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SOCIOLOGIE:

ORDEM E POLÍTICAS SOCIAIS NA ATUALIDADE

2

MARCELO MÁXIMO PURIFICAÇÃO
MARIA FILOMENA RODRIGUES TEIXEIRA
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Prezado leitor, saudação.

Colocamos à sua disposição a obra - “Sociologie: Ordem e política sociais na atualidade”, organizada em dois volumes. Uma obra que nasceu marcada pela força e expansão de seus discursos no campo das ciências sociais e áreas afins, requerendo diálogo e reflexão sobre questões que nos são caras, necessárias e urgentes nesta nova ordem social. Uma obra editada em várias mãos e idiomas, envolvendo pesquisadores de vários países, comprometidos com a reflexão permeada por ordens políticas e sociais que emergem em contextos sociais ao redor do mundo. Neste primeiro volume, os textos apresentam grande diversidade e estabelecem vínculos com as seguintes palavras-chave: Anatomia do idoso; Atualidades; Comunidade marginada; Desenvolvimento socioêconômico e humano; Desenvolvimento urbano; Engajamento; Estudo comparativo; Família; Feminismo; Gênero; Jornalismo colaborativo; Licenciatura; Liderança comunitária; Mediação da informação; Movimento Social; Mulher; Organizações; Pandemia; Política de cotas; Políticas sociais; Prática docente; Preconceito; Sociedade; Sociedade civil; Sociologia. Desejamos a todos você uma excelente leitura.

Marcelo Máximo Purificação
Elisângela Maura Catarino
Cinara Miranda Chaves

SUMÁRIO

CAPÍTULO 12

VOICES REFLECTING THE BURDEN OF DISEASE IN MEXICO

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ABSTRACT: The health profile of the Mexican population today is very different from that of a few decades ago. Talking about the new face of health care in Mexico requires approaches that are not only based on quantitative approaches. **Objective:** To analyze the experiences of people with different diseases in order to understand the paths they navigate in seeking health care and the perceived quality of service received. **Material and methods:** A qualitative study was carried out with semi-structured interviews and focus groups, as well as analysis based on categories indicative of the health-care process. **Results:** The family network was identified as the most important resource for people who are ill. The response from health services was insufficient, with families and social networks promoting diversified health-care options. The experiences analyzed reflected lack of warmth and quality of care on the part of public healthcare providers, as well as the need for families to incur out-of-pocket expenditures in order to cover their health needs. **Conclusions:** From the perspective of health-care systems, the voices of those reached by this study indicate multiple challenges for the health sector, particularly for public health services, as regards resources and quality of care.

KEYWORDS: burden of disease, qualitative study, seeking health care, quality of health care

VOZES DO FARDO DA DOENÇA NO MÉXICO

RESUMO: O perfil de saúde da população mexicana hoje é muito diferente do de algumas décadas atrás. Falar sobre a nova face da saúde no México requer abordagens que não se baseiam apenas em abordagens quantitativas. **Objetivo:** Analisar as experiências de pessoas com diferentes doenças a fim de entender os caminhos percorridos na busca de cuidados de saúde e a percepção da qualidade do serviço recebido. **Material e métodos:** Foi realizado um estudo qualitativo com entrevistas semi-estruturadas e grupos focais, bem como análises baseadas em categorias indicativas do processo de atendimento à saúde. **Resultados:** A rede familiar foi identificada como o recurso mais importante para pessoas que estão doentes. A resposta dos serviços de saúde foi insuficiente, com as famílias e as redes sociais promovendo opções diversificadas de assistência à saúde. As experiências analisadas refletiram a falta de calor e qualidade do atendimento por parte dos provedores públicos de saúde, bem como a necessidade de as famílias incorrerem em gastos extra-orçamentais a fim de cobrir suas necessidades de saúde. **Conclusões:** Da perspectiva dos sistemas de saúde, as vozes dos atingidos por este estudo indicam múltiplos desafios para o setor de saúde, particularmente para os serviços públicos de saúde, no que diz respeito aos recursos e à qualidade do atendimento.

PALAVRA-CHAVE: carga da doença, estudo qualitativo, procura de cuidados, qualidade dos cuidados.

1 I INTRODUCTION

The health profile of the Mexican population today contrasts sharply with the face it presented several decades ago. Each year, fewer children and women die prematurely, and fewer sudden deaths occur as a result of infectious diseases. Presently, people remain ill longer and suffer from several health conditions simultaneously, disease-related disability increasingly restricts the ability of patients to meet the requirements of daily life, and the moment of death is receding: people are dying later, but not necessarily healthier.[1-3]

Discussing the current health profile of Mexico[2] requires approaches that do not rely on numerical measurements and statistics alone; decoupling people and numbers from the social, cultural, educational, environmental and political contexts where they evolve does not permit an accurate understanding of the complexities inherent to implementing and ensuring the sustainability of health interventions. The process of providing care for people, whether they are healthy or ill, requires complementary viewpoints that enable a better understanding of behavior in the face of a wide spectrum of complex and varied health needs. As well as providing a more comprehensive understanding of the statistics based on a more humanitarian, caring, and just standpoint. To truly consider health as universal human right, it is essential to understand it from the perspective of healthcare service providers and the experiences of those who are ill and their families.[4]

Based on a humanized perspective, our study captured the experiences of a group of individuals suffering from different diseases. Our objective was to explore not only the paths they navigated when seeking medical attention, but also their perception of the quality of care they received from public healthcare providers.

2 I METHODS

We designed a qualitative study in order to recover the experiences and voices of individuals - and/or their family members - affected by the most representative health problems as identified in a recent study of the Burden of Disease in Mexico.[2]

Our selection of diseases included the principal causes of premature death and disability tabulated by the Global Burden of Disease Visualizations Hub (2010).[5] We analyzed the data by age group and sex,[5] taking into account the magnitude and representativeness of the diseases in relation to their burden at various levels: physical, emotional and service demand. The study population was composed of males and females within the following age groups: children under five years of age, children aged five years and older, adolescents, individuals of reproductive age, adults, and older adults. Table 1 shows number of informants by group.

Age	**Health Condition**	**Location Contacted**				**Total Informants**
		Chihuahua	**Morelos**	**CDMX**	**Chiapas**	
0 – 4	Congenital malformation	CREE*	CREE	CRIT£	Community Shelter	23 mothers, 2 fathers
5 – 14	Epilepsy	CREE		CRIT		11 mothers
12 – 18	Adolescent pregnancy	CAPSβ	CREE		Women's Hospital	4 mothers 7 adolescent women
15 – 49	Musculoskeletal problems/ Injuries, violence	CEPAVIΩ	CREE		Home Address	8 women 5 men
50 – 64	Diabetes/ Hypertension/ Cervical Cancer / Breast Cancer	UNEMEα Hospital Gral.		ISSSTEπ	Home Address	10 women 10 men
65 y +	Diabetes / Limited mobility	Health Center	CREE	ISSSTE	Home Address	17 women 8 men

Table 1. Number of informants by age group, health problem and interview location.
*CREE Rehabilitation and Special Education Center
£CRIT Infant Rehabilitation Center
βCAPS Primary Health Care Center
ΩCEPAVI State Center for Domestic Violence Attention and Prevention
αUNEME Medical Specialist Groups
πISSSTE Institute of Security and Social Services of State Workers.

The following health conditions were analyzed: congenital malformations, epilepsy, musculoskeletal problems, diabetes, hypertension, cervical cancer (CCA), breast cancer (BrCa), limited mobility, as well as accidental injuries, adolescent pregnancy, and gender-based violence.

Data were collected under convenience sampling in four states of Mexico (north, Chihuahua; center, Mexico City and Morelos; south, Chiapas).

To identify potential informants, we followed several strategies: mothers of children with congenital malformations and epilepsy (0-4 and 5-14 years old, respectively) were invited to participate through Telethon Children's Rehabilitation Centers (*CRIT* by their Spanish initials), the Rehabilitation and Special Education Center (*CREE* by its Spanish initials), and a community hostel; adolescents (12-18 years old) were contacted at the Advanced Centers for Primary Health Care (*CAAPS* by their Spanish initials), and subjects of reproductive age (15-49 years old) were approached at outpatient health services and a State Center for Prevention and Treatment of Domestic Violence (*CEPAVI* by its Spanish initials). Subjects with musculoskeletal problems were contacted at rehabilitation centers, and adults (50-64 years old) as well as older adults (65 years and older) at promotional, self-help and sharing groups pertaining to public health services, as well as in Medical Specialty Units (*UNEME*s by their Spanish initials) at public hospitals.

Additionally, 12 focus groups were organized (comprised of six-to-eight participants each) by age group and location (state), and 15 in-home semi-structured interviews were carried out where group formation was not possible. Both techniques were performed according to a thematic guide describing the health-care process for each of the selected diseases; the objective was to capture the experiences of the participants throughout their health-care process. The guide was organized into the following thematic categories: (a) perception of the health problem; (b) life experiences of individuals with a health problem; (c) paths to medical attention; (d) perception of healthcare quality; and (e) obstacles to medical attention.

We performed a qualitative content analysis based on the preceding categories. Data were coded using Atlas-ti v.7 software. To analyze the data collected, we organized the testimonies of the participants around the five aforementioned categories indicative of the health-care process. The results provided a description of the experiences that the participants or family members in the study groups endured throughout their care-seeking process, as well as a summary of the attention they received at healthcare facilities.

This project was approved by the ethics and investigation committee of the Instituto Nacional de Salud Pública. Informed consent was obtained orally for all participants once the study objectives, extent of participation required, and the management of participant confidentiality and privacy was explained. All information collected was transcribed, and participant information was deidentified. Those that agreed to participate were given a card with the contact information of the research team responsible for the study. An investigator of the team with a background working with vulnerable groups and in crisis containment training was responsible for the information collection.

3 I RESULTS

a) Perception of the Health Problem

According to the narratives of participants, the medical diagnoses were never well received. They were accompanied by a cascade of emotions including pain, anger, suffering, impotence, sadness, anguish, devastation, hopelessness, and annoyance. Even an adolescent who mentioned feeling happy knowing she was pregnant acknowledged feeling dread and fear at the same time.

In general, the participants expressed the need to gain a better understanding of their health condition - whether acquired or congenital – and to obtain more information about its origin, evolution and treatment. Those without medical information about their condition constructed explanations interweaved with religious beliefs, tradition, probability assumptions, and allusions to professional errors. For instance, the majority of older adults with diabetes were unable to clearly identify the origin of their disease: many mentioned hereditary factors while others referred to life experiences (traumas) as the cause of their condition.

b) Life experiences

The experiences of both the patients and those surrounding them were disrupted by the disease. It was not unusual for guilt to be associated with virtually all of the health conditions analyzed and to be assumed by the sufferers, who regretted not having taken care of themselves - the causes of their conditions ranged from poor diets to intake of toxic substances - not having recognized their condition in time and failing to act accordingly (particularly in cases of violence), and not having followed recommended medical treatment. They were also blamed by others for their situation, for example, the mothers of children with congenital malformations were often viewed as responsible for the condition of their children by family members. Testimonies of participants are presented in Table 2.

Category	Testimonial
a) Perception of the health issue	
Causes	*"…but in general, you're saying to yourself, seeing so [healthy] many children, it's not that they've done you wrong…but was it medical negligence? Was it because God wanted it that way? Better yet, I don't know if I should say God wanted it or not, or because it was time, or for some reason He sent this, there are so many things…" (Mother of a child with epilepsy)*
Blame	*"…for my husband's family, I'm to blame for what happened to the girl, I was always to blame. Why? -why didn't you take care of yourself, why didn't you eat better, why this, why that- and how would they know if I took care of myself if they never saw me during my pregnancy? We're married and they would put ideas in my husband's head -but no, she is to blame, if I were you, I'd leave her to carry her burden." (Mother of a child with a congenital malformation)*
b) Life experiences	
Changes	*"Well, the difficult thing about having diabetes is getting together with family and friends, it's not the same as when you didn't know about diabetes, because you could go out with friends or have family parties and grill steak and drink alcoholic beverages, so now what happens when the family has a reunion is that you isolate yourself, you leave to avoid the temptation (…), there are foods you shouldn't eat, so many times what one does, at least in my case, is have a small sample of everything and then leave, (…) -it's a lot of sacrifice to be here enduring this-…" (Man with diabetes)*
Feelings	*"- Well what happens when one realizes that they have diabetes is that one loses a lot of self-esteem, it is a matter of feeling as if you can't do anything, everything tires you out, you create an excuse for work, exercise, and even interacting with family, but I'm being well cared for and with control you can come back, like people say, to life, you are better again, you live better and exercise, you try to be useful, you don't stop being who you are -I'm sick and here I am- Right? So, with medication and help they give me, I move forward, while the diabetes can't be removed, it can be controlled…". (Man with diabetes)*

c) Pathways to medical attention	
Allopathic medicine	*"…when they see me and I meet those kind of people [people that do not visit clinics] I tell them, -no, look, they already took one [they removed one of her breasts], because I did not get a check-up on time and that's what's going to happen to you if you're stubborn like me, if you don't go and get checked- and they stay quiet, and then they start asking me questions, -what does it feel like, something?-, and I start to give my speech, I tell them -go and tell a family member to go too, and if you find something abnormal go, don't be stubborn like me-, I told them, -because you will end up just like me-…". (Woman with breast cancer)*
Traditional medicine	*"…I give him a special tea and look, he stopped convulsing (…), they cleansed him, maybe it was just the cleansing, well because my oldest brother mentioned that he was also like that, that he didn't want them to give him anything, he also says they cleansed him with an egg, and using herbs. (…) there are some things that are scientifically true, right? Especially when talking about if [healers] are actually effective, not all of them are charlatans, there are some where you say, -No, he is good…" (Mother of a child with epilepsy)*
Domestic Medicine	*"…we massaged him ourselves, with the ointments they prescribed and the compresses and nothing more…". (Mother of an adolescent son that suffered accidents and injuries)*
Syncretism	*"…when [my daughter] was in grave condition, in front of the house there lived a women that did cleansings and all of that, so my father in law went to that women and then called me, he told me, -you know what? The woman read my fortune and she told me someone with whom you have problems has hurt [your daughter] and that is why she is sick, since she is not baptized, all of the bad they were sending you fell onto the girl instead (…), they wanted to hurt you but it fell to the child and now what they want is to finish her, the woman also says that you should cleanse her with an egg and send her [to the woman] in order for her to see what is going on and so she can perform a vigil with a candle (…)-;I took an egg with me, and there in intensive care, I secretly cleansed [my daughter]…". (Mother of a child with epilepsy)*

d) Perception of healthcare quality	
Long wait times	*"…the wait for a consultation, they always give us one after two and a half or three months, for example now that I had a [muscular] tear, they did not attend me like they should have, I had to go to the Red Cross, so that they could give me a prescription for the pain, for the medicine, they gave me a shot there because when I arrived I could not walk, whereas at the Seguro Popular they will not attend you and well [I said], -doctor, I have a tear-, [they said] -well we can see you in two and a half months-…". (Woman with mobility issues)*
Efficiency	*"…so that is what is most difficult, that there is no timely and prompt medical attention, it is not difficult to wake up at 3 in the morning, at 4 in the morning, that is not hard, what is hard is that there is no decent medical care for us (…) you know? You go to the hospital and unfortunately there is no medical personal, the secretary is not there, the social worker is not there, the doctor has not arrived, and they start to hand out your number and you wait for two hours, that's it, why do you have to wait so long? (…) Here, do you have an emergency? Sit over there in a chair, a very uncomfortable chair, and you wait your two hours…". (Mother of a child with a congenital malformation)*
Information	*"…they didn't give me information, instead they told me, -you need to be in a course-, but they don't tell you for what reason, or why, so after 15 days you go to one of the courses and they [finally] tell you what they are for, so I say that the doctor should tell you, -you know what? You have cancer, this is what it is, they should tell you -the problem you have is this, you have to analyze the situation,- (…) I had to go to other places because I didn't know what cancer implied, what it was, nothing, they bombard us with information but we don't actually know what it means…" (Woman with breast cancer).*
Treatment	*"When Guillermo was born, honestly, I had to fight, fight is the correct word, I had to get down from the hospital bed after just giving birth, after a cesarean, with my catheter and my baby because he wouldn't eat, so I knew he needed something, I'm not a doctor but I'm also not ignorant, they wouldn't listen to me, until I left my bed and told them, -hey, my son hasn't eaten for 4 hours, he won't eat, he won't latch- (…) far from being rude, I had to be vulgar, but the only thing I gained was that they sent [my son] to the third floor, he didn't need an incubator but he did need some type of catheter (…) he needed platelets and I told the doctor, -doesn't the hospital have a [blood] bank? Please realize what you're asking me to buy, where do I look for [platelets]? Where can I find them?- as if I could just go to OXXO [a store] to buy platelets, when in the hospital they had platelets…". (Mother of a child with a congenital malformation)*

d) Obstacles to medical attention	
Limited Resources	*"…we have IMSS [insurance] but even so, there are times when the child needs medicine or catheter kits and we have to buy it all ourselves, medicine that sometimes our insurance does not have, we also have to buy ourselves, so yes, sometimes our insurance helps, but there are times we really need help, and we are pressed for money…". (Mother of a child with a congenital malformation)*
Costs of the illness	*"…the doctor told me, -no, you know what? We have to perform a biopsy because it looks like there is something wrong-. So then I asked the doctor, -well, how much money are we talking about for the biopsy?-, -around 5 to 8 thousand pesos- he told me, so I said -I don't have that, but it's not much, I can get it, but what happens if I am sick? He then says -if there is something wrong it will cost you an arm and a leg-, so my children told me -mom, stop there because we don't have the means, if they remove that, then it will be like pruning the cancer, it will just return with more-, [the cancer] would invade [my body] faster…". (Woman with breast cancer)*
Social values	*"…I have neighbors, that no matter how many times I tell them to get checked [they say], -oh, later on-, -oh no-, -I'm scared-, -I don't have time-, -I'm too embarrassed-, but it's better to lose a short time than everything…". (Woman with breast cancer)*
Discrimination	*"…we live in a society where we still do not have that culture where special children are treated equally, they are people and they make different sounds because they are different, that is, children can be cruel, but even adults are cruel sometimes with their stares, it's the type of stare, you don't know what the child is feeling, but when the child starts to understand, when they look in the mirror or when people look at them differently, they start to feel depressed…". (Mother of a child with a congenital malformation)*
Lack of social networks	*"It is because of the problem I have [the illness], because before [my daughters] would come see me, they would visit me when I was fine, when I worked, and all of that and now that I can't work, not anymore, they don't come anymore…". (Man with limited mobility)*

Table 2. Testimonials about the perceptions of the health care process.

The lives of the participants were changed by disease. Their conditions posed specific needs that forced them and their families to modify their lifestyles. One of the adjustments made most frequently by the families of adolescents with injuries was to reduce recreation and leisure, thereby limiting their interactions with other family members.

On receiving a diagnosis of breast cancer, the women interviewed felt compelled to immediately adhere to the restrictions indicated by the medical staff and distribute their household tasks among other family members, most frequently their sons and daughters, although their partners also shared the work.

Men with diabetes repeatedly recounted the activities they could no longer perform and the restrictions they had been forced to accept as a consequence of their disease, especially emphasizing diet changes. They also reported changes in their character and mentioned the need to "once again learn how to live, but differently" in virtue of all the adjustments they had been obligated to make, beyond diet changes and regarding their interpersonal relations and family lives.

The participants related feeling discouraged and disappointed by their situation, with lower morale and affected self-esteem. It is noteworthy, however, that these emotions may be overcome or eliminated if their conditions were properly controlled and monitored.

c) Paths to Medical Attention

The paths to health care were contingent on circumstances involving both the disease and the patient (e.g., age and sex). Participants were motivated to seek care for a number of reasons. For instance, women with BrCa recalled symptoms that drew their attention such as nipple discharge and lumps or bulges, and then with information they had heard through various sources such as television or other women, they became concerned enough to seek medical attention. Other women recognized, however, that the presence of these signs and even information from outside sources, had not been sufficient reason for them to take action. In many cases, the influence of people who were close to them and had experienced the same problem was key to seeking assistance early on and in identifying and adopting preventive behaviors.

Persistent pain was the symptom that most frequently compelled participants to seek medical care. Disability was also cited as a cause for seeking care, with a large proportion of older women postponing the search for assistance until reaching a state of immobility without knowing why. In some cases, family members contributed to a delay in seeking care by underestimating the symptoms and/or discomfort expressed by the participant.

The testimonies of the participants concurred that allopathic medicine and its various options represented the optimal health-care recourse, in which they had placed their hopes and expectations for improvement in either their own condition or that of their sons and daughters. However, the course of events surrounding their illness had forced them to knock on other doors and seek alternative resources for their needs. For instance, as regards emergency services, women and their partners felt an urgency to receive care, which tended to differ from the perceptions of the medical and administrative staff. Therefore, participants did not receive assistance when requested and were thus forced to seek other providers and/or spaces to be attended to.

Likewise, affiliation with a public health institution did not always guarantee the provision of care. For instance, several families covered by the Seguro Popular government insurance program had been forced to seek other health-care options since the Seguro Popular did not include many of the healthcare interventions they required.

Participants with sufficient economic resources utilized private healthcare providers, which they believed provided more a accurate diagnosis due to the usage of better technology. Some participants also mentioned practice of traditional and domestic medicine, as well as religious rituals. When health-care services became inaccessible due to lack of resources or other reasons, some patients continued their care at home.

d) Perception of Healthcare Quality

When participants sought medical attention at public healthcare providers, they were met with long wait times and delayed appointments which gave rise to a perception of a system that offered neither efficiency nor quality.

An examination of some of the diseases included in this study revealed difficulties associated with the quality of healthcare services that were received. For example, many who sought medical assistance at public health facilities for congenital malformations described the care as mistreatment, characterizing it as inappropriate, rough, rude, unfriendly, and inhumane, with some women reporting that they were forced to demand timely care, as they had neither been listened to nor acknowledged. In addition to the quality of the care itself, the constant rotation of service providers was identified as a problem that often interfered with follow-up care for their condition.

The lack of information provided by medical professionals was a recurring complaint of patients and their families, along with insensitivity on the part of personnel on different occasions. Women with BrCa reported that the information they received from medical staff was limited, preventing them from making sense of the numerous interventions recommended by staff themselves, and from pursuing any needed additional measures. This situation combined with what patients had heard from people outside the medical profession (lay knowledge) led to erroneous explanations that lacked medical expertise and in turn mitigated the anxiety of patients; this gave patients a false sense of security. In contrast, individuals receiving care for certain chronic diseases such as diabetes reported that they had received a favorable response from medical providers.

e) Obstacles to Medical Attention

The respondents faced many obstacles in their care-seeking process. Firstly, they were often forced to see multiple professionals in order to receive the most complete diagnosis and treatment possible. This led to increased expenses, given the need to buy medications, pay for required therapy and cover the travel costs incurred when referred to other providers. Those with congenital malformations often faced out-of-pocket expenses despite being insured through a health institution. In general, the cost of care (for transportation, medication and rehabilitation) often exceeded the ability of patients to pay, becoming the principal obstacle to seeking and obtaining medical attention. Some conditions such as diabetes and accidental injuries required prolonged care and/or rehabilitation. Several women also mentioned the need to pay for follow-up treatment of their adolescent children until their resources were depleted. Among older women, problems of mobility were often complicated by the lack of employment, limiting their income and hence their access to medical care. Women frequently listed the following reasons for their procrastination in seeking medical attention: the need to take care of their children – their highest priority - excessive work both inside and outside the home, the lack of support from their partners, and limited resources.

Several respondents emphasized that diseases such as cancer required many years of specialized treatment not guaranteed by health services. For women with BrCa, the lack of access to public health services and the high cost of care were problems which interfered with the need to address their health condition. Notwithstanding these limitations, they continued to seek alternatives when possible.

Older adults with diabetes explained that controlling their condition obligated them to take on more responsibility as they required in-home procedures. However, for them, this sort of domestic follow-up was difficult, as it represented additional expenses (buying glucometers and test strips) which they were unable to afford.

Many participants had manifested symptoms that were misunderstood or not seen as linked to serious health problems, leading them to postpone seeking medical assistance in a timely manner. Moreover, some health conditions went unnoticed, such as domestic violence, which had in many cases been normalized and become part of the difficulties of daily life. In these cases, somatization was common, with participants often failing to connect these symptoms to the violence, at times even refusing to acknowledge it. Women also frequently mentioned that medical professionals had little time to explore the underlying causes of their symptoms, making it difficult to identify domestic violence as a health problem in a timely fashion.

Another kind of obstacle reported pertained to the social sphere, specifically as regards discrimination. Several participants were discouraged from seeking care for reasons related to the fear and shame of being criticized and/or judged.

For most participants, support networks were present at the beginning of the life cycle but weakened or disappeared with age. Illness itself affected the social networks, since it involved not only the patients, but also the family and the people around them. As stated by one woman with cancer, “when one has cancer, the whole family is sick,” referring to the involvement of family members who shared the burden of the diagnosis and arranged treatment for the disease. According to the self-reports of participants, particularly of older adults with diabetes, it also fell to the family, mostly the daughters, to offer words of encouragement and help motivate their mothers, who often felt downhearted.

Even if family was a bulwark of support for many facing illness, this resource was not always present for all health conditions, nor in all stages of life. Accounts from older adults with limited mobility indicated the loss of their support networks after retirement. The departure of children from the family home, with the consequent lack of needed practical and emotional support that this entailed, affected older women, who became more vulnerable as they no longer enjoyed the autonomy of youth, and were forced to face their risks and need for care alone. Main results are concentrated in Figure 1.

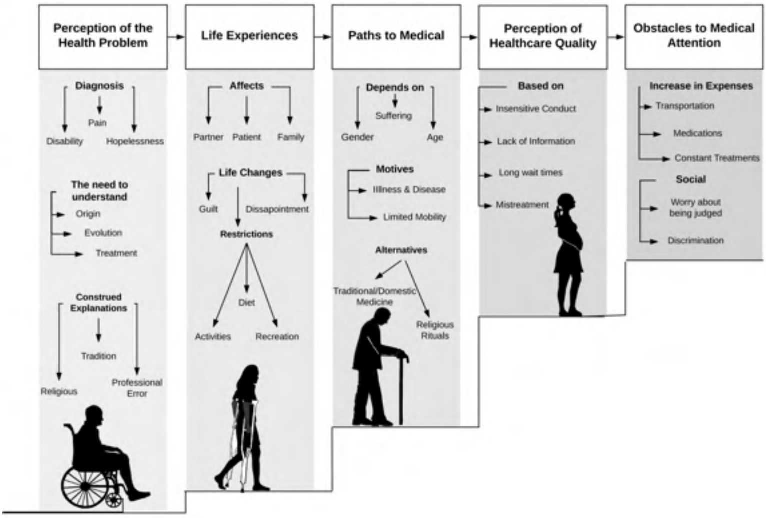

Figure 1. Perception of network support.

DISCUSSION

The health situation prevailing in Mexico today reflects a complex epidemiological reality combining communicable diseases with a growing burden of chronic and degenerative conditions affecting an increasingly older population.[6,7] Health services confront a continuing demand for consultations where conditions are no longer acute or unique but chronic, and resulting from multiple causes (e.g., comorbidity). Solutions therefore require a more sophisticated and comprehensive medical framework.[8,9] It is imperative to adapt the Mexican model of care to the new health demands. Given the qualitative nature of our work, listening to the voices of ill people and/or their families allowed us to clearly visualize the gap between the experiences of people suffering from the most relevant health problems in Mexico and the response of health services charged with resolving them. Our findings point to a number of opportunities for improvement in the care offered by providers and health services.

It is clear that seeking medical attention is not always synonymous with finding satisfactory assistance, because of failures in the health-care system. Furthermore, care is often not sought at all or is delayed because of cultural factors such as the lack of importance accorded to individual health, and/or a perception of low risk with regard to certain health conditions. As other authors have noted, understanding these factors is necessary for implementing actions to improve the organization of health services in pursuit of a more effective, equitable, efficient, and accessible response to the health needs of the population.[11,12] Listening to the voices of service users clearly indicates the need to adapt health-care institutions towards providing continuity of care for long-term conditions (e.g., diabetes mellitus, congenital malformations, problems of mobility among older adults, breast cancer, and somaticized domestic violence). The experiences analyzed also spotlight the need for incorporating new treatments and rehabilitation programs[13] (particularly for congenital malformations, injuries, limited mobility and gender-based violence). The voices of the ill, and/or their families were expressed as a wave of complaints regarding the quality of health services. Above all, the interpersonal aspect of care, one of the main criteria for judging all health care systems was reported as having inadequate or completely lacking dignified treatment of patients, timely and clear information, and patient education to promote better decision making in regard to disease treatment.[12,14-16]

The narratives of our informants also point to gaps in the supply and coverage of health programs, lack of interventions targeted at problems characterized by their frequency as opposed to their severity, persistent out-of-pocket expenses, and the devastation of having to pay for catastrophic health care as documented by other authors.[17-19]

Although the health-care system undertakes actions that – from the perspective of our respondents – represent good service and generate important advances, the challenges persist. Actions must be oriented around the needs – rather than the diseases - of patients, thus fostering a person-centered model. Additional approaches promoting new strategies for services and care are also needed.[20-23]

All the health conditions discussed in this study immediately alter the course of life, not only for the patients, but also for those close to them, a phenomenon also documented by other authors.[24] Emotions marked by rejection, fear, anger, guilt or self-blame, as well as the need to make adjustments to the environment, also require the creation of new or improved approaches to care including psychological strategies and sources of support capable of promoting wellbeing in the population.

Studies on the burden of chronic degenerative diseases[2] situate these among the principal causes of multimorbidity. Conditions not prevented or detected at the primary-care level – with the patients often having to consult several physicians before receiving a diagnosis - ultimately require care that is expensive from a social, physical and economic perspective, and become a burden for services as well as for patients and families. In light of the current health needs of the population, coupled with the ongoing socio-demographic and epidemiological transition in Mexico, health services must be reoriented not only towards health promotion and disease prevention, but also towards strategies for controlling chronic illnesses. Special emphasis must be placed on ensuring long-term care, avoiding obstacles and providing services that are able to resolve the needs presented by patients.[25]

Long-term health conditions, such as those addressed in this study, affect not only the patients, but the families too, as all share the experience of suffering. The support and care provided by the family are vital for recovery. However, families dynamics have sustained significant changes - partly as a result of migration and employment demands - and are often no longer in a position to provide the care and support that patients may need.[26,27] This is a relevant factor which the health-care system must take into account.

One of the limitations of this study is that the states in which information was collected were chosen for convenience, and thus, do not necessarily represent a methodological criteria that could amplify the diversity of the patient experiences within different contexts and enrich the understanding of the subject.

Nevertheless, we consider this study a first approach that may enrich future quantitative analysis of the disease burden in Mexico.

In conclusion, the voices in our study underscore the importance of drawing on public input in determining health-care needs and priorities. Taking the affected population into account, and understanding their experiences with disease as well as their life conditions, environments and needs provide guidelines for improving the organization and provision of health services. We hope that the present document contributes to this effort.

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