

Oncologists' perspectives on patients' autonomy within advance care planning in Mexico City

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Abstract

Background: Patients' autonomy (PA) and advance care planning (ACP) are cardinal features within the doctor–patient relationship. Nonetheless, little is known in Mexico about oncologists' perspectives on these issues. **Objectives:** To explore the roles and responsibilities medical oncologists working in Mexico City perceive themselves as having when discussing and implementing ACP, supporting PA, and the challenges they encounter on these issues in their practice. **Methods:** Qualitative, semi-structured, in-depth interviews with 10 oncologists working in Mexico City. A thematic analysis approach was used for interpreting interviews. **Results:** Paternalism has an influence in and beyond the medical field in Mexico, and so it may be better understood as a cultural script. Further, ACP is mainly understood as end-of-life care planning, and the concept of relational autonomy is almost unknown. Health system fragmentation and a lack of communication skills are identified as additional obstacles. **Conclusion:** To narrow the gap between theory and practice, it is important to develop a consensus over ACP's definition, aims, and scope. Finally, it is important to understand better how Mexican paternalism, as a cultural script, reinforces the paternalistic model of care, which limits PA.

Keywords: Advance care planning. Patient autonomy. Relational autonomy. Paternalism.

Perspectivas de los oncólogos sobre la autonomía de los pacientes dentro de la planificación anticipada de la atención en la Ciudad de México

Resumen

Antecedentes: La autonomía del paciente y la planeación anticipada del cuidado son fundamentales para la relación médico-paciente. Sin embargo, poco se conoce en México sobre la perspectiva de los oncólogos en estos temas. **Objetivos:** Explorar la perspectiva de oncólogos médicos sobre su papel y responsabilidad en la planeación anticipada del cuidado, considerando la autonomía del paciente y los retos que enfrentan en su práctica clínica. **Método:** Se realizaron entrevistas semiestructuradas y en profundidad a 10 oncólogos médicos que ejercen en Ciudad de México. Para su interpretación cualitativa se llevó a cabo un análisis temático. **Resultados:** El paternalismo en México rebasa el campo médico y constituye un patrón cultural. Asimismo, la planeación anticipada del cuidado se entiende fundamentalmente como planeación del final de la vida y el concepto de autonomía relacional es poco conocido. La falta de habilidades de comunicación y la fragmentación del sistema de salud se identificaron como obstáculos adicionales. **Conclusión:** Para cerrar la brecha existente entre teoría y práctica, es importante consensar la definición, objetivos y alcance de la planeación anticipada del cuidado. Finalmente, es necesario profundizar en cómo el paternalismo, como rasgo cultural, refuerza el paternalismo médico, limitando la autonomía del paciente.

Palabras clave: Planeación anticipada del cuidado. Autonomía del paciente. Autonomía relacional. Paternalismo.

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Introduction

Cancer patients endure physical, psychosocial, and spiritual issues that need to be addressed through open and honest doctor-patient communication¹. Moreover, the need to individualize patients' care and the increase in medical interventions in both number and complexity are some of the reasons why it is important to understand the best way of discussing and documenting patients' care planning². Thus, the doctor-patient relationship is as complex as it is fundamental for patients' experiences with cancer. Two cardinal features of this relationship are respect for patient autonomy (PA), understood as the right that autonomous agents have to make decisions aligned with their values³, and advance care planning (ACP), the process of documenting patients' decisions and preferences along their entire illness trajectory⁴⁻⁶. Further, these decisions are informed by individuals' sociocultural backgrounds^{7,8}. Consequently, it is important to acknowledge the interconnections present between these two concepts-PA and ACP-because how patients and doctors conceptualize autonomy affects how they approach the discussion and implementation of ACP⁹.

The concept of PA has gained popularity and has increasingly informed health policies; however, it has also been considered individualistic and narrow^{9,10}. Further, although it is often taken for granted in theory and policy, it differs from what actually happens in the clinical field. When institutional values or doctors' personal values vary from those of the patient, such autonomy may be restricted¹¹. Furthermore, doctors may avoid disclosing information to their patients because they lack the training and support needed to engage in ACP conversations¹². Despite ACP aiming to respect patients' autonomy (PA), enhance their quality of life, and avoid overtreatment¹³, it is not regularly practiced^{14,15}. Research shows that ACP poses specific challenges for oncologists, such as uncertainty over when to start ACP conversations¹⁶, their fear of damaging their relationship with patients, their drive to save lives, and the complexity present in prognostication^{17,18}. Other challenges include the insidious biomedical model of care, applied even when treatments become futile¹⁹, misunderstandings of what ACP is^{20,21}, and the subjectivity present in assessing the patient's capacity for agency⁹. Altogether, these prevent ACP conversations from taking place²².

Overall, different patients' and doctors' perspectives on autonomy lead to diverse stances that may be viewed as part of a continuum: at one extreme lies a

paternalistic model of care grounded in the doctor's authority, and at the other, an individualistic model of care grounded in the patient's autonomy. Between both extremes, a shared-decision approach known as relational autonomy (RA) is gaining attention. This approach aims to create a space to share sociocultural values and views, facilitate the patient's decision-making, and help them cope with their identity as patients^{23,24}. Within a relational approach, both patients' desires and beliefs, as well as doctors' expertise, are acknowledged¹³. Yet, there is a lack of consensus on the meaning and scope of RA⁸.

Mexican medical scholars hold differing views on where Mexico lies on the paternalistic-individualistic continuum of care models. Some suggest that the paradigm in Mexico is shifting from a paternalistic to an autonomous model of care²⁵, while others claim that paternalism is prevalent within the traditionally unbalanced doctor-patient power relationship²⁶⁻²⁸. This article explores Mexican oncologists' perspectives about PA within ACP discussions, with particular attention to the influence of medical and cultural paternalism.

Methods

A purposive sample of twelve oncologists who practice medical oncology in Mexico City, in two tertiary public hospitals and two private hospitals, were invited, and ten accepted to participate (the other 2 did not respond to the invitation) (Table 1). Participants received a plain language form, a consent form, and a privacy note. They were interviewed as individuals, not as representatives of any institution or employer. The inclusion criteria were as follows: (a) being a medical oncologist practicing in Mexico City and (b) treating adult patients (those aged 18 years or more). The interviews took place from April 10 to May 24, 2023. Each interview lasted between 30 and 45 min. An audio recording of the interviews was made, and notes were taken as necessary. Eight interviews took place face-to-face, at each participant's workplace, and two were conducted through Zoom. I transcribed them verbatim as the only researcher involved in this project. The interviews were semistructured, with open-ended questions that gave the participants the opportunity to communicate their views and opinions as comprehensively as possible. The interview guide is provided in table 2. The consolidated criteria for reporting qualitative study guidelines were considered.

Thematic analysis using Braun and Clark's framework²⁹ was used to analyze and interpret the data, complimented with an abductive perspective to gain the flexibility needed to engage with findings within the

Table 1. Participants

Participant ID	Gender	Years of experience	Public practice	Private practice	Recruitment
Dr. 1	Male	38	Yes	Yes	Direct contact
Dr. 2	Male	21	Yes	Yes	Direct contact
Dr. 3	Female	19	Yes	Yes	Snowball
Dr. 4	Male	11	Yes	Yes	Direct contact
Dr. 5	Female	23	Yes	Yes	Direct contact
Dr. 6	Male	1	No	Yes	Snowball
Dr. 7	Male	7	No	Yes	Snowball
Dr. 8	Male	6	Yes	Yes	Direct contact
Dr. 9	Female	15	No	Yes	Snowball
Dr. 10	Female	19	Yes	No	Direct contact

Table 2. Interview template

1	How often does a patient discuss, initiate, or ask you any issue related to advance care planning? Could you tell me more about this?
2	What role or responsibility do you have as an oncologist in supporting and implementing a patient's advance care planning?
3	What does the principle of patient autonomy mean to you?
4	What is your opinion on relational autonomy?
5	Can you identify any barriers or obstacles to addressing the issue of advance care planning with your patients? If so, can you tell me more about this?
6	Would you like to add anything else?

data as well as consider existing theoretical approaches to the phenomena under study³⁰. The analytical process required me to be aware of my previous knowledge of the phenomena under study and of my personal assumptions and experiences within oncology as a psychologist who has worked with cancer patients for 30 years. The process began with an immersive reading and coding process. Then, the coding phase resulted in clusters of codes. The interpretation and theme generation required the author to engage actively to ensure, to the best of her ability, that the study's aims would be answered in a consistent and coherent way. A code book, reflexive journal, and presentation of draft themes helped to ensure analytical robustness.

After three preliminary drafts, a final thematic map was developed. The analytical process resulted in the

generation of three themes and eight subthemes (Fig. 1). Direct quotations from the participants and relevant literature support each theme.

Ethics

This study has obtained clearance from the University of Glasgow Ethics Committee, application no. CSS SIS 2022038, and it was considered to have a low risk for participants. All participants received the consent form, the plain language form, and the privacy note attached to the invitation.

Findings and discussion

Theme 1: patients understand and act on their autonomy differently

Participants asserted that patients rarely initiate an ACP conversation, and they described how patients understood and acted on this right differently.

PATIENTS WHO KNOW THEY ARE AUTONOMOUS

Most participants described a small group of patients who understand their medical condition, ask the oncologist for the specifics they need, and make their own decisions when ready.

"I provide them with the information related to the disease, the different options they have. They analyze the data and communicate their decision" (Dr. 1).

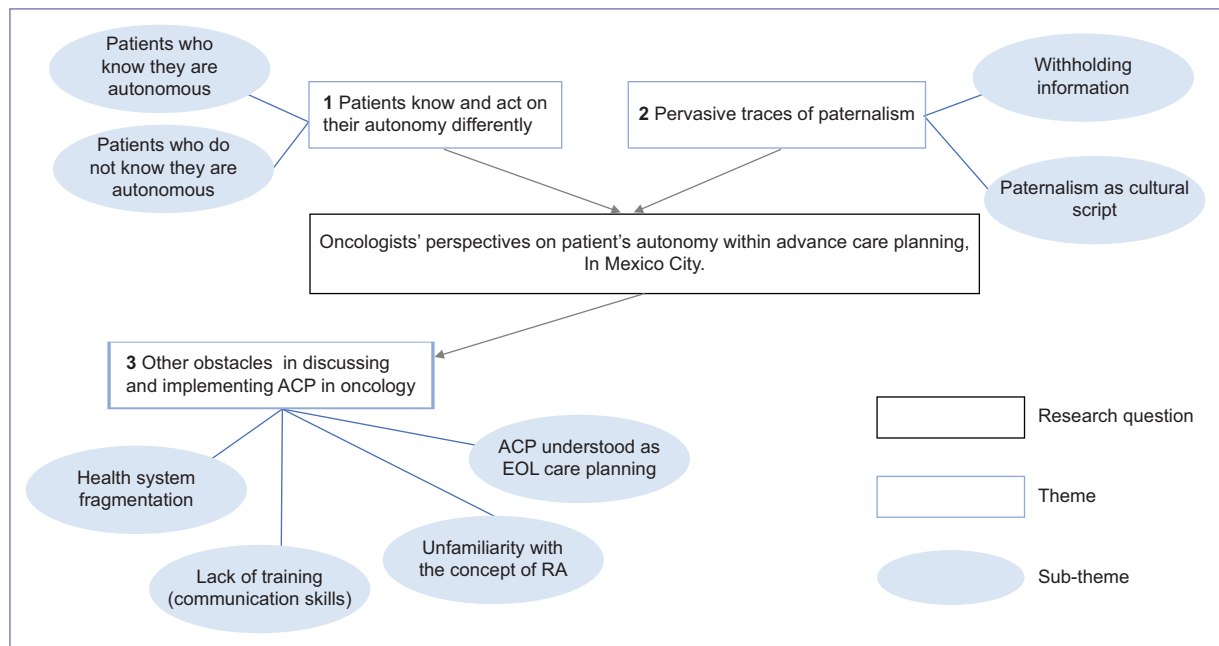


Figure 1. Thematic map.

At the same time, participants described most patients within this “autonomous” group as still wanting the oncologist to make the decisions for them. In other words, the patient knows that they are autonomous, are well-informed about the treatment choices they have, and are aware of the possible benefits and hazards. Yet, they still delegate treatment decisions to the oncologist.

“Patients fear making a wrong decision, even if I tell them all options are good. They do not want to be burdened with this responsibility” (Dr. 8).

While some participants feel comfortable with this stance, others feel compelled to embark on longer or different explanations intended to empower patients, so the patients feel confident enough to make their own choices.

“I give the patients the information and explanations they need... They are the ones who should decide; not me, ever” (Dr. 2).

PATIENTS WHO ARE NOT AWARE OF THEIR AUTONOMY

Participants also described patients who do not recognize themselves as autonomous agents. Further, some interviewees mentioned that they believe these patients have never acted with autonomy in their wider familial and sociocultural contexts. It also seems that

patients’ passive attitude also relates to the belief that doctors hold the power²⁷.

“They have lived subjugated by their family, and they do not express any opinion or take any decisions about the care they want (or not) to receive” (Dr. 8).

“The truth is that most patients want us (oncologists) to decide for them” (Dr. 9).

Interviewees reacted differently to the patients’ passive role. While some showed a sort of conformity, others disputed the status quo and argued it was part of their role and responsibility to support patients so they felt comfortable exercising their autonomy.

“They do not necessarily come to me knowing they are autonomous agents... We need to... let them know... they have the right to make decisions about the care they want to receive” (Dr. 4).

This dichotomy in perspectives leads us to the next theme, which describes how oncologists’ sociocultural contexts and beliefs are in constant interplay with those of patients, and they impact how they appraise PA.

Theme 2: pervasive traces of paternalism

Most participants’ narratives suggested that in Mexico City, some medical paternalistic traits remain present in oncology. Some participants found leaving out any trace of paternalism to be challenging; some may

not be fully aware of this or do not find it easy to recognize this trait openly. These findings support the idea that some internalized presuppositions remain about overprotective doctors' roles toward their patients in Mexico²⁷.

WITHHOLDING INFORMATION

Some interviewees expressed the need to hold back information about the fine details of the treatment, often using the third person plural, saying things such as "doctors sometimes withhold information from patients," although they were clearly referring to their own struggle over deciding how much information they should disclose to their patients. This evidences the tension between what medical best practices say about truth telling and the need some doctors feel to withhold information they consider may be too difficult. Concealment of some of the challenging aspects of prognosis or treatments seems to be rooted in an internalized mandate to protect the patient. Previous studies have found that the more paternalistic the doctor is, the less willing they are to disclose information to the patient²⁶. At the same time, this may also be another consequence of medicalization and the increasing complexity that oncologists face in making prognoses and appropriate benefit-risk evaluations for treatments, which might lead to iatrogenic harm¹⁵.

"Oncological treatments may have detrimental consequences for the quality of life... Patients sometimes receive unnecessary treatments" (Dr. 5).

Participants' perspectives also offered some clues about the concerns oncologists have about patients' capacity to endure bad news or to understand complex information. While it is important to assess an agent's capacity, the dilemma is over how objectively oncologists evaluate patients' understandings and perceptions¹⁰. There are those who think most patients are not capable of making decisions as fully autonomous agents, and there are those who believe most patients are fully capable after the patient becomes well informed. As one doctor described:

"We sometimes underestimate the patients' capacity for agency" (Dr. 10).

This supports the argument of how doctors' own understanding of what is good sometimes trumps the patients' values and preferences¹². Thus, if the patient is not fully informed before consenting, the consent cannot be interpreted as fully autonomous, no matter how good the oncologist's intentions are.

Further, some participants argued that full disclosure is important because there are patients who are determined to try if the possibility of living longer remains, even if a high risk of enduring adverse effects or disability is present.

"There are patients who accept treatments that offer very slim chances of benefits because hoping is a qualitative, not a quantitative, perspective" (Dr. 1).

Finally, some oncologists reported that they withheld some information from their patients due to a lack of training and support necessary to engage in these conversations.

PATERNALISM AS A CULTURAL SCRIPT

Factors such as gender, class, ethnicity, education, economics, and culture are associated with different understandings of the individual's personal agency. One finding of this study is evidence of how Mexican paternalism is rooted in social norms that go beyond the medical field. Paternalism appears to be reinforced at the microlevel (individual and familial), mesolevel (communal and institutional), and macrolevel (societal, political, and systemic) social systems. In Mexican culture, it is common for people to conform to what societal norms dictate of them, which traditionally has been a hierarchal, family-focused, and conservative religious world view³¹.

"There are patients who expect their families to take the decisions for them. They have never been autonomous" (Dr. 3).

Paternalism, viewed as a sociocultural Mexican trait, may explain the difficulties some oncologists experience in moving away from this paternalistic model of care. In addition, some oncologists view respecting autonomous patients' choices as challenging another principle, beneficence, which implies the duty to act in the patient's best interest³. Thus, when the doctor perceives these two principles in conflict, the ubiquity of certain paternalistic traces becomes evident. Paternalism in medicine is still present, at least in part, because there are patients who believe in the exceptional power of the doctor and because they also value obedience in their interactions with the doctor^{27,32}.

"Many patients expect a paternalistic bond with the oncologist... Discussion about decision-making is out of their expectations" (Dr. 6).

Nevertheless, the decision-making process is always informed by the patients' sociocultural contexts⁶. Further, doctors' personal sociocultural contexts also

influence how they approach their patients in the decision-making process^{7,11}.

“There are oncologists who feel totally free to decide for their patients without being aware of their paternalistic and arbitrary decisions” (Dr. 9).

Overall, the study findings show modest changes in the paradigm, from paternalistic and frequently arbitrary practices to heightened awareness of the benefits of a shared-decision model of care and sensitivity to the spectrum of paternalistic, relational, and autonomist perspectives. These findings align with those who argue there is a progressive change from paternalism to a model of care in which the patient’s RA is at the forefront of the doctor-patient relationship²⁵.

Theme 3: other obstacles in discussing and implementing ACP in oncology

WHO IS THE DOCTOR OF WHOM? HEALTH SYSTEM FRAGMENTATION

Research has shown that fragmentation in the Mexico health system provokes inefficiencies and care inequities. Fragmentation also makes it harder for vulnerable populations to navigate the system, which leaves many of them without the care they need³³. Patients are frequently treated by different oncologists along their illness trajectory, which makes it difficult for doctor-patient bonds to form or to ensure continuity of care. Furthermore, system fragmentation supports oncologists’ divestment of responsibility when discussing ACP with their patients.

“It is not possible to make bonds; you have many patients, they see different doctors, and there is no time” (Dr. 7).

Furthermore, for ACP to be successful, it needs to be viewed as a process that ideally begins with diagnoses and lasts for the whole illness trajectory, potentially evolving over time^{5,16}.

“ACP requires us to make pauses to talk and plan. The patients may wish for something... and then things change, and their wishes might also change” (Dr. 6).

THE LACK OF TRAINING IN DOCTOR-PATIENT COMMUNICATION

Participants asserted that neither their medical school nor their medical residency prepared them to engage in ACP conversations.

“We need... better skills to communicate sensitive information” (Dr. 3).

Some participants shared that they have created their own communicative style through experience, inspired by mentors and colleagues. Some of them described their own active efforts to improve their communication skills through self-learning activities.

“I learned communication strategies abroad. In Mexico, we do it badly” (Dr. 2).

This persistent gap of capacity in Mexico is worrisome, as this lack of skills threatens the wellbeing of all the actors involved – doctors, patients, families, and all members of the health team, and it has been extensively documented in the medical literature^{12,15}.

ACP UNDERSTOOD AS END-OF-LIFE (EOL) CARE PLANNING

Interestingly, most participants understand ACP narrowly as EOL care planning. When asked about how oncologists understand PA within the context of ACP, their responses focused on issues related to the late stages of the cancer trajectory. In particular, they referred to the challenges they find in facilitating the patient’s transition to palliative care. Further, some interviewees interpreted advance directives (ADs) as synonymous with ACP.

“I think this is not exactly part of the oncologists’ role... cancer patients, especially those with a metastatic condition, are referred to a psychologist... to help them complete their ADs” (Dr. 2).

This last excerpt is an example of the existing confusion over ADs and ACP in Mexico²⁰. While ADs focus primarily on EOL issues, ACP aims to discuss and align medical interventions with patients’ preferences and values during the whole cancer trajectory^{5,16,19}. Thus, during the interviews, I paraphrased the question specifically using the phrase “advance care planning”. Some participants, however, kept the focus on the challenges they encountered in navigating the patient’s transition to palliative care.

“The transition to palliative care is felt by the patient as abandonment, and I do not find out what happened with that particular patient” (Dr. 3).

Misconceptions about the aims and scope of ACP may also be fueled by the complexity that some oncologists experience in EOL conversations, and their fear of leaving patients feeling hopeless¹⁸:

“I think we have been evading these conversations by transferring the patients to the palliative care team” (Dr. 10).

UNFAMILIARITY WITH THE CONCEPT OF RA

Despite increasing interest within the medical literature in understanding ACP as a relational process, in Mexico, it seems that the term RA is almost unknown. Unfamiliarity is partly a consequence of the lack of consensus over the meaning and scope of RA^{8,25}.

“Leaving all decisions to patients is unfair. These are to be shared. Some call it guided paternalism or shared paternalism” (Dr. 4).

Despite their unfamiliarity with RA, most participants actively promoted the inclusion of key actors from the patient's social world in this decision model.

“I like to explore... if they want to involve their family” (Dr. 4).

Conclusion

This study shows how oncologists' beliefs about PA in ACP are in constant interplay with other cultural scripts, including those of their patients. Thus, doctors' and patients' understandings of autonomy result in different stances in communication and decision-making. Oncologists reported that many patients remain passive actors and that some oncologists still make care decisions for them. Further, this study shows that paternalism in Mexico exists beyond the medical field and is rooted in wider sociocultural norms. These new insights may inform future steps within this field. This study's main limitations are that it relies on the participants' answers, and all of them practice in Mexico City. Thus, any transferability needs to be translated into local contexts. The study provides the necessary details for assessing its applicability in other contexts. My own biases cannot be totally disregarded, although I made all possible efforts to ensure my approach was reflexive. Further, to narrow the existing gap between theory and practice, it is important to reach a consensus on the definition, aims, and scope of patients' RA in ACP. In addition, it is important to know better how Mexican paternalism as a cultural script limits PA and prevents patients and doctors from moving toward a shared-decision or RA approach within the field of oncology.

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The author declares no conflicts of interest.

Ethical disclosures

Protection of people and animals. The author declares that no experiments have been carried out on humans or animals for this research.

Data confidentiality. The author declares that she has followed their workplace's protocols regarding the publication of patient data.

Right to privacy and informed consent. The author declares she has obtained informed consent from the patients and/or subjects referred to in the article. This document is in the possession of the corresponding author.

Use of artificial intelligence to generate texts. The author declares that she has not used any type of generative artificial intelligence in the writing of this manuscript or for the creation of figures, graphs, tables, or their corresponding captions or legends.

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