, since they account for inter- and intragroup differences, and show interactions and interrelations within inequity structures.²² In this sense, this study grouped subjects based on their social class, as a construct in which several inequity determinants converge, such as the socioeconomic status of the housing, monthly income, educational level and occupation, which, at the same time, converge into three types of health regime in Colombia. As a result, the intersectionality of these characteristics was evidenced, seeing low-stratum subjects with low income, low educational level, those who are unemployed and affiliated with the subsidized regime, experiencing the most inequitable situations (oncological care that does not meet their basic needs), which is the result of the multiple barriers to timely diagnosis and dignified specialized care, treatment, and discharge. This confirms the vicious circle formed by poverty, higher disease risks, barriers to timely healthcare, high chances of developing severe stages of the disease, increased risk of getting poorer because of the disease, among other feedback mechanisms (the perpetuation of poverty and disease) that evidence the importance of acting against cancer inequities and their socioeconomic determinants.^{23,24}

The Colombian government measures vulnerability with a score system based on which access to social welfare programs is determined.²⁵ In order to be part of the subsidized regime, subjects have to be within levels 1 and 2, that is, they have to be identified as part of a poor, vulnerable population. In this sense, some experts²⁶ have stated that values

supporting the Colombian public health system are consistent with “neoliberal governing styles”. Given the overcost issues experienced by welfare institutions all over the world during the 1970s,²⁷ especially in terms of medical care management, governments have applied formulas in which health is regarded as a tradable market good. The division between a contributive and a subsidized regime reflects a specific form of risk government in which individual safety and the inclusion of focalization programs are promoted.²⁸ This is a form of governing over uncertainty, based on an individualistic understanding of society in which subjects have to “take care of themselves”.

Focalization policies proposed by the neoliberal development model, seeking to compensate individuals and human groups left aside by market competition, are part of this utilitarian theory of justice which aims to maximize welfare at the expense of these relegated individuals and human groups.²⁹

This highlights the complexity of WHO’s concept of health inequity and some limitations of quantitative approaches. At the same time, it shows the importance of giving back to the patients’ voices, since their experiences and lived experiences can help compensate for the complexities and limitations mentioned above. This is done by evidencing that their diagnostic, specialized care, treatment and hospital discharge processes are inequitable from the affected parties’ point of view, who are at the center of clinical-epidemiological actions and public management. This study shows that social inequities create three extremely different pictures in terms of patients’ interactions and lived experiences with the SGSSS: for low-class patients, healthcare is experienced as a limited, precarious process, subject to multiple administrative uncertainties. Middle-class participants experience medical care in a dehumanized and impersonal way, an additional burden for patients and their family. Finally, high-class participants reap the benefits of a patient-centered medicine.

Inequities Associated with Access to Specialized Medical Care and Diagnosis

In this study, vulnerable-class participants affiliated to the subsidized health system reported the worst conditions in terms of access to an oncologist and different diagnostic aids, highlighting untimely, segmented care, with long waiting times. On the other hand, those belonging to the middle-class (and affiliated to the contributive regime) received timely care but had to pay high costs and experience longer waiting times. This was not reported for high-class patients who were affiliated to supplementary health-care plans and additional policies. This is consistent with other quantitative studies that have described poverty or low income,^{4,6,8} the lack of medical infrastructure,⁴ unequal distribution of treatment centers (which would be the equivalent to the concentration of certain services for patients with health policies),⁷ poor quality of care,⁴ costs associated with diagnostic aids, additional therapies, transport, palliative care services,³⁰ type of health insurance and socioeconomic status as the main inequity determinants in patients with cancer.¹¹

On the other hand, our results differ from what is reported by Colombian health authorities, which state that the average waiting time for specialized care is 4.9, 9.8 and 3.1 for patients affiliated to the subsidized regime, the contributive regime and a prepaid plan, respectively, although no oncological data is reported. In this sense, studies suggest that the median waiting time for diagnosis and treatment initiation in breast patients with cancer is 91 days from the first consultation to the actual diagnosis and 137 days before treatment initiation. Diagnostic and treatment initiation times are shorter for women with higher educational levels and those affiliated to special social security regimes and in a better socioeconomic situation.³¹ Furthermore, health authorities state that coverage has increased from 29.2% in 1995 to 97.8% in 2020,³² which basically would mean universal coverage. However, the WHO commission of social determinants described coverage as:

when every inhabitant of a country can access the same service offer (of good quality) based on their needs and preferences, regardless of their income level, social stratum, residency or capacity.

For this reason, based on participants’ narratives, it can be said that there is no universal health coverage in Colombia and, for the time being, we are far from achieving it.³³

Consistently with the afore mentioned, there has been clear and significant advances in terms of the legal configuration of the Colombian health system. However, these legal securities are not transferred to the population entitled to those rights, as evidenced by the narratives included in this study, particularly the ones by low- and middle-class

subjects. In this sense, it is worth mentioning that the right to healthcare in Colombia has gone through several phases: firstly it was considered to be a mere labor benefit right; secondly, as both a constitutional and aid right; thirdly, as a constitutional right on the basis of connection, a constitutional right connected with certain populations (elderly, disabled and displaced individuals), a constitutional right connected with the contents of the Mandatory Health Plan and, finally, as a constitutional right per se, although aside from these legal considerations, users still consider it to be a labor benefit right or a right connected with other fundamental rights.³⁴ This is consistent with the reports of this research, in which the administrative perspective prevails in healthcare, increasing patients' burdens, who have to treat their disease and face a complex system, mainly by writ for the protection of their constitutional rights and other resources, in order to receive timely care. In this sense, oncological care should be the right to healthcare applied as a constitutional right per se,

since it is universal, non-waivable, inherent to the human person, integral and integrative, essential for the materialization of a dignified and good quality life, and crucial to ensure that the material equity principle is actually efficient.³⁴

Inequities Experienced During Oncological Treatment

Among low-class patients affiliated to the subsidized regime, treatment was characterized by high physician turnover, chemotherapy interruption and lack of family support. Middle-class patients affiliated to the contributive regime experience physician replacement, although their treatments are not interrupted, and they are accompanied by their relatives. Finally, high-class patients can choose their physicians, their preferences are taken into consideration, treatment is uninterrupted, and they are highly supported by their families. Initially, it is worth mentioning that these findings are hard to compare with prior scientific literature, since qualitative studies in this field are scarce, and quantitative studies have mainly pointed at access to screening tests, detection tests, and initial care as main inequity issues,^{4–8} but have not studied the course of treatment in depth.

It is also difficult to compare our findings with Colombian scientific literature, since the available data describes inequities associated with access by means of quantitative approaches, that are focused on serious patient outcomes such as survival, and not on treatment course. In this sense, statistically significant differences in the survival of patients with breast, lung, prostate and stomach cancer have been documented, based on their health affiliation regime as being worse among those insured individuals or individuals affiliated to the subsidized system. Differences in the survival of patients with lung and prostate cancer have also been reported based on the housing's socioeconomic stratum. In the case of the affiliation regime and socioeconomic stratum, authors suggest that the inequities found may be explained by greater underlying comorbidities, late diagnosis or barriers to timely and effective treatment.¹¹ Moreover, regarding cervical cancer, women affiliated to the contributive and special regime report lower mortality rates than those affiliated to the subsidized system or those who are uninsured. A higher risk of death is also observed among young women with low educational level.³⁵

This evidences that inequities during the course of treatment, such as chemotherapy interruption, changes in treating and follow-up physicians, family support and accompaniment during oncological treatment and being able to involve patients' preferences during this stage of their disease are unprecedented lines for the study of oncology inequities. The lack of studies analyzing these and other inequity determinants during treatment may suggest the following important issues:

- (i) Researchers and institutions interested in this field assume that, once the patient has been diagnosed and treatment has started, the process is consistent and the patient ends treatment with no setbacks, which is not the case for Colombia, in which the insurance model (except for voluntary plans) leads to healthcare segmentation and incoordination, where market rationale prevails and cost reduction is emphasized, also a lack of interest on therapeutic success and the patients' wellbeing is observed by the administrators of these benefit plans.
- (ii) The health social security system does not have adequate information systems for the surveillance and assessment of the treatment phase, since patient records are not entered into a centralized system, but are part of each healthcare institution. This segmentation of data may challenge the study of inequities in the treatment phase.

- (iii) The health system has perverse and lawless incentives for benefit plan administrators, so the latter have to apply economic strategies such as reducing costs to maximize profit and permanently changing health service providers and medicinal product suppliers, which affect patients who cannot access voluntary plans.
- (iv) Clinical history is not usually conducted in a comprehensive manner because among other reasons consultation times are short, which would account for the absence of relevant variables over the course of treatment described in the few studies available in Colombia.

Finally, the fact that the low-class subjects included in this study needed a legal mechanism to protect their rights, such as the writ for the protection of their constitutional rights, is consistent with the report by the Colombian office of public defense, which stated, for the fifth time in a row, that patients with cancer filed the highest requests for these writs. Pharmacy claims accounted for 12.6% of cases, which is a 37.7% increase between 2018 and 2019. Although the report reflects that the amount of writs filed by subjects affiliated to the contributive and subsidized system is similar,¹¹ the impact on low-class subjects is higher because of the following reasons: i) their economic capital is smaller, so their chances of accessing these services with their own resources, traveling from one IPS to another and traveling to and from different judiciary and health institutions are smaller; ii) their social capital is smaller, so their chances of socializing with people within the health system (physicians, administrators, managers) and/or the legal system (lawyers, judges, representatives) who can help them are smaller; and iii) their cultural capital is smaller, so they are not familiar with the constitutional mechanisms and control organisms (such as the national superintendency of health) that can help them protect their rights.³⁶

Health Inequities Experienced at the Time of Hospital Discharge

After hospital discharge, low-class patients feel deprived and abandoned by health-care providers and they perceived their homes to be an additional burden for their disease and the hospital a quiet place in which they would get better. Middle-class patients also felt deprivation and abandonment, since they felt that administrators did not care about their wellbeing but about reducing costs. Finally, high-class patients experience hospital discharge with satisfaction, since their homes are suitable for recovery. As is the case for the treatment phase, our findings cannot be compared with other reports since the available Colombian studies do not address aspects related to the discharge phase.^{11,31,35,37} Moreover, in international studies, the privileges resulting from these inequities are associated with survival or other serious outcomes.^{5,6,8,11}

However, the results of this study are consistent with the findings of a mixed study about the degrees of satisfaction by patients with cancer, in which affected subjects note the importance that their physical and emotional needs are met, respectful treatment is given, and the daily requirements secondary to cancer and its treatment associated with pain, fatigue and depression³⁸ are met. In cervical cancer, health system and social factors have proven more relevant than biological-individual factors when compensating health inequities.³² Overall, access to good quality healthcare and a satisfactory discharge after treatment reflect the overlying of social, historical and environmental factors that affect patients' environment and life experiences.³⁹

It was observed that family represented an additional burden for low-class patients, since these subjects do not live in supporting and quiet places. For this reason, hospital is considered a quiet place in which they can recover. It is important to highlight that the family aspect has generally been studied based on psychological theories of social support, and there exists hardly any research developed explaining the sociological or economic aspects of this situation. In this sense, a study about the importance of home for patients with advanced cancer and economic difficulties reported that their caregivers usually have limited resources and opportunities to look after themselves and their patient, which would increase the severity of patients' situation.⁴⁰

It is important to remember that WHO defines health as "a state of complete physical, mental and social wellbeing, and not just the lack of affections or diseases".⁴¹ For this reason, the healthcare of oncological patients should go beyond hospital and expand into the family and social context in which patients live. This expansion cannot depend, either operatively or financially, on the health system alone; other administrative government departments should also intervene, since health is not the result but the reflection of inequities, and no health system in the world would be able to fight on its own against the structural inequities of a population.

On the other hand, structural inequities, their reproduction into health inequities and their reflection onto housing such as the ones described by the participants of this study show that inequities are not only reflected in the health outcomes traditionally studied within the clinical-epidemiological field (morbidity, mortality, etc.); they exacerbate other traditionally non-studied effects, such as the feeling of abandonment and deprivation. Based on this, we can suggest that inequities associated with care, treatment and hospital discharge need to be considered so as to increase patients' survival and reduce the psychic and social burdens associated with such inequities. Although the categories "abandonment" and "deprivation" are not included in the health inequities field, scientific literature about cancer does include dehumanization, which can be interpreted in different ways, such as a malaise aside from the burden of the disease, "cold" interactions with institutions and care staff, objectification of the body by the medical staff, a sort of elimination of a person's dignity, a medicalization of a patient's identity, and being treated like an object, among other factors contributing to the deprivation and abandonment narratives of this study. These topics should be prioritized when studying oncological care inequities.^{42–45}

To summarize, this third axis of oncological care inequities becomes relevant since it shows unusual situations associated with hospital discharge, which reflect the convergence of healthcare and structural problems such as the ones mentioned by low-class patients, who do not live in a place that fosters their recovery and who consider the hospital as the best place for this, which is why they refer to hospital discharge as a process that does not value their dignity or identity, since their health and wellbeing seem to be ignored.

Limitations

The main limitations of this study are the fact that the population is institutionalized, so results cannot be extrapolated to oncological patients that have not been admitted by healthcare institutions. Moreover, it is worth mentioning that language does not fully reflect experience, since narratives are the result of experience, reflection and interpretation, and they depend on the subjects' background culture. In other words, language always has individual and group elements, and is the narration of one's own experience articulated along with others' experience.^{15–17} As a consequence, even though the lived experiences of this study reflect patients' individual constructions of healthcare, we should bear in mind that any lived experience reported can be influenced by the subject's structural or social aspects, so patients' characteristics should be emphasized when transferring the findings of this study.

Conclusion

In this study, patients with cancer' lived experiences reflect inconsistencies and disagreements between both legal and constitutional apparatus and the development of effective mechanisms allowing low-class populations to manage all the adverse situations that are limiting their daily lives.

The experiences narrated by our study participants show a series of obstacles and problematic events that determine the way in which they manage a complex disease situation. This reflects the considerable obstacles posed by the Colombian government structures, which should provide citizens with the necessary means to solve any difficulty affecting their wellbeing and interests. Despite the presence of several constitutional provisions the neoliberal government styles of risk that govern the Colombian social security system do not seem to be effective enough, and they do not allow low-class citizens to overcome a series of social determinants that condemn them to precarious situations in which they feel abandoned. In other words, patients' lived experiences and experiences associated with cancer reflect complex social situations, in which social determinants affect the level of citizens' empowerment and self-management against the risks of disease and death. Being part of low and middle social classes means being subject to a dehumanized, cold, impersonal and discontinuous context, in which patients are regarded as sick entities and healthcare is obviously focused on the disease instead of individuals' preferences and values. On the other hand, patients belonging to the high-class have the necessary resources to face risks, which ensures access to more humanized and individualized healthcare.

Data Sharing Statement

Data has not been deposited in a public repository. Anonymised data is available on reasonable request to Luis Felipe Higuita Gutiérrez e-mail: luis.higuita@campusucc.edu.co.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the Declaration of Helsinki, resolution no. 8430 by the Colombian Ministry of Health, and the ethics, bioethics and scientific integrity policy for Colombia promoted by Colciencias (currently the Ministry of Science, Technology and Innovation). Informed consent was obtained and recorded in audio and/or video for all participants. The participants informed consent included publication of anonymized responses. Procedures were authorized by the bioethics subcommittee of Universidad Cooperativa de Colombia, under record no. 027-2020.

Acknowledgments

We gratefully acknowledge the contributions of all our participants who took the time to share their stories with us.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This study was supported by the Universidad Cooperativa de Colombia.

Disclosure

The authors declared no potential conflicts of interest with respect to the research and publication of this article.

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