


# BMJ Open Dimensions of suffering and the need for palliative care: experiences and expectations of patients living with cancer and diabetes and their caregivers in Mexico – a qualitative study

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## ABSTRACT

**Objectives** Over 40 million people in low-income and middle-income countries (LMICs) experience serious health-related suffering (SHS) annually and require palliative care. Patient and caregiver experiences of SHS in LMICs are understudied despite their importance in guiding palliative care provision. Diabetes and cancer are the second-leading and third-leading causes of death in Mexico, causing a significant SHS burden on patients, families and health systems. This study examines SHS and palliative care from the point of view of patients with cancer and diabetes and their caregivers.

**Design** A qualitative descriptive study based on in-depth telephone interviews was conducted between August 2021 and February 2022. Data were analysed through inductive thematic analysis.

**Participants** Overall, 20 patients with end-stage cancer, 13 patients with diabetes and 35 family caregivers were interviewed individually.

**Setting** Participants were recruited from two family medicine clinics and a pain clinic in Mexico City.

**Results** Seven themes emerged: (1) suffering as a multifaceted phenomenon, (2) diversity in perceptions of suffering, (3) different coping strategies, (4) need and perceived importance of relief from suffering, (5) barriers to accessing services to relieve suffering, (6) demand for the health sector's active and humane role in addressing suffering and (7) preferences and need for comprehensive care for relief from suffering. The primary coping strategies included family companionship, protective buffering and faith-based support. Participants lacked knowledge of palliative care. They expressed the importance of relief from suffering, viewing it as the health sector's responsibility and requesting more humane, personalised care and access to medicines and pain clinics.

**Conclusions** The multifaceted nature of SHS highlights the health system's responsibility to provide high-quality palliative care. Policies to enhance access to palliative care should integrate it into primary care, redesigning services towards patient and caregiver biopsychosocial and spiritual needs and ensuring access to medicines and competent health personnel.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study presents new qualitative data on the significance of serious health-related suffering (SHS) and the experiences of Mexican patients with cancer or diabetes and their caregivers in coping with SHS, their awareness of palliative care, and their expectations of the health system.
- ⇒ Participants with diverse ages, schooling and clinical characteristics were included, which allowed for a comprehensive understanding of the studied problem.
- ⇒ The study's trustworthiness was ensured by a 'thick description' of the participants, settings and methods; the use of multiple perspectives throughout data collection and the triangulation of the analysis by three researchers.
- ⇒ The study followed COREQ consolidated criteria to ensure methodological rigour and transparency.
- ⇒ The study findings cannot be generalised to all Mexican patients with cancer or diabetes and their caregivers; however, it provides relevant insights into the participants' lived experiences with SHS and can be used as a justification for improvements in priority-setting and investments in the Mexican health system aimed towards achieving universal access to palliative care and pain relief.

## INTRODUCTION

Serious health-related suffering (SHS) stems from life-threatening illnesses that compromise physical, social, spiritual and emotional functioning and require palliative care.<sup>1</sup> The Lancet Commission on Global Access to Palliative Care and Pain Relief revealed that over 61 million people worldwide experience SHS annually and need palliative care, yet over 80% lack access and the majority live in low-income and middle-income countries.<sup>1</sup> Lack of access to palliative care is a barrier to achieving universal health coverage and reducing health inequalities in most countries.<sup>1</sup>

Lived experiences of SHS are configured by historical, social and cultural determinants, as well as intersecting identities—such as ethnicity, religious identity and socio-economic status—which in turn shape beliefs, values and customs that influence individual perceptions of SHS and coping strategies.<sup>2 3</sup> For instance, in Asian cultures, the ability to tolerate suffering, known as stoicism, is recognised as a virtue, while a lack of pain tolerance is considered a sign of weakness, resulting in a reluctance to complain of pain.<sup>4 5</sup> In comparison, expressiveness of pain is more prevalent in Hispanic, Italian, Egyptian and African-American populations.<sup>6</sup> In addition, some religions, including Catholicism, which is widely practised in Latin America, may espouse a belief that with pain and suffering comes spiritual growth, using prayer as a form of healing and a salve.<sup>7</sup>

SHS has been primarily measured by the number of people or days of suffering, but the meaning, experiences of SHS and relief from SHS have not been extensively explored despite the importance of this information for palliative care policy-making.<sup>1</sup>

Palliative care aims to minimise SHS and improve the quality of life of patients and families facing life-threatening illnesses by preventing and relieving their suffering.<sup>8</sup> Palliative care in Mexico faces challenges. First, healthcare delivery is fragmented by public and private providers, and insurance coverage is dependent on employment. Formal sector employees and their families (around 68.5 million people) are covered by the Mexican Institute of Social Security (IMSS), and bureaucrats and their families (13.5 million) by the Institute for Social Security and Services for State Workers. From 2004 to 2018, people without social security (~54 million) were covered by Seguro Popular—public health insurance.<sup>9</sup> Since 2019, this population has lacked explicit health insurance and access to healthcare as the newly elected government terminated the Seguro Popular.<sup>10</sup> Second, in 2020, Mexico had 0.92 palliative services/teams per million inhabitants.<sup>11</sup> This rate is three times less than the Latin American average of 2.6 palliative care services/teams per million. Third, Mexico has a severe shortage and unequal distribution of opioid pain relief medication. The stock covers less than one-third of the need, and wealthier states have 10 times more access to opioid medications than poorer states.<sup>1 12</sup> Yet opioid pain medication is essential to SHS relief, particularly in patients with moderate to severe pain, not responding to other analgesics.

Research on how SHS affects patients and caregivers is critical to improving Mexico's palliative care services. In Mexico, most research on this topic has focused on the beliefs, attitudes and decisions of health professionals, who lack training and have challenges talking with terminally ill patients about their prognosis.<sup>13</sup> Patient and caregiver perspectives are absent from academic studies despite extensive social sciences research documenting how social values and cultural beliefs shape individuals' experiences with suffering.

Currently, in Mexico, diabetes and cancer are the second-leading and third-leading causes of death, causing an enormous SHS burden on patients, their families and health systems.<sup>14 15</sup> Therefore, the objective of this study was to explore the meaning and experiences of SHS and relief from SHS among patients with cancer or diabetes and their caregivers.

## METHODS

### Study design

We conducted a qualitative descriptive study based on in-depth interviews and in alignment with the protocol and interview guide developed by Bhadelia et al (2023).<sup>16</sup>

### Participants and setting

The study included three groups of participants older than 18 years: (1) patients with a diagnosis of advanced-stage cancer (ICD-10: C00–C97); (2) patients with diabetes (ICD-10: E10–E11) living with SHS (eg, severe pain, severe diabetes complication with disability in daily living activities) and (3) primary family caregivers.

Participants were recruited from three IMSS facilities in Mexico City: two family medicine clinics (FMCs) and a pain clinic. One FMC comprised a large clinic with 62 family physicians covering about 153 000 people and a mid-size clinic with 40 family physicians covering 100 000 people. The mid-size PCC was in a middle-income neighbourhood, while the large PCC and a pain clinic were in low-income areas. At FMCs, healthcare is provided by family physicians working under the same clinical standards (eg, evidence-based cancer and diabetes care guidelines) together with nurses, medical assistants and social workers. In addition, most mid-size and large-size FMCs have a psychologist, a nutritionist, a clinical laboratory and a pharmacy. The pain clinic was staffed by three physicians specialising in palliative care, two nurses, a thanatologist, a nutritionist, a psychologist, a social worker, two medical assistants and a group of Palliative Medicine Residency Programme residents. IMSS is a prepaid social health insurance system that delivers healthcare and medicines at no cost at the point of service.

We used cancer and diabetes patient registries to identify those with potential SHS. We applied purposive sampling to establish a sample with diverse socio-demographic characteristics (by gender, age and level of schooling) and varied caregiver–patient relationships. Patients who could carry on normal activities or those severely disabled and too ill to participate were excluded (Karnofsky performance status score  $\geq 80$  or  $\leq 30$ , as recorded in patient registries or described to us by patients or caregivers).

### Procedures

A licensed psychologist (IPM-V) with 14 years of clinical and research experience identified patients with potential

SHS from cancer and diabetes registries, performed invitations of the study participants, acquired their informed consent and conducted in-depth interviews.

The invitations to the study were performed through phone calls. During the invitation, potential participants received information about the study objectives, nature, duration and relevant ethical considerations (eg, voluntary participation, possible risks and benefits, data custody, security, and confidentiality protections).

The study was conducted during the COVID-19 pandemic between August 2021 and February 2022. Considering that people with advanced cancer and diabetes are at increased risk for COVID-19 complications, as well as their caregivers should avoid COVID-19 contagion and its transmission to the patients, participants were offered three interview options: (1) in-person interview, (2) interview by video call or (3) by phone (audio-only).

The decision to offer phone interviews was also based on the evidence regarding feasibility, equivalence in generating the same amount of data richness, and advantages of conducting in-depth telephone interviews compared with in-person interviews (eg, flexibility, participants' comfort),<sup>17–21</sup> including in vulnerable groups of patients, such as persons with mental disorders and multimorbidity.<sup>17</sup> In addition, evidence supports that psychological interventions through phone (audio-only) and video calls can “reduce symptoms related to mental health conditions and have been found to be non-inferior to in-person care”.<sup>21–23</sup>

In this study, most participants chose a telephone interview. Only one patient and two caregivers preferred a face-to-face interview; additionally, one patient with diabetes chose the Zoom call but did not want to turn on the video camera, having only the audio connection. The main reasons for not choosing in-person interviews were the fear of the COVID-19 contagion and not feeling well enough to go to the suggested health facilities; in the case of caregivers, in addition, it was the lack of time and transportation expenses.

All interviews followed a semistructured guide of open-ended questions (online supplemental material panel 1).<sup>16</sup> The duration of the interviews varied between 45 min and 1 hour and a half, with an average time of 60 min. The distress management protocol was used to identify and manage the participants' emotional distress (online supplemental material panel 2). The interviews were audio recorded and transcribed. Sociodemographic data were gathered.

### Sample description

Seventy-eight potential participants were identified and contacted. Four patients and six caregivers refused to participate; the former was due to fatigue, weakness or pain, and the latter was due to lack of time. The study

included 68 participants: 20 patients with cancer, 13 patients with diabetes, 20 family caregivers of patients with cancer, and 15 caregivers of patients with diabetes. We interviewed ~11 patients and caregivers from each clinic. In most interviews, participating patients and caregivers were unrelated. Seven patients agreed to participate together with their caregivers but were interviewed separately. Also, we interviewed eight caregivers of recently deceased patients. About half of the patients and 75% of the caregivers were women. The median age was 56 years for patients (range: 26–73) and 50 years for caregivers (range: 27–75). Patients were evenly distributed across different levels of education. Among the caregivers, there were fewer with low levels of schooling (four with primary school and nine with secondary school). Moreover, 45% of caregivers were spouses, and 40% daughters or sons of the patients, the rest included four siblings and a patient mother (online supplemental tables 1 and 2).

The number of interviewed participants was defined by the principle of thematic saturation,<sup>24</sup> considering a point during data analysis at which five incoming interviews do not produce new categories or themes relative to the study objectives, with a base size of seven initial interviews for each type of participant.<sup>25</sup>

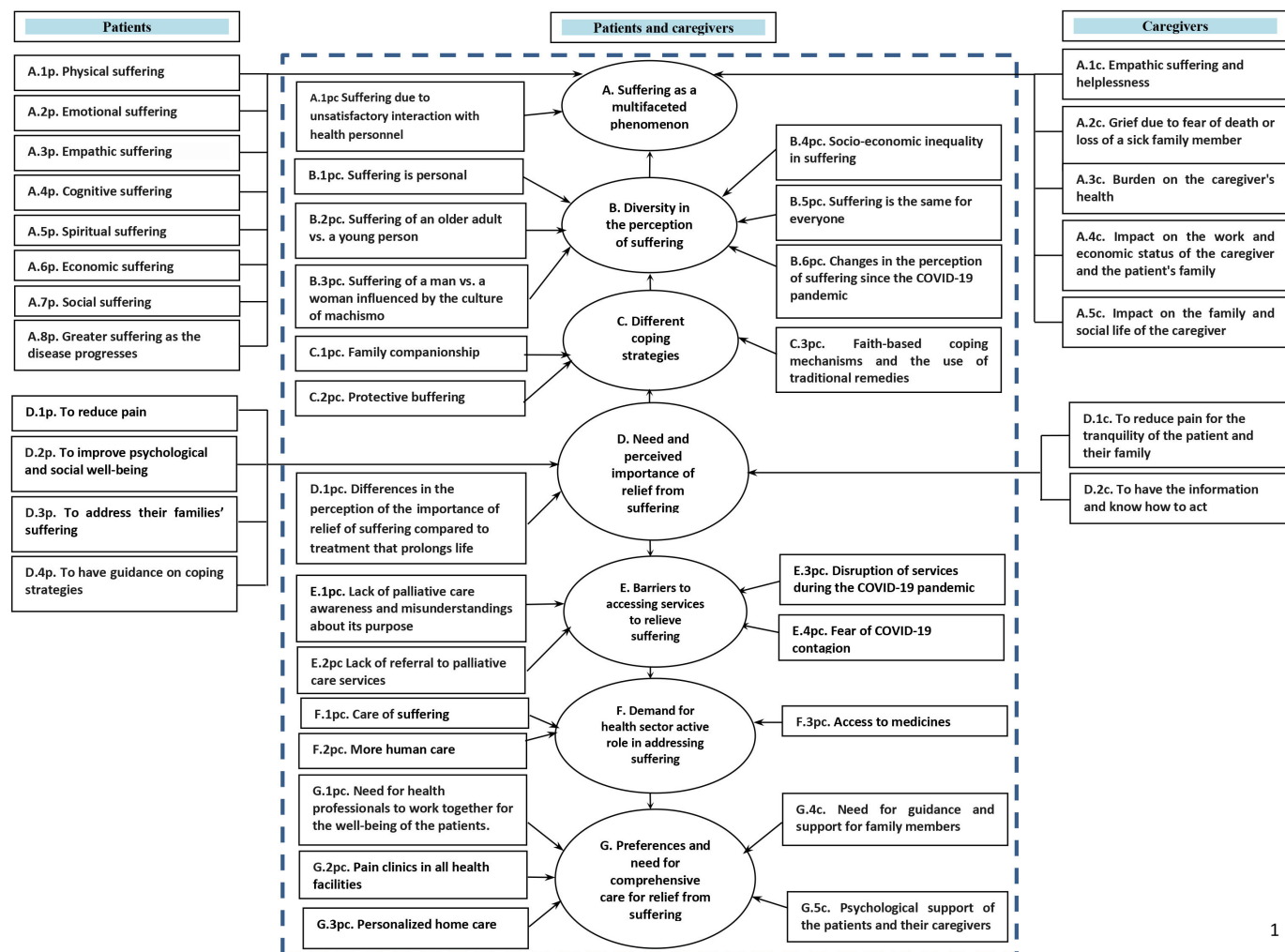
### Data analysis

Data were analysed through six stages of inductive thematic analysis<sup>26</sup>: (1) familiarisation with the data; (2) creation of initial codes through an inductive process; (3) search for subcategories, categories and themes in the interview responses and grouping of minor codes under each of these; (4) review of themes; (5) definition and naming of themes and (6) preparation of the manuscript. Illustrative interview excerpts were labelled using participant identifiers (patient: p; caregiver: c), disease type (cancer: Ca; diabetes: DM), gender, age and the caregiver's relationship to the patient.

Three researchers with master of science and doctor of science degrees and experience in qualitative research (SVD, DP-M and IPM-V) evaluated the transcripts independently. Individual decisions on emerging themes and response coding were cross-checked for consistency. Discrepancies were discussed to reach a collective agreement on their classification. The analysis focused on identifying common and specific themes for each group of participants and generating a thematic map.

### Activities to guarantee the study's trustworthiness

We ensured credibility (ie, data collected is accurate/representative of the phenomenon under study) by using multiple perspectives throughout data collection and analysis (eg, data triangulation by three researchers). The transferability (ie, the extent to which the findings are transferable to similar contexts or individuals) was ensured through thick description by providing adequate details on the site, participants and methods used to collect data during the study. The dependability was ensured by an in-depth description of the study methodology to make



**Figure 1** Thematic map.

the study replicable. Finally, we ensured that the data and findings were not due to participant or researcher bias (ie, confirmability) through data analysis triangulation by three researchers.

### Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

## RESULTS

We identified seven main themes: A. Suffering as a multifaceted phenomenon; B. Diversity in perceptions of suffering; C. Different coping strategies; D. Need and perceived importance of relief from suffering; E. Barriers to accessing services to relieve suffering; F. Demand for the health sector's active and humane role in addressing suffering and G. Preferences and needs for comprehensive care for relief from suffering (figure 1, tables 1–3 and online supplemental tables 3–5).

### Theme A: suffering as a multifaceted phenomenon

The first word that came to mind when participants were prompted with the concept of 'serious-health related suffering' was 'pain', followed by 'distress', 'anxiety', 'desperation', 'disability' and the idea of not being able to care for oneself. When asked what SHS meant to them, patients and caregivers agreed that suffering encompasses multiple aspects; however, patients and caregivers differed in which aspects they highlighted.

### SHS for patients

For most patients, suffering was physical and psychological (or 'of the body and soul'). Pain was the predominant facet of physical suffering. Patients also described their dependence on relatives for care and to carry out basic daily activities as part of physical suffering because the 'body no longer works'. They mourned 'not being able to fend for themselves'. Emotional suffering was the second facet, described as emotional pain, distress, anxiety, desperation, sadness and depression. Both patients with cancer and diabetes highlighted 'the uncertainty of what will happen tomorrow' and 'living the unknown' as



**Table 1** Suffering as a multifaceted phenomenon

Categories and subcategories	Theme A: suffering as a multifaceted phenomenon Quotations
Patients	
A.1p. Physical suffering ▶ A.1p.1. sensorial suffering: pain or other physical symptoms ▶ A.1p.2. suffering due to dependency: disability, depending on other people, not being able to take care of oneself A.2p. Emotional suffering ▶ A.2p.1. emotional pain, anguish, anxiety, despair, sadness, depression ▶ A.2p.2. uncertainty, living the unknown A.3p. Empathic suffering: seeing the suffering of your family A.4p. Cognitive suffering: wanting to die so as not to suffer and for their family not to suffer A.5p. Spiritual suffering: soul suffering A.6p. Economic suffering: ▶ A.6p.1. due to no longer working ▶ A.6p.2. due to paying for medication and other care expenses A.7p. Social suffering A.8p. Greater suffering as the disease progresses	<p><b>Categories A.1p, A.2p, A.3p, A.6p</b>  pQ1. “Suffering is something that encompasses many things—for instance, mental and physical suffering. I say mental because suffering is thinking about not being able to do this, not being able to do that, and physically you can’t do it and yes, it hurts. Suffering is seeing that your family suffers because they see that you are suffering. That suffering is even more painful than your own suffering... And apart from that there is economic suffering—although one does not want to see it as such. But yes, when there is a lack of income, this is suffering because there are shortages of certain things. This is suffering, part of it. Suffering is carrying so many problems, like, for example, thinking about what is going to happen tomorrow, one also carries this suffering. It is also to depend on my family for everything—emotionally, physically, even financially.” (p26-DM, 58-year-old man)</p> <p><b>Categories A.1p, A.2p, A.3p, A.5p</b>  pQ2. “...suffering of the body, which is the main thing, and suffering of the soul, as sometimes one feels very worn out, very sad, that one does not assimilate what one is going through. ...and the family too. I feel that it is despairing for them to see us suffering, to see that they cannot do anything...” (p21-ovarian-Ca, 45-year-old woman)</p> <p><b>Categories A.1p, A.2p, A.4p, A.5p</b>  pQ3. “Your suffering is powerlessness; it is pain; it is wanting to leave this world, so your family no longer suffers.” (p23-liposarcoma, 36-year-old woman)</p> <p><b>Categories A.6p</b>  pQ4. “I was paying a series of expenses that I did not anticipate. I had to borrow money, which, we’ll see how we manage later. Taking the ambulance from my house to Social Security, due to the health emergency, cost me fifteen hundred pesos. And some medicines that the (IMSS) insurance prescribed me, but they did not have them in stock, I had to buy them myself, and each medication cost me between one thousand and two thousand pesos and that did affect me financially. ... They gave me the prescription, I went to the pharmacy, and there they told me, ‘We don’t have it,’ ‘(patient) And what do I do?’, ‘(pharmacy) I don’t know, it will arrive in a month.’ And do you think I’m going to bear the pain for a month?” (p10-prostate-Ca, 68-year-old man)</p> <p><b>Categories A.7p</b>  pQ5. “I no longer go see my family, or my neighbours, or anybody, ... even the visits start to bother me... everything that is social. It even bothers me that they see me, see this change that I have. I prefer not to go out anymore, I better stay at home.” (p23-liposarcoma, 36-year-old woman)</p> <p>pQ6. “I can’t go to parties anymore, even if they invite me, not anymore... Suddenly I feel like I’m isolated, because I can’t even go for coffee with the girls anymore.... all coexistence has been lost.” (p18-DM, 65-year-old woman)</p> <p><b>Categories A.8p</b>  pQ7. “The more time passes, understandably the more I suffer, because there is more pain... The more time passes, the suffering increases both for me and for the family, because the family as well; my children—imagine—my brothers, it is not easy to see me like this in bed. (p20-prostate-Ca, 50-year-old man)</p>
Caregivers	

Continued

Table 1 Continued

Categories and subcategories	Theme A: suffering as a multifaceted phenomenon Quotations
<p>A.1c. Empathetic suffering and helplessness: “Seeing the suffering of your loved one and not being able to help him (or her)”</p> <p>A.2c. Grief due to fear of death or loss of a sick family member</p> <p>A.3c. Burden on the caregiver’s health</p> <p>► A.3c.1. Burden on emotional health</p> <p>► A.3c.2. Tiredness and physical exhaustion</p> <p>A.4c. Impact on the work and economic status of the caregiver and the patient’s family</p> <p>A.5c. Impact on the family and social life of the caregiver</p>	<p><b>Categories A.1c.</b></p> <p>cQ1. “Suffering due to illness is seeing another person suffer pain, anguish, and not being able to help him and feeling desperation—not being able to do anything for this person.” (c12-of-husband-with-prostate-Ca, 72-year-old woman)</p> <p>cQ2. “... I saw him suffering. I said to him, ‘What do I do? What can I do for you?’ Because, yes, I was suffering a lot too, seeing him how he was. It is very sad, very painful. It is unfortunate seeing that a person is dying and how he suffers.” (c4-of-husband-with-DM, 67-year-old woman)</p> <p><b>Categories A.2c</b></p> <p>cQ3. “Suffering is pain that you have to bear daily. ...It hurts because, seeing a person turning off, how he is declining. ...Seeing that he was there, suffering pain, and not being able to help him was my greatest suffering. I used to say, ‘I cannot help you; I have nothing to help you with.’ ...I feel that it is like a pain that one brings from knowing that the person who has been with you for a long time is going to leave at a certain moment.” (c7-of-husband-with-DM, 56-year-old woman)</p> <p><b>Categories A.3c</b></p> <p>cQ4. “...I have to take care of my mother during the day and work at dawn—three or four in the morning. That is hitting me hard because it is a fatigue that I now feel; I didn’t care about it before and didn’t feel it. ... The fact that we have to move my mother has affected our health in terms of muscle pain, hip pain due to not knowing how to move her.” (c17-of-mother-with-liver-Ca, 51-year-old woman)</p> <p>cQ5. “It was a nightmare; perhaps because the full weight of his illness was on me, economically, with the responsibility of my work, of my daughter. I was the one who had to do everything. ...For me, my daily activities were very exhausting. I was very stressed.” (c30-of-husband-with-DM, 40-year-old woman)</p> <p><b>Categories A.4c</b></p> <p>c Q6. “He no longer works and sometimes we don’t have food, or I have to get him to the doctor and I don’t have gas. In other words, my husband’s illness has affected me a lot financially because there are times, like right now, when there have been no medicines (at IMSS); you have to buy them for him.” (c22-of-husband-with-prostate-Ca, 50-year-old woman)</p> <p><b>Categories A.5c</b></p> <p>cQ7. “I have given up many moments with my family to be here with him (father), to be here supporting him, so that he feels that his family loves him. ...Yes, (my family) has told me that I am barely with them anymore, that I spend a lot of time here...” (c9-of-father-with-DM, 45-year-old woman)</p>
Patients and caregivers	
1pc. Suffering as a result of unsatisfactory interactions with health providers	<p><b>Categories A.1pc</b></p> <p>pcQ1. “...I have come across some doctors who, unfortunately, I believe are tired of giving guidance and all they do is issue prescriptions, just like that, without saying take this, because it will be useful for this, no, they just prescribe...” (p25-DM, 50-year-old man)</p> <p>pcQ2. “I think that human quality is really lacking. One day I saw that an older female arrived ten minutes late for her consultation with the oncologist, and the oncologist came out and yelled horribly... the poor female’s blood pressure went up, she was in really bad shape, the nurses were taking care of her....Why normalise that, if you are going to IMSS, they are going to mistreat you. In other words, why go with the mentality that I have to put up with them being as they are, because if not, they will not give me the service.” (c8-of-mother-with-breast-Ca, 27-year-old woman)</p>
Capital letter ‘Q’ refers to ‘quotation’; lowercase letters ‘p’, ‘c’ and ‘pc’ refer to ‘patient’, ‘caregiver’ and ‘patients and caregivers’.	

emotional suffering. Empathetic suffering in response to seeing their family’s suffering was the third facet. Patients expressed cognitive and spiritual suffering as feeling helpless to the disease and wanting to die to relieve their own suffering and that of their families

(table 1, themes A, patients’ quotations (pQ) 1–3). Economic suffering due to the inability to work and unexpected healthcare expenses, such as medicines was the sixth facet experienced by more than half of patients (table 1, theme A, pQ4). The seventh facet

**Table 2** Diversity in perceptions of suffering and different coping strategies

Categories and subcategories	Quotations
Theme B: diversity in perceptions of suffering patients and caregivers	
B.1pc. Suffering is personal	<b>Category B.1pc</b>
B.2pc. Suffering of an older adult vs a young person	pcQ1. "Everyone lives their pain. I don't feel what another person feels. So, it's different for everyone." (p1-DM, 51-year-old woman)
B.3pc. Suffering of a man vs a woman influenced by the culture of machismo	<b>Category B.2pc</b>
B.4pc. Socio-economic inequalities of suffering	pcQ2. "In my case, I suffered from cancer, as well as my father. We are different ages, and I think our responses to the disease were very different. I think adults are a little more resigned to the fact that there is an age when suffering is inevitable. As a younger person, you perceive it more as something that shouldn't be happening because you're a young person who was healthy, with a lot of things to do. Regarding the people who are caring for a person with an illness, I think that we also perceive suffering differently. As young people, we are not able to perceive their pain or their emotional concerns, and as adults, I think we can understand this a little better and work on it better." (c1-of-father-with-colon-Ca, 40-year-old woman)
B.5pc. Suffering is the same for everyone	<b>Category B.3pc</b>
B.6pc. Changes in the perception of suffering since the COVID-19 pandemic	pcQ3. "Culturally, the man must always be strong; he must endure everything. If he breaks a hand, he must bandage it up and go to work. In the case of women, no, women should be more delicate. If the girl fell, pick her up, caress her, and take her to the doctor." (c11-of-wife-with-breast-Ca, 62-year-old man)
	<b>Category B.4pc</b>
	pcQ4. "If someone has money, the suffering is less because they will no longer have to think that he will not have enough for this or for that. When you have the money, you don't think about that; you just focus on healing yourself and suffering as little as possible. On the other hand, when you don't have the money, you suffer; first, because you don't have money to pay for medical appointments, you don't have money for medicines. In my case, it is not having money for diapers, not having for wipes, not having for paper, not even for toothpaste." (p13-breast-Ca, 34-year-old woman)
	pcQ5. "I think that (the suffering) does change because of money because, at the end of the day, you have money, you hire a nurse, and you are not so aware of the suffering of a sick person at home." (c30-of-husband-with-DM, 40-year-old woman)
	pcQ6. "As a caregiver, I think suffering is perceived differently when you are a high-income caregiver and a low-income caregiver. I think they do perceive it differently. Because it is more difficult to perform caregiving (when income is low), it is very difficult to manage a disease and see that your resources are insufficient to provide care to your patient." (c1-of-father-with-colon-Ca, 40-year-old woman)
	<b>Category B.5pc</b>
	pcQ7. "...the pain is the same, because it is a human body. We are human beings, and we feel the same, no matter the social classes, no matter the age." (p31-ovarian-Ca, 64-year-old woman)
	<b>Category B.6</b>
	pcQ8. "As we say, it is normal, many people are dying. I don't work in the health sector, but I see that we have also become a little apathetic, like suffering and death are normal." (c6-of-mother-with-DM, 30-year-old man)
	pcQ9. "I became more empathic with the people who had COVID....People were dying without seeing their relatives. And it made me be quite empathetic, to talk about the fact that we can all suffer, all of us..." (p23-liposarcoma, 36-year-old woman)
Theme C: different coping strategies patients and caregivers	

Continued

Table 2 Continued

Categories and subcategories	Quotations
C.1pc. Family companionship C.2pc. Protective buffering C.3pc. Faith-based coping mechanisms and the use of traditional remedies ► C.3pc.1. Getting closer to God ► C.3pc.2. The Catholic religion prohibits euthanasia ► C.3pc.3. Use of traditional remedies	<p><b>Category C.1pc</b>            pcQ1. "...now that my illness has progressed, my whole family is worried; I have a lot of support, they suffer with me." (p1-DM, 51-year-old man)            pcQ2. "Despite the fact that we were not very close with the rest of the family, they began to come to visit him. In those moments of illness, the family begins to get together..." (c28-of-son-with-testicular-Ca, 59-year-old woman)</p> <p><b>Category C.2pc</b>            pcQ3. "(How have you coped with your suffering?)Honestly, I try to do it alone, not to affect them (family members), to harm them as little as possible. If I suddenly can't do it, obviously they realise it; they try to support me in everything and be there because they are family. But I estimate that 95% out of 100% I try to do alone." (p7-neuroendocrine-Ca, 47-year-old woman)            pcQ4. "My family is not used to being sick. When I have pain, they give me my medicine to relieve pain; they are there with me, but if I start to cry or something like that, "Oh, you're going to cry! And they get upset. So, I prefer to isolate myself and suffer alone, and I feel better because there is no one to tell me anything; there is no one who reproaches me for crying or saying that it is my fault that they cannot work because they have to take care of me. Therefore, I prefer to suffer alone." (p13-breast-Ca, 34-year-old woman)            pcQ5. "There are certain situations in which you cannot show your relative the weakness you have because if you fall, your family does too. ...So you cannot show your pain, your frustration, and you have to do it alone so that you say, "I have to be strong because I need to be strong for what's ahead." (c19-of-brother-with-liver-Ca, 35-year-old woman)</p> <p><b>Category C.3pc.1</b>            pcQ6. "This (suffering) has brought me closer to God, much closer. I had faith in God and now I have more faith in God. I did not know how to pray, and I learnt to pray on my own. God and I are hand in hand, he holds me by his hand, and he helps me." (p33-lung-Ca, 56-year-old woman)            pcQ7. "...seeing him sick, not being able to help him, ...praying for him is the only thing we do all night—prayer, prayer, because it is stronger than medicine, because the hands of God heal and with faith who has one, I think it is stronger (than medicine)." (c12-of-husband-with-prostate-Ca, 72-year-old woman)</p> <p><b>Category C.3pc.2</b>            pcQ8. "I am against taking a life, against euthanasia. Yes, I am against that—it is until God says." (c4-of-husband-with-DM, 67-year-old woman)</p> <p><b>Category C.3pc.3</b>            pcQ9. "We are so rich in herbs in the villages. Right now, all that has been lost, but for me a tea is better than a pill." (p30-DM, 67-year-old woman) pcQ10. "Witchcraft, healers, herbalists, all these kinds of things are cultural, and the primary intention is to avoid suffering and cure illness, to achieve health." (p3-prostate-Ca, 70-year-old man)            pcQ11. "Unfortunately, many people get carried away just because of what others say, but they don't investigate. This can sink you or lift you, but we have to be careful where we get the information and what we are taking and more so because we are talking about our body, we are talking about our life..." (p22-kidney-Ca, 53-year-old man)</p>

was the disruption of social life—being too ill and in pain to go out with friends, opting for self-isolation and not talking to others about their illness. Some patients expressed, 'it even bothers me they see me', as they did not want friends to see their physical deterioration (table 1, theme A, pQ5–6), and mentioned that suffering worsened with disease progression (table 1, theme A, pQ7).

### SHS for caregivers

Most caregivers experienced suffering from seeing their loved ones suffer and being unable to help (table 1,

Theme A, caregivers' quotations (cQ) 1–2). They experienced anticipatory grief (table 1, theme A, cQ3) and identified fatigue, physical and emotional exhaustion as critical components of their suffering (table 1, theme A, cQ4–5). Being a caregiver had a negative impact on their work, social life and the family's economic status (table 1, theme A, cQ6–7).

### Suffering because of unsatisfactory interactions with health providers

Half of patients and caregivers reported unsatisfactory interactions with healthcare providers as a cause of



**Table 3** Need, importance and barriers to accessing services to relieve suffering

Categories and subcategories	Quotations
Theme D: need and perceived importance of relief from suffering.	
Patients	
D.1p. To reduce pain D.2p. To improve psychological and social well-being D.3p. To address their families' suffering D.4p. To have guidance on coping strategies	<p><b>Category D.1p</b> pQ1. "...one suffers from knowing that their life is exposed to a serious illness. If they (health professionals) could at least help us... to avoid pain; especially the real pain of cancer, that is when it attacks you seriously. Psychologically, even remembering that pain scares me... You can't control it by breathing or thinking about nice things... As an act of humanity, relieving a person from these pains is the least that a human being can do, if he has the ability to do it, to minimise and take away the pain that is the minimum." (p7-neuroendocrine-Ca, 47-year-old woman)</p> <p><b>Category D.2p</b> pQ2. "For me, relief from suffering is important because that helps you. Although you have the illness, it helps you to improve your psychological state, your state of health, and your interaction with your loved ones; it is very important." (p5-DM, 53-year-old man)</p> <p><b>Category D.3p</b> pQ3. "When you feel good and do not suffer, you will transmit it to others, and others will obviously leave the concerns aside, so one's well-being is immediately transmitted to others." (p25-DM, 50-year-old man)</p> <p><b>Category D.4p</b> pQ4. "There are many fears that you have, many doubts... What is going to happen? How should I be with my family? How should I react? You need someone from the outside who listens to you and can help you understand more about the illness, the situation you are going through, and the suffering you are having. You need someone to guide you." (p5-DM, 53-year-old man)</p>
Caregivers	
D.1c. To reduce pain for the tranquillity of the patients and their family D.2c. To have the information and know how to act	<p><b>Category D.1c</b> cQ1. "When you see your patient...in a bearable or stable situation ...you also find peace of mind. But, if you are seeing that the person you are caring for can't find it, you will also start to feel bad, to have frustration." (c19-of-brother-with-liver-Ca, 35-years-old woman)</p> <p><b>Category D.2c</b> cQ2. "...just having medical care is not enough. In my case, the fact of not knowing how to tell my mother how things are—I think a specialist could guide me on how to make my mother aware of the situation. ... Also, the fact that we have to move my mother has affected us in terms of health, muscle pain, and hip pain due to not knowing how to move her." (c17-of-mother-with-liver-Ca, 51-year-old woman)</p>
Patients and caregivers	
D.1pc. Differences in the perception of the importance of relief from suffering compared with treatment that prolongs life. ► D.1pc.1. Greater importance of relief from suffering ► D.1pc2.Equal importance of both treatments	<p><b>Category D.1pc</b> <b>Subcategory. D.1pc1. Greater importance of relief from suffering</b> pcQ1. "Relief from suffering is more important to me. If I felt good, I would be happy, but in the situation I find myself in, who wants to feel like this all the time?" (p29-DM, 72-year-old woman) pcQ2. "...I think (the relief from suffering is) superior because what palliative care is looking for is to improve quality and it seems to me that treatments to prolong (life), what they seek is only the time that a person remains, but it is very important that this time is in decent conditions—and I think that's offered by palliative care. At least in my experience, palliative care was not only the physical issue, but also the support to be able to understand the situation that is happening..." (c1-of-father-with-colon-Ca, 40-year-old woman)</p> <p><b>D.1pc2. Equal importance of both treatments</b> pcQ3. "I think it's the same, I think they go hand in hand and those that prolong life and those that help pain. Suffering from pain in some way ends you, so I believe that controlling it has the same effect and goes hand in hand with improving your life." (p25-DM, 50-year-old man)</p>

Continued

**Table 3** Continued

Categories and subcategories	Quotations
Theme E. Barriers to accessing services to relieve suffering Patients and caregivers	
E.1pc. Lack of palliative care awareness and misunderstandings about its purpose E.2pc. Lack of referral to palliative care services and other services delays E.3pc. Disruption of services during the COVID-19 pandemic E.4pc. Fear of COVID-19 contagion	<p><b>Category E.1pc</b> pcQ1. “I understand it as complementary medicine or as complementary medicine to the medical one.” (p5-DM, 53-years-old man) pcQ2. “...you can’t look for something you don’t know or something that you don’t know exists. It’s been 2 years with this (cancer) now. I would have taken it (palliative care services) from the beginning. Maybe it would have prevented me from many things. ...It is for intelligent and advanced human beings to help in the palliative part. It exists? <i>Caramba!</i> I had no idea. I was never informed anywhere, at all levels (of care) where I was, from doctors here at IMSS—I think that even they don’t know, even they aren’t aware!” (p7-neuroendocrine-Ca, 47-year-old woman) pcQ3. “I was not aware of palliative care. Yes, it is an obstacle of not being aware.” (c30-of-husband-with-DM, 40-year-old woman)</p> <p><b>Category E.2pc</b> pcQ4. “... I had such severe discomfort, and I told the doctor, and the doctor just told me, ‘Take this.’ There wasn’t someone who said, ‘You know, we’re going to send you to the pain clinic.’ No, no. At my clinic and hospital, it was never mentioned until we got there (to the pain clinic).” (p22-kidney-Ca, 53-year-old man) pcQ5. “Unfortunately... doctors don’t tell us, ‘Look, your family member or your patient is seriously ill. Look, I offer you to take him to the pain clinic or to a clinic where they can help him, and we will follow the procedure, but we offer you this additional alternative.’ They don’t offer it to you. I’ve been with this (cancer) for almost half a year. I did not know about the pain clinic and found it fifteen days ago.” (c19-of-brother-with-liver-Ca, 35-years-old woman)</p> <p><b>Category E.3pc</b> pcQ6. “There are many, many patients who are not receiving care right now, because most are COVID hospitals and they (patients) are becoming depressed and need mental health, they need psychological help. The pandemic is going to be a long time coming. So, during this time, palliative medicine and psychologists are very much needed. The nephrologist doctor told me yesterday that Los Venados (hospital) only provides two services: cardiology and nephrology; the rest have already been closed again because this is a COVID hospital.” (p5-DM, 53-year-old man). pcQ7. “... the (pain) clinic where she was sent was converted to a COVID clinic, and they (health professionals) did not want to admit her. So, they told us to wait until her doctor sent her to another clinic. So there has been no palliative care. (How long have you been like this?)About 2 months. It is like a barrier due to COVID that does not allow your patient to be treated correctly.” (c34-of-mother-with-ovarian-Ca, 40-year-old woman)</p> <p><b>Category E.4pc</b> pcQ8. “In my case, there were like eight appointments in which I could not come to be assessed and be given medication personally due to my illness. Because I have low immunity, I can’t be exposed to being outside for long periods, much less in a hospital. So (my relatives) went for my medicine, and I was treated for a long time with a medicine, which made me hallucinate. So, for 8 months, I suffered from that. When the pandemic settled down a little, I was able to come to the medical service when they identified that this medicine was not suitable for me, and they changed it.” (p13-breast-Ca, 34-year-old woman) pcQ9. “The pandemic generated total uncertainty in our family about going to public health institutions. The last thing we wanted was to expose my father to contagion.” (c1-of-father-with-colon-Ca, 40-year-old woman)</p>

suffering. Lack of information about their illness and care and lack of empathy were sources of suffering (table 1, theme A, pcQ1–2).

### Theme B: diversity in perceptions of suffering

Participants were asked about their perceptions of suffering for different groups, such as men and women,

young and older adults, and low-income and high-income people. Half of participants referred to pain and suffering as individual experiences (table 2, theme B, pcQ1), another half noted that suffering was different between young and old, men and women, and rich and poor. Young people were thought to 'have the strength of youth' and could 'resist disease and suffering more' and they 'do not perceive the seriousness of the disease' and 'perceive the disease as something that should not be happening'. In comparison, older adults were more likely to see suffering as inevitable given that 'they [had] already lived' (table 2, theme B, pcQ2).

Gender differences were partly attributed to 'machismo'—the cultural norm that men are expected to be 'colder', 'hide suffering', and that 'if a man cries, this is a weakness'. In contrast, women were viewed as 'more emotional in the way they express suffering' (table 2, theme B, pcQ3).

Patients and caregivers believed there was inequitable suffering based on socioeconomic differences. Patients with more resources could access private doctors and professional caregivers, acquire necessary accessories for personal care and food to comply with diet among others. In contrast, those with limited resources faced hardship (table 2, theme B, pcQ4–6). However, some participants considered that suffering was 'the same pain for everyone' (table 2, theme B, pcQ7).

Several patients and caregivers believed that perceptions of suffering had changed during the COVID-19 pandemic: 'the pandemic made us see that at some point we can all suffer'; 'we have become apathetic, seeing suffering and death as normal'; and 'the pandemic has helped to humanise us, lead us to become aware, to value, to support people' and to 'be more empathetic' (table 2, theme B, pcQ8–9).

### Theme C: different coping strategies

Most patients and caregivers stated that they relied on family support: 'my relatives have supported me in everything I have needed'; 'I depend on my family for everything'; 'my family cares'; '[my family] suffers together with me' (table 2, theme C, pcQ1).

Many caregivers indicated leaning on other relatives and sharing their suffering with them: 'with the disease, the family begins to get together'; 'I share it or talk about it... to get it off my chest and see the best way to help'; 'we share the pain'; 'we support each other' (table 2, theme C, pcQ2).

Some patients and caregivers chose to handle their suffering alone. This behaviour is known as 'protective buffering' when patients or caregivers—hiding their suffering from their family to protect them. Two patients preferred to suffer alone to avoid criticism or blame (table 2, theme C, pcQ3–4). Several caregivers kept their suffering hidden: 'not showing relatives the weakness that you have, because if you fall, your family could also fall' (table 2, theme C, pcQ5).

Faith-based coping mechanisms and use of traditional remedies were reported. Catholic patients and caregivers mentioned that suffering had 'brought them closer to God,' perceiving faith in God as a refuge and prayer as 'a spiritual quality that helps nourish the soul' and that can be 'stronger than medicine' (table 2, theme C, pcQ6–7). Moreover, participants mentioned that the Catholic Church prohibits euthanasia; a patient and a caregiver expressed they were also against it, while one caregiver favoured it (table 2, theme C, pcQ8).

Several patients and caregivers commented on traditional remedies, such as purifications by healers and shamans, holy water and herbs for pain relief. Some described trying them, while others thought that their use was part of 'the Mexican culture of the quick remedy' and that many people used such remedies without being properly informed (table 2, theme C, pcQ9–11).

### Theme D: need and perceived importance of relief from suffering

All participants agreed on the importance of alleviating suffering to (1) reduce pain, (2) improve their psychological and social well-being, (3) address their families' suffering and (4) have guidance on coping strategies (table 3, theme D, pcQ1–4 and cQ1–2). Most patients—but less than half of caregivers—rated alleviation of suffering as more important than life-prolonging treatments. Seventeen caregivers and nine patients rated both treatments as equally important, and two caregivers considered that treatment prolonging life was more important (table 3, theme D, pcQ1–3).

### Theme E: barriers to accessing services to relieve suffering

Most participants were unfamiliar with palliative care, understanding it as complementary medicine. Pain clinic patients and caregivers believed palliative care was for pain relief. Most interviewees noted that they had not received palliative care and considered that lacking knowledge and information were significant barriers to accessing such services (table 3, theme E, pcQ1–3). In addition, lack of referral to palliative care services and other services delays were reported (table 3, theme E, pcQ4–5). Furthermore, most interviewees stated that the disruption of health services during the COVID-19 pandemic and the fear of contagion were barriers to accessing palliative care (table 3, Theme E, pcQ6–7 and pcQ8–9).

### Theme F: demand for the health sector's active and humane role in addressing suffering

SHS relief was seen as a duty of IMSS and the health sector (table 4, theme F, pcQ1–2). More than half of the participants asserted that IMSS should provide more humane care and shared unsatisfactory experiences (table 4, theme F, pcQ1–4). They reported shortages of pain relief medications, which they had to buy at private pharmacies, and demanded the health sector accountability for ensuring access to medicines (table 4, theme F, pcQ5–7).

**Table 4** Demand for the health sector's active and humane role in addressing suffering and need for comprehensive care for relief from suffering

**Theme F: demand for the health sector's active and humane role in addressing suffering**

**Patients and caregivers**

F.1pc. Care of suffering should be Health Sector responsibility  
F.2pc. More humane care  
F.3pc. Access to medicines

**Categories F.1pc and F.2pc**

pcQ1. "Providing palliative care should be an enormous responsibility (of the IMSS). I also believe they should do it out of humanity and as a right of the patient. When providing this type of care, it should be until the last day, until the last hour, until the last minute." (p11-DM, 46-year-old man)

pcQ2. "...it should be the responsibility of the IMSS to implement palliative care services, and more than that, it would be a very humane and very good act to do so." (c8-of-mother-with-breast-Ca, 27-year-old woman)

**Category F.2pc**

pcQ3. "Obligation—I believe, to treat people like human beings. Doctors are very inhuman. I told them, 'For you, it is a job. You come to earn a salary, and the lives of many here do not matter to you at all. You didn't give me reports, and you focused on other things.'... doctors, in general, have to be more humane, more understanding, more sensitive to the pain of others, to the suffering of others." (c3-of-wife-with-ovarian-Ca, 51-year-old man)

pcQ4. "I think there should be a culture of training for health professionals. Unfortunately, they become very insensitive to the pain of others. This is something that must be eliminated in social security and the health sector." (c2-of-sister-with-neuroendocrine-Ca, 44-year-old woman)

**Category F.3pc**

pcQ5. "Obligation is to provide care to all patients who need special treatment. Obligation to have medicines, that there are no shortages." (p19-breast-Ca, 56-year-old woman)

pcQ6. "I understand that many people are suffering, but I feel that for this stage of palliative care, there should always be good treatment because it is the last thing, and we are suffering. And that there should always be medications—that this be guaranteed." (p23-liposarcoma, 36-year-old woman)

pcQ7. "...something very important, that they have the necessary medicines to help people who need it. ...many times, there are no medicines, or you have to wait for them to arrive. So, it is a recommendation that they should have enough medicine, because the resources of the patients sometimes are not sufficient, to be able to acquire medicines from the outside." (c18-of-father-with-tongue-Ca, 58-year-old woman)

**Theme G: preferences and need for comprehensive care for relief from suffering**

**Patients and caregivers**

Continued



**Table 4** Continued

G.1pc. Need for health professionals to work together for the well-being of the patients.  
 G.2pc. Pain clinics in all health facilities  
 G.3pc. Personalised home care  
 G.4c. Need for guidance and support for family members  
 G.5c. Psychological support for patients and their caregivers

**Category G.1pc**

pcQ1. "It is difficult to take care of all physical, emotional, and psychological aspects, but I think this can be very helpful. ...It is important to work together because a patient doesn't come for just one need and it is not enough to tell him, 'Go get your medicines and I will see you in a year,' but to say to him 'Look, you are going to see a psychologist, you are going to see a nutritionist, you go to a cardiologist, and we are all going to work together to achieve (your) well-being.'" (c6-of-mother-with-DM, 30-year-old man)

**Category G.2pc**

pcQ2. "Many people do not have access to a pain clinic. We have been lucky. More pain clinics in various parts of the state would make the illness less burdensome for the people. The illness itself is enough, and carrying the pain is even harder. There should be more pain clinics, so transportation is not difficult." (p27-testicular-Ca, 26-year-old man)

**Category G.3pc**

pcQ3. "I would like the service to be more personalised—that maybe they (healthcare providers) could go to households and see the conditions in which the patients live so that in that way they also realise how they can support them more. In my case, we are experiencing a very difficult situation. So, if someone goes and sees the situation, I feel they can help us more than just telling them what we are going through here." (p13-breast-Ca, 34-year-old woman)

**Category G.4c**

cQ4. "... Giving guidance to relatives about what your patient requires—I think it is important because we are lost in what to do with a patient. ...I think that support is needed for family members. I think a lot of awareness is needed on how to treat the patient with this type of illness." (c1-of-father-with-colon-Ca, 40-year-old woman)

**Category G.5c**

cQ5. "It would be great if there was psychological support. That you could go to two sessions—both the patient and the caregiver, that there was such a follow-up outside the (medical) treatment, outside the (medical) consultations, like, 'Ok, we already checked your health, we have already given you (medicine) for your (health) problem, but we will see how you are dealing with this (problem)'. (c8-of-mother-with-breast-Ca, 27-year-old woman)

### Theme G: preferences and needs for comprehensive care for relief from suffering

Participants—especially patients with low education—had difficulty expressing their preferences and needs for comprehensive care to alleviate suffering. Some patients and caregivers agreed that health professionals should work together to improve patients' well-being (table 4, theme G, pcQ1). They also called for pain clinics in all primary care facilities and hospitals (table 4, theme G, pcQ2), and personalised home care (table 4, theme G, pcQ3). In addition, caregivers expressed their need for guidance in their roles (table 4, theme G, cQ4) and for psychological support (table 4, theme G, cQ5).

## DISCUSSION

This study provides evidence on SHS's complexity and the need for comprehensive palliative care for patients and caregivers. It also offers recommendations on responding to the SHS burden.

### Experience of suffering and coping strategies

Consistent with the integrated model of suffering that recognises its multidimensional and dynamic nature,<sup>27</sup> study participants described physical, emotional, empathetic, cognitive, spiritual, economic and social affectations and unsatisfactory interactions with health providers as elements of SHS.

The results align with the concept of reciprocal suffering<sup>28</sup> and the theory of social suffering, which indicates that disease-related 'pain and suffering are not limited to the individual who suffers it but extend to the family and their social network'.<sup>29</sup> Caring for a sick family member can lead to depression, anxiety, absenteeism, disruption and loss of employment and interferes with social life.<sup>30 31</sup> Counting on family companionship was the primary coping strategy for alleviating suffering. This strategy is consistent with the concept of familism in Latino cultures, characterised by strong family identification, interconnection, mutual support.<sup>32</sup> Familism prompts individuals to fulfil the caregiver role.<sup>33</sup> Therefore, family-centred interventions to relieve SHS might be pertinent in Mexico.

Participants' coping strategies give insight into the role of cultural beliefs in alleviating suffering. Faith-based and spiritual support approaches can promote a sense of meaning and purpose, an acceptance of death<sup>34</sup> (and rejection of euthanasia),<sup>35</sup> an ability to maintain satisfactory social roles,<sup>36</sup> and a perception of better health.<sup>37</sup> Trust in traditional remedies is based on beliefs in mystical causes of diseases not treatable by conventional medicine.<sup>38</sup> Protective buffering—concealing illness-related concerns from others—is another strategy influenced by cultural beliefs; yet, this strategy can cause distress and harm to relationships and decrease patient and caregiver self-efficacy.<sup>39</sup>

Gender, age and socioeconomic inequities influence suffering experiences. Commonly accepted gender norms of machismo and marianismo in Latin America define men as strong, fearless breadwinners who do not experience pain and women as submissive, family-oriented and sensitive. These concepts influence patient and caregiver expressions of pain and suffering<sup>40</sup> and contextualise gender-based differences in Mexico. Similar to our findings, older patients with cancer receiving palliative care in high-income countries have reported better emotional health and less pain<sup>41 42</sup> and feel more prepared for death than young people.<sup>43</sup> Furthermore, inequities in suffering relief based on socioeconomic status is a widespread challenge reported in China, Sri Lanka, India, Vietnam, Myanmar, Canada and Denmark.<sup>44–46</sup>

### Health system responsiveness

Access to palliative care is essential for SHS relief.<sup>47</sup> Consistent with previous evidence on the relevance of palliative care,<sup>8 47</sup> patients and caregivers placed high importance on relief from SHS in terms of symptoms management and overall improvement of their physical, psychological and social well-being.<sup>48</sup> However, most participants were not knowledgeable about palliative care. Lack of awareness of palliative care is a widespread barrier to seeking and accessing services, also found in high-income countries.<sup>49</sup> In one study, between 17% and 53.2% of respondents in the USA, Sweden, Italy, Canada and Ireland had not heard of palliative care and between 49% and 73% in the USA, Korea and Scotland could not define it.<sup>49</sup> The level of awareness of palliative care in low-income and middle-income countries is unknown. Education and awareness programmes are necessary to improving public knowledge of palliative care. Furthermore, improving access requires addressing opioid supply shortages and barriers to prescribing medicines to alleviate suffering.<sup>1</sup>

In Mexico, the COVID-19 pandemic disrupted the delivery of multiple health services due to the redistribution of resources towards COVID-19 patient care, and efforts to reduce overcrowded health facilities.<sup>50</sup> This study corroborated the disruption and need to

maintain and recover palliative care services amid ongoing surges of COVID-19 cases.

The opinions of patients and caregivers serve to guide palliative care priority-setting. Mexican patients considered SHS relief to be more important than treatment to prolong life, while caregivers felt that both interventions were equally important. Differences in treatment preferences between patients and caregivers have been previously reported.<sup>51</sup> A study from Singapore focused on patients with advanced cancer found discordance in 60% of patient–caregiver dyads; “caregivers wanted a balance between prolonging life and symptom control, while patients preferred life-prolonging treatment”.<sup>51</sup> This discrepancy affects the burden on caregivers' time and health.<sup>51</sup> Health professionals should encourage communication and ensure that caregivers better understand patient preferences on treatment to alleviate SHS.

Participants favoured continuous, comprehensive, family-centred care to alleviate SHS. They explicitly requested improved collaboration between health professionals to promote patients' well-being, the availability of pain clinics in all health facilities, provision of home-based personalised care and psychological support. These preferences coincide with the WHO recommendation of integrating palliative services into primary care<sup>52</sup> to ensure universal access while respecting patient preferences. For primary care workers, providing SHS care requires basic training in palliative care and the availability of effective and low-cost drugs.<sup>52</sup> Official standards should be established that would enable primary care physicians to easily transfer patients to a higher level of care to alleviate refractory suffering.<sup>52</sup>

Unsatisfactory interaction between health personnel, patients and caregivers is an additional facet of suffering. Patients with cancer and diabetes have identified insufficient knowledge and a lack of training among health professionals on alleviating SHS.<sup>53</sup> In addition, a recent systematic review<sup>54</sup> of health professionals during the COVID-19 pandemic identified increases in emotional exhaustion, depersonalisation and compassion fatigue. Compassion and empathy are necessary for understanding and responding to suffering. To this aim, health organisations must foster a culture of compassion to provide safe, high-quality, user-centred care.

Most participants in this study suggested that the health sector and IMSS were responsible for improving alleviation of SHS, with more humanity and access. This finding is consistent with the resolution of the World Health Assembly,<sup>55</sup> which indicates that the integration and provision of palliative care, including people-centred care and access to medicines, is an ethical responsibility of public health systems.

Based on our findings, the strategies for strengthening the Mexican health system to address the SHS burden should (1) prioritise the alleviation of SHS

alongside life-prolonging intervention; (2) promote policies for the advancement of palliative care research and practice; (3) integrate palliative care into primary care to guarantee access to services that alleviate SHS; (4) secure the availability of effective and low-cost drugs for relief from SHS; (5) improve health system preparedness to avoid or minimise service disruptions during public health emergencies as much as possible; (6) ensure personalised care focused on the biopsychosocial and spiritual needs and preferences of patients and their families; (7) provide patients with evidence-based information on complementary and complementary medicine; (8) train healthcare professionals on the provision of comfort and compassionate care and effective communication and information sharing with patients and caregivers; (9) facilitate communication between patients and informal caregivers; (10) develop effective protocols to address health workforce burn-out, including in the context of public health emergencies; (10) explore further the relationship between SHS and the concept of social suffering; (11) investigate the implications of caring for patients with SHS from a health system perspective and (12) focus research on people experiencing SHS who do not have social security and live across different Mexican states. These strategies can be also relevant for other Latin American countries in similar situations.

### Strengths and limitations

To ensure the methodological rigour and transparency of our study we followed consolidated criteria for reporting qualitative research.<sup>56</sup> To ensure credibility, we performed qualitative data analysis through investigator triangulation (SVD, DP-M and IPM-V). In addition, the study included participants with diverse age, schooling and clinical characteristics, which allowed for a comprehensive understanding of this problem. However, our study was limited to patients affiliated with IMSS and receiving care in three healthcare facilities in Mexico City; as a result, our findings are probably not entirely transferable to those consulting other healthcare providers in Mexico or in other countries. According to Lincoln *et al*,<sup>57</sup> “the degree of transferability is a direct function of the similarity between two or more contexts”. A reasonable expectation of this study is that their results can be transferable to SHS patients and their family caregivers who use IMSS health facilities, as most primary and pain clinics at IMSS have similar infrastructure and are ruled by the same clinical standards. In addition, it can also be transferred to other similar settings in low-income and middle-income countries; in this case, as Lincoln *et al* pointed “the judgement on transferability should be performed by readers, as they are more familiar with their situation and can infer if the transfer is reasonable and if the results of the research would be similar to their context”.<sup>57</sup>

### CONCLUSION

The multifaceted nature of SHS challenges the health system to provide holistic, high-quality palliative care. Policies directed towards expanding access to palliative care should consider integration into primary care, ensuring personnel are trained and medicines are safely accessible and redesigning services to satisfy the needs of both patient and caregiver.

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