

# Community and health staff perceptions on non-communicable disease management in El Salvador Health System: a qualitative study

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## Research article

**Keywords:** Non-communicable diseases, community health, El Salvador, qualitative methods.

**Posted Date:** January 30th, 2020

**DOI:** <https://doi.org/10.21203/rs.2.16156/v2>

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**Version of Record:** A version of this preprint was published at BMC Health Services Research on May 27th, 2020. See the published version at <https://doi.org/10.1186/s12913-020-05249-8>.

## Abstract

Non-communicable Diseases (NCDs) are the leading cause of global mortality and disability, with a rising burden in low- and middle-income countries. Their multifactorial aetiology, and their requirement of long-term care, imply the need for comprehensive approaches. From 2009, the Ministry of Health (MoH) in El Salvador has developed a national public health system based on comprehensive primary health care. This study aims to describe the different stakeholders' perceptions about the management of NCDs along the pathways of care in this health system. During three fieldwork periods in 2018, three complementary qualitative data collection methods were deployed and conducted in high prevalence of NCDs settings within El Salvador. First, we used illness narrative methodology to document the life histories of people living with a chronic disease and being treated in second and third level health facilities. Second, through social mapping, we analysed support-resources that NCD patients used throughout the process of their illness within the same settings. Third, semi-structured interviews were conducted in the same locations, with both chronic patients and health personnel working at different levels of the primary health care setting. Participants were recruited through purposive and snowball sampling, and a deductive approach was implemented for coding during the analysis phase. After grouping codes into potential themes, a thematic framework was elaborated through a reflexive approach and triangulation of the data. This innovative approach of combining three well-defined qualitative analysis frameworks identified key implications for the implementation of a comprehensive approach to NCDs management in resource-poor settings. The following dimensions are identified: 1) social risk factors and barriers to care; 2) patient pathways to NCDs care; 3) resources available identified through social connections mapping; 4) trust in social connections; 5) community health promotion and prevention of NCDs management. The Salvadoran public health system has been able to strengthen its comprehensive approach to NCDs, combining a clinical approach – including long term follow-up – with a preventive community-based strategy. The structural collaboration between the health system and the (self)organized community has been key to identify failings, discuss tensions and work out adapted solutions.

## Background

Non-communicable diseases (NCDs) are a major health priority in low- and middle-income countries (LMICs).<sup>(1)</sup> In 2016, over three quarters of NCD deaths (31.5 million) occurred in these countries, with near to half of these deaths before the age of 70.<sup>(2)</sup> Though largely preventable, these illnesses are the leading cause of global mortality and disability, and have complex social, economic and environmental aetiologies.<sup>(3,4)</sup> The burden created by NCDs undermines individual and family well-being and hampers social and economic development, with a particular threat to vulnerable populations.<sup>(5)</sup>

In El Salvador, NCDs are a leading cause of early death among the adult population. Lifestyle behaviours such as low consumption of fruit, vegetables and water, excessive consumption of saturated fats and sugary drinks, but also exposure to agrochemicals, are the main risk factors, directly linked to social and structural barriers. During the period of 2011-2015, the Ministry of Health (MoH) recorded 48,554 NCD deaths, with cardiovascular diseases accounting for 12.0% of the total deaths registered nationwide, followed by chronic kidney disease (CKD) at 6.3%, cancer at 5.4%, and diabetes mellitus type 2 (DM) at 3.0%.<sup>(6)</sup> Though the World Health Organisation (WHO) does not consider CKD to be part of the NCD group, it was included in this study due to its high prevalence in the country.

Since 2009 – within a context of important levels of poverty and social violence – the Salvadoran government developed a strong primary health care (PHC) policy, increasing access to care, with emphasis on remote populations.<sup>(7)</sup> In this context, the current study explores the different stakeholders perceptions about the management of NCDs along the pathways of care in this health system. Our hypothesis is that a well-structured and sufficiently resourced PHC system can ensure adequate pathways for diagnosis, care and long-term treatment for people living with NCDs.

Due to the high burden of NCDs, there is a growing interest in effective strategies to address complex community health issues, especially when health systems face significant resource constraints.<sup>(8)</sup> Hence, this study also describes the extent to which an intensive coalition between the public health care system and an organized community can support a comprehensive approach to NCD care. For this, three complementary qualitative approaches were combined and conducted in the same locations within the country. At the hospital level, we elicited narratives of patients with a long NCD history on their illness experiences and health seeking. In communities, we mapped health care resources reported by patients, and how these were used. And within primary health services we examined the experiences of both patients and PHC providers in the diagnosis and management of NCDs. This study is on line with other studies reporting on a scarce resource country, like Cuba. In this trial,, Stein and Susser<sup>(9)</sup> had the opportunity to observe the Cuban health system during a consultancy undertaken for the World Health Organization and found that postrevolutionary Cuba had placed a high priority on health, and aimed to create a health service that is comprehensive in scope and content, in population covered, and in organizational forms and levels of specialization. They highlight that their achievements cannot be understood without an appreciation of the social and political context within which they occurred.

Furthermore, community-based noncommunicable disease interventions have been shown to be effective in the management of NCDs in developing countries<sup>(10)</sup>; this study reveals how programmes should be planned, run and evaluated according to clear principles and rules, collaborate with all sectors of the community, and maintain close contact with the national authorities.<sup>(10)</sup> This is a novel study as it describes how NCDs are managed in low resource setting by taking into account not only a comprehensive health system approach but also taking into account the social, economic and political environment that impact on the NCD management and therefore including the communities in their healthcare management.

El Salvador, the smallest country in Central America, has suffered several periods of armed conflict during its history. The 20<sup>th</sup> century alone included a military dictatorship from the early 1930s to 1979, and a civil war from 1980 to 1992, during which 75,000 civilians were killed. A long and complex process led to a peace agreement in 1992 and the transition to formal democracy. In this period, the Farabundo Martí National Liberation Front (FMLN), a leftist guerrilla organization, became a political party, which later played a key role in the development of a comprehensive health reform. From 1992 until 2008, neoliberal governments ruled the country. This period saw structural neglect of the public health system accompanying health sector privatization, further developing an already dramatic socially divided country.<sup>(11)</sup>

Currently, the war between gangs ("*maras*") among the young population, remains a serious social problem, leading to displacements and thousands of deaths every year. The UN has classified El Salvador as one of the deadliest countries in the world outside of a war zone, with more than 108 homicides per 100,000 inhabitants in 2015. Young people are the most affected by violence: more than half of the victims of homicide in El Salvador, Guatemala and Honduras in 2015 were under the age of 30. El Salvador continues to have one of the highest murder rates in the world with 3,605 homicides per year in 2017; 429 of which were femicides.<sup>(12,13)</sup>

From 2009 until 2018, the FMLN played an important role in the government. The *right to health* was core to their political programme. The new MoH embraced and further developed community participation in the preparation, development and management of the health reform.<sup>(14,15)</sup>

Over the last decade, El Salvador has developed a strong integrated public health system, in which organized social participation – defined and implemented as a structured democratic space for the accountability of health care institutions – played an essential role in *building trust* between the public health system and the population.<sup>(14)</sup>

The Salvadorian approach builds on the extensive experience of the People's Health Movement on how organized communities can support – or even accelerate – the implementation of comprehensive approaches to community health. The struggle for accessible health care has always been part of a broader movement for health equity and social change.<sup>(16)</sup> Moreover, health providers can play a strong supporting role in strengthening people's empowerment.<sup>(17)</sup> Opportunities for this depend on the context in terms of national health policies and existing levels of community organisation or involvement. In El Salvador, the National Health Forum (NHF), a broad national movement of organized civil society, strongly supported the rollout of the health reform, encouraging community participation at all levels.

Through its empowering strategies and active mobilisation, the NHF aimed at strengthening the participation of community leaders in the co-management and control over health policies, practices and services. The movement also mobilised in support of the health reform's efforts towards universal access, universal health coverage, and the pursuit of equity.<sup>(18)</sup>

Within this context, the MoH launched its "*Multi-sectoral National Strategic Plan towards the Comprehensive Management of Non-Communicable Diseases in El Salvador*".<sup>(19)</sup> The plan implemented interventions for the prevention and control of NCDs recommended by the WHO Global Action Plan of NCDs 2013-2020.<sup>(20)</sup>

It addressed three aims: first, the development of programmes for NCD management, aiming at prompt prevention and effective treatment, pursuing an efficient system of early diagnosis, and the development of educational programmes; second, the coordination of activities with other public institutions and with community organizations for the prevention and control of NCDs, aiming at a comprehensive and multidisciplinary national programme; and third, multi-sectoral interventions with broad social participation to reduce NCD morbidity and mortality. Hence, our study also described the part that social participation played in the implementation of these proposals, and the lessons for structured processes of social engagement with care and prevention of NCDs in settings of fragility.

This work relates to other Global Health research from the [NIHR Research Unit on Health in Fragility \(RUHF\)](#), at the Institute for Global Health and Development at Queen Margaret University (QMU) in Edinburgh, emphasizing strengthening the provision of quality care for non-communicable diseases and mental health in fragile settings: Syrian refugees and host communities in Lebanon, fragile communities in Sierra Leone, and El Salvador.

## Methodology

### 3.1 Study setting

This study was conducted in two urban and five rural locations across five regions throughout El Salvador: the departments of San Salvador and San Miguel (phases 1 and 2), Usulután (phase 2), and Chalatenango, Morazán and Bajo Lempa (Usulután) (phase 3) (Figure 1). The health facilities visited, which were located in the central, oriental and metropolitan regions; were selected to represent variation in size of health infrastructure, population served, geographical characteristics, and prevalence of chronic conditions (Table 1). Access to data collection sites was facilitated by members of the MoH, social movement members, and medical staff from the health facilities where data were collected. The three phases were conducted in the same regions but used different methodologies and study population as described later.

### 3.2 Study design

Along with a documentary review, this study used the triangulation of three complementary qualitative methods to give voice to participants and gain an in-depth understanding of patient and provider experiences related to NCD care.

- 1) The collection of illness narratives of patients with chronic kidney disease (CKD) and diabetes mellitus through in-depth interviews in a national and a regional public hospitals.
- 2) The analysis of social connections of NCD patients, aiming at obtaining an insight into the social networks of NCD patients. For this, an adapted version of a participatory tool<sup>(21)</sup> was used. This tool was designed to map social relationships in humanitarian contexts to gain an understanding of the social resources available to communities affected by conflict <sup>(21)</sup>. Here, the tool was used to provide detail on the social networks of NCD patients in *the specific fragile conflict affected context* of El Salvador. The methodology enables communities to participate in identifying levels of connection and trust among the people and organisations that can provide support with their NCD management within their context. The tool was implemented with technical support of QMU researchers who have already used it in other fragile and conflict affected settings.
- 3) The semi-structured interviews with patients and staff members in primary health care setting aimed at understanding the pathways of NCD care within the health system from the viewpoint or perception of the participants, emphasizing community perspectives and the role of social participation to strengthen NCD services. One of the objectives was to identify the role of the social movement in NCD care.

### 3.3 Data collection

Data were collected to inform on the two levels of care: specialized and primary health care and what resources are available to manage NCDs; in three respective phases, taking place in November 2017, March 2018 and June 2018.

#### 3.3.1 Patient illness narratives using in-depth interviews

Through in-depth interviews, six illness narratives were collected during the first phase of data collection. Three of the illness narratives were secured with patients at Rosales Hospital. Rosales hospital is the National and public hospital of El Salvador. It's located in the metropolitan region, where there are more cases of the main NCDs within the country <sup>(6)</sup>. Patients were therefore selected from this hospital as it attends people coming from all over the county, hence the research team selected it in order to explore the different experiences and pathways of support among patients coming not just from the capital but also from very remote areas of the country. Moreover, it is the main hospital where severe complications of NCDs are treated.

In addition, three interviews were obtained at San Juan de Dios Hospital, in the city of San Miguel, in the eastern part of the country (oriental region), where there is highest incidence of CKD in the country. This hospital is a referral public hospital for CKD management with an interdisciplinary approach and promotion of Ambulatory Peritoneal Dialysis. The hospital also has a dialysis unit where interviews were conducted. Patients were selected from this hospital to explore in detail the management of a "less common" NCD due to its high prevalence (El Salvador rates among the highest worldwide), and a hospital located in a rural setting.

CKD and DM patients were purposively selected for illness narrative interviews, given the high prevalence of these diseases in the country (487,785 patients with CKD and 459,114 with DM) <sup>(22)</sup> and also because of the social factors involved in the aetiology of both diseases (e.g. diet, access to fresh water, sedentarism, violence, pesticide use).

The interviews elicited information on the patients' background, family history, social networks and health, with emphasis on detailed patient experiences with treatment initiation, follow-up, care and support, communication with providers at each stage of treatment, and the broader social and structural determinants of health care accessibility and quality.

The illness narratives were developed in the hospital environment (endocrinology unit, nephrology unit and dialysis unit). Hospital settings are supposed to be the last step of care, giving an opportunity to explore the “causes of the causes” and the different stages in the development of the disease and the pathways of care. <sup>(23)</sup> Furthermore, the information on existing support through social networks and community structures was included.

Illness narratives are a useful means to access patients’ perspectives on illness. They provide a means to gain an in-depth understanding of the pathways of care and treatment of people living with NCDs, taking the sociocultural and political context into account. <sup>(24)</sup>

### **3.3.2 Mapping participants’ social connections using a social connections mapping tool**

The second phase of this study aimed at getting an insight in the formal and informal support resources available to people with NCDs, by mapping their network of social connections and their levels of trust with the connections identified.

Mapping participants’ network of connections was ensured through a series of participatory mapping workshops, designed to elicit awareness of local social connections and resources. Participants were asked about the different people and organizations in their communities they identified to be helpful if encountering problems during the stages of care.

Five workshops of four participants each were carried out to cover communities organized under the auspices of the NHF social movement, as well as those that were not organized under the NHF movement. Workshops were held in two urban areas of San Salvador: District 1 (organized) and San Jacinto (non-organized), and three rural areas: Nueva Granada, Usulután (organized); Tierra Blanca, San Miguel (organized); and Pamchimalco, San Salvador (non-organized). These settings were selected to capture urban and rural settings. They were developed in community settings chosen to be near the hospitals assessed in phase 1 (illness narrative interviews), Rosales Hospital and San Juan de Dios Hospital, hence, as aforementioned, where more cases of NCDs are present.

During the workshops, participants were presented with three disease-based problem scenarios – diagnosis, acute episodes, and follow-up in order to determine who they might contact and to whom each of these connections might pass them on to, if necessary. Responses were plotted on paper linking persons or organizations to the problems for which they were accessed.

After mapping social connections and resources in the different stages of care, participants were interviewed individually to determine the level of trust placed in each of the identified sources. For all connections identified, participants were asked to grade the level of trust they placed on each of them. This process was facilitated through a card sorting activity where the researchers produced a set of cards with each of the identified connections written clearly on each card. Participants then graded the cards by placing them in one of three piles representing either no trust in that resource, some or little trust in that resource, or high trust in that resource.

### **3.3.3 Semi-structured interviews with NCD patients and staff members in the first line setting**

The third phase of data collection involved conducting semi-structured interviews with NCD patients and their health providers, building on the findings from the illness narratives and social connections mapping. The objective was to gain an extensive understanding of patient and provider experiences with NCD care in the first line setting.

The study population consisted of staff members working in PHC facilities and of patients with one or more NCDs attending these units. Purposive and snowball sampling methods were used to recruit participants, as is it useful to study networks and when the researcher know little about a group or organization to study or “hard-to-reach” populations. Sampling used the snowball approach as it uses a chain- referral where staff members and patients were initially identified by referral of the health units coordinators which assessed eligibility; and purposive sampling as we identified participants from specific locations of the target community’s characteristics. Participants were interviewed at their place of choice, either in the workplace or domicile.

Interviews were conducted with 14 NCD patients and 12 staff members using a semi-structured interview guide. Patient inclusion criteria was being over 35 years of age, living with an NCD, and receiving care from the PHC units. The age group was determined based on the WHO-defined ‘higher risk group’ for NCDs. <sup>(23)</sup> Patient interviews covered aspects of their experience seeking and/or receiving care at the PHC facility, and included questions on treatment initiation, care and support, communication with providers at each stage of treatment, and the broader familial and social context of their medicine-taking (or other aspects of care seeking) behaviour.

The 14 NCD patients interviewed suffered from cardiovascular disease, DM and/or CKD (Table 2). The median age of those interviewed was 64 years old.

Staff member interviews were included to incorporate a comprehensive understanding of the PHC system by presenting the providers’ perspective of NCD care. Health professionals working in different levels within PHC were selected to participate (Table 3.)

### 3.4 Data management and analysis

All interviews and participatory workshops were conducted by the researchers in Spanish, and were digitally recorded. For data analysis qualitative information collected was transcribed. After transcribing, audio recordings were permanently deleted.

All qualitative data were then coded, both manually and using NVivo Qualitative Analysis Software version 10.0. A deductive approach was used to develop an open coding system around the topics of patient pathways to care, and patient and provider interactions and experiences of care. The last step involved collating the coded data into a unique pre-defined thematic framework (Table 4). In Table 4 we also report the piece of qualitative data that was extracted from each of the methodologies used

Data collected through each of these methods were analyzed separately, and subsequently triangulated to identify consistencies or variations across the dataset and therefore, fulfil our thematic framework.

### 3.5 Ethical considerations

This study was approved by the National Health Ethics Committee of El Salvador (CNEIS/2018/005\_A) and by the ethics committee of Queen Margaret University in Edinburgh. All participants were provided with information sheets detailing the objectives of the study and their rights as participants. Written informed consent was obtained from each participant prior to their involvement, with participants being informed of their right to decline to take part and/or leave at any time.

## Findings

From across the three sources of data collection, the following key issues were identified:

1) social risk factors and barriers to care; 2) patient pathways to care; 3) resources available identified through social connections mapping; 4) trust in social connections; 5) community health promotion and prevention of NCDs; management. These are described below.

### 4.1 Social risk factors and barriers to care

Social violence due to the long war and unrest suffered in the country, along with the ongoing disputes among criminal gangs, has strongly affected communities' health and their ability to secure continuity of care. This social violence has a long history, from the period of military dictatorship (1930-1979), over the civil war (1980-1992) and the social consequences of a neoliberal economic and social policy (1992-2008). This protracted situation of social unrest had an important impact on the mental health status of the Salvadorian population, worsening the management of their chronic condition. Many chronic patients interviewed related their illnesses to stress situations and shocks derived from this situation. More than a real causal relationship, it illustrates the tensions for the poorer layers of the population during that neoliberal period.

*They found I had high sugar, but at the beginning, the doctor told me that maybe it was just because of stress, because look, so much that we lived during the war, for 12 years. That is why one has acquired so much harm. Then, I went to consultation and the family doctor told me that these are the consequences of the war. (Patient with DM)*

During the interviews in, specially primary health settings (phase III); social violence, unhealthy lifestyles and economic barriers were mention as the main social risk factors for developing an NCD.

Health providers further identified lifestyle factors such as diet as a major barrier to care, highlighting that participant backgrounds and economic situation needs to be considered in order to facilitate healthcare access.

*The biggest challenge is that patients need to comply with taking their medication or following other recommendations. Especially when these recommendations have to do with lifestyle, principally with the diet. (General practitioner)*

*"The economy is the main reason for not changing the diet, they look for the most economical way for their families and here the "pupusas" are very common, all the people here eat them because they are cheap and accessible, most people eat fried meals even if it is so unhealthy." Health educator.*

Patients also emphasized that economic barriers contribute to these risk factors.

*It is expensive to maintain a healthy diet. I can't, and not everyone has everything, we can only buy very little. (Man with hypertension and CKD).*

It's in the primary health care settings where we observed a comprehensive approach to lifestyle behaviors by promoting community-based NCD management that considers the population's social and economic environment. An example of this was a local radio, set up by a collaboration between the PHC centre of La Palma and the local school, which engages adolescents to promote health eating and other healthy lifestyle behaviour through a weekly program, as reported by one of the nurses of Chalatenango.

#### 4.2 Patient pathways to NCD care

Given the above challenges, it was important to consider how these issues affect patient and provider experiences of NCD care. There is a clearly reported pathway a chronic patient follows. In the case of hypertension and DM, patients go to primary health care with the onset of symptoms such as fatigue. In some instances, patients may present at the PHC facility because they feel scared due to the ongoing social violence, causing them to have chest pains or even depression.

*For me this started because of some problems that the family had with people. The problem was, they told me that they were going to kill a son of mine .... From that I was left with that distress. And from there I got a lot of affliction, I had a lot of sadness with a desire to cry, I had no joy, and a strong pain in my chest. (Patient with hypertension)*

Related to CKD, patients present a severe condition of their disease at the moment of diagnosis, hence revealing a big problem of underdiagnosis. Therefore, the hospital (specialized care) is the entry point in many cases.

*Several factors may influence in that they are seen at the hospital level, because they have not been followed previously in the first level of care and they go to the hospital when they are already serious, others because of lack of access. (Intermunicipal Coordinator)*

Also, CKD patients with a higher socio-economic status reported that they were diagnosed in private facilities as there is still the belief that paying for medicines means they are better. Patients may also receive diagnosis during or because of an emergency, which often happens when public facilities are closed or there are long distances to get to these facilities.

*When I have an emergency, I prefer to go to the private clinic of San Salvador because there are no medicines in La Palma [public PHC centre] that can be given as good as in the private one. In the private clinic I do not wait, they attend you at the time you arrive. (Patient with hypertension).*

Health promoters play a very important role in identifying patients at risk of a chronic condition.

*Our strategy is based on the fact that health promoters are the eyes of the health centre, of everything that happens in the community, they are the first to tell us that there is a person who might suffer from a chronic disease, knowing that, we schedule a visit to go to that patient's home. (Nurse).*

Once patients are diagnosed, the follow-up is normally done in the PHC facilities, where they receive their medication and follow-up examinations. For this reason, the health reform reinforced the visits of specialized teams to the communities. The health reform reinforced the visits of specialized teams to the communities to assure a comprehensive approach also in remote areas giving access to gynecologist, paediatrician, psychologist, physiotherapist, nutritionist, health educator, sanitary inspector and family doctor.

*"The specialist physicians have programmed approaches to go to the communities, they evaluate the patients and identify those who need to attend a health facility or they leave them in control; in this approach, home visits can also occur and also there is a comprehensive family care visit at their home" (Departmental Coordinator).*

However, the referral system still lacks strong coordination, but has been reported to have improved with the health reform, giving patients a more comprehensive response to managing their disease.

*As family doctors, when a patient can no longer be given their medication, or a disease is difficult to control, or if there is an emergency, we refer the patient to the hospital. For example, if it is a renal patient, there is a whole area for that, there they are assessed by an internist, and if [the internist] considers that the patient has to continue their follow-up there, the patient stays there. If not, they send us a referral to continue the patient's follow-up here in PHC, engaging the patient in preventive activities with, for example, the health educator. (Family doctor).*

Continuity of care has been reported to have improved and involves a comprehensive system of care that guides and tracks patients over time through a comprehensive array of health services, spanning all levels of intensity of care for NCDs.

*The first time I visited the specialized health unit, they requested I stay the whole morning and I saw a lot of health professionals who explained different things about my chronic illness, what I eat, for example. (Woman with DM)*

### 4.3 Available Resources

The social connections mapping exercise highlighted the resources available to, and used by, participants through the three stages of their illness: diagnosis, acute episodes and follow-up. Five workshops were held: three in rural settings and two in urban settings. Within each location, a workshop was conducted in more “organized areas”. These were identified and selected by a key stakeholder, the Ministry of Health. Organized areas were defined as those with higher social capital levels and more presence of social and community organizations such as the social movement, the *National Health Forum*. Figure 2 shows how the resources were identified and mapped in one of the workshops. Figure 3 shows the resource used for each of the three scenarios: diagnosis, acute episodes and follow-up.

Within the diagnosis scenario, the hospital, as a public institution, is usually the place where people are diagnosed, although, the private sector accounts for high burdens of diagnoses, as many patients reported being diagnosed at their work place (during annual examinations).

The same pattern is followed during acute episodes of the disease, with participants mainly seeking help from the public sector, particularly hospitals. This was reported as a change in the patient behaviour, with the private sector used in cases of emergency.

*At the [public] clinic, normal exams are conducted and they do all of that, but they don't give us what we need most, and this is specifically to do with our individual illnesses. For me, it's my kidney and all my organs, and they can't test for this in the clinic. I think a lot of people are dying because of this, because they can't pay for this [private clinic]. (Man with DM)*

This is considered a big achievement of the health reform, as access to remote communities has improved due to the implementation of specialized community teams.<sup>(24)</sup> However, emergency situations often occur at times of difficult access to hospitals, for example, at nights where there is limited public transport. This may lead to significant indirect costs. Family members were often called upon to assist with financial support, and to accompany the patient to the hospital.

During the follow-up phase the greatest variety of different resources are used. Primary health care play an important role. The public system following the health reform, with extended first line services, including the presence of supporting specialists, reaches out to more remote areas, and patients can ensure a follow-up of their illness in a comprehensive manner. Natural medicine is also widely used, since it is cheap and easy to access and there is a perception that there is no risk in its use. Extensive popular knowledge of these alternative medicines is in evidence.

Overall, in rural communities, private practitioners (mainly naturopaths) were regularly drawn upon during diagnosis and follow-up, due to easy access and more economic options compared to urban areas. Religion is also predominant as an ‘institution’, as gathering in the church was seen to strengthen community cohesion, becoming more predominant as the disease progresses. During follow-up is where there is a greater use of religious resources, revealing the relevance religion has in the management of chronic diseases, particularly for psychosocial aspects.

The most predominant organization resource was the health social movement, the *National Health Forum*, which played a predominant role in tackling health social inequalities, affecting chronic conditions such as access to clean water.<sup>(37)</sup>

Finally, family support is evident throughout the progression of the disease and mainly used for transportation and social support.

### 4.4 Trust in social connections

As shown in Figure 4, there were higher levels of trust in public institutions. This may have been

due to greater trust felt in first levels of care (PHC), relative to trust placed in hospital care. In addition, access to free medicine following the abolition of fees for both medicines and consultation due to the health reform, may have also constituted a trust factor.

There were varied levels of trust expressed in the private sector. Participants had more confidence in examinations done in private rather than public centres, but there was less trust during follow-up due to economic constraints.

Regarding religion, the participants commonly referenced confidence in God and felt uplifted by the church environment.

*I think God gives us help and strength, because a lot of people I know with these illnesses, have gotten very depressed and even suicidal. That's why I think that being in a group and being in church helps to lift one's spirits. Because God says that he is here. (Woman with DM)*

In our study, we included and compared communities with a strong level of organization and communities that had not yet organized themselves. Participants who belonged to an organized community felt empowered to form local associations. Although overall there was not

much trust in other members of the community due to the current situation of violence, however participants from organized communities reported high levels of trust in their communities and believed they could better respond to their health needs.

*Thankfully we are part of an organized community, because of this we formed an association. And in that association, we were able to get professional support. So, we had to form our own groups in order to mutually help each other.* (Woman with hypertension)

Gender differences were also observed while analysing levels of trust at the family level, with some positing higher levels of trust to female over male family members.

*...with men, it's like they see the worst, they don't place the same importance on things as women. We [women] are more careful to notice other people's problems.* (Woman with DM)

#### 4.5 Community health promotion and prevention of NCDs

An interesting aspect of our analysis in El Salvador was the high level of organization at the community level. It was reported by staff members that people had gained strong organization levels during the civil war period and therefore there was a strong commitment of people to participate in decision-making. The *National Health Forum* was born from people of the communities which commenced advocating for the right to healthcare in the early 90s. This community bonds were reinforced due to the need for organized activism for structural change to overcome the current social, economic and political aspects that impact on health.

This perspective implies activist advocacy for comprehensive health policies, in which the structural causes of poverty and inequality are addressed through a whole society approach, linked to an extending network of empowering community activism and organization.

*For us, there is strength in counting on social participation, because they are in a way, the guards of the health system...Who better than they to visualize and follow-up, since a lot of the time we are not able to due to work...It is the communities that are organized, or those which the NHF has organized, that participate the most in our programmes, such as vaccinations, or controlling dengue fever and chronic illnesses. In the territories where the NHF is present, the population is very organized. The people know what their obligations are. We collaborate also, but they know that this is a shared responsibility...[empowered communities] know that health is for everyone, it is not just the responsibility of the MoH. It is not just about being cured, but it should be more about prevention. This is where the people of the NHF are helping the most"* (Regional Director of Primary Health Care).

In line with the "health in all policies" framework, the community collaborates with the health system by identifying their needs and by participating in the design of strategies to improve the NCD care and follow-up at community level. An example of this was in the region of Bajo Lempa and the management of CKD by involving all community assets. More attention is advocated towards the prevention and early diagnosis of renal insufficiency, linked to pesticide intoxication, the so called *chronic interstitial nephritis of agricultural communities* (CINAC), in this region the promotion of community peer support groups for NCDs was advocated, where patients can learn from each other, as further described on another study developed by the same research team. <sup>(37)</sup>

## Discussion

In view of the growing burden of NCDs worldwide, this experience in El Salvador on the development of a comprehensive strategy of NCDs management highlights the following findings:

the results of our study, which combines different qualitative methodologies within different levels of care and in the community level, helps to better understand the comprehensive approach that is needed in NCDs management. Through the experiences of people living with an NCD in EL Salvador and health care staff, the social risk factors and barriers to care were identified to have a strong impact in the management of NCDs. Lifestyle factors and economic barriers were also mentioned as the social risk factors affecting the healthy lifestyle behaviors needed when presenting and in preventing NCDs. Regarding the patient pathways to care, the implementation of PHC have enable a more accessible NCD follow up with a holistic approach by combining a multidisciplinary PHC staff and specialized teams going to the communities. While assessing the resources in health available, there is a clear change in health seeking behaviours from when the patient is diagnosed (still a high dependence on the private sector) up until they are followed-up, where it showed psychosocial needs were mainly covered through family support and also through falling back on religion strong resilience factors at the community level; finally, organizations such as the National Health Forum are used to empower patients. This has improved shared decision-making, leading to a better understanding of the patients' health needs.

Participants from organized communities reported high levels of trust in their communities and believed they could better respond to their health needs. Finally, in regard to community health promotion and prevention of NCDs, high organized communities are participating in the

identification of the needs and in the design of strategies to improve the NCD care and follow-up at community level. The important role of health social movements, such as the *National Health Forum* in promoting “fight to health policies”, and promoting NCDs strategies which considers the population needs.

It was highlighted the community-based NCD programmes along the study and it might be useful for other settings. The essential elements to discuss and adapt to other contexts, are related to the role of the organized community as a complementary approach and support for the health services.<sup>(10,27)</sup> In these studies, community-based interventions are used to support individuals, families and communities to overcome obstacles towards ensuring continuity of care, from diagnosis to follow-up, with the guidance of the health services, based on the well-developed NCD guidelines.<sup>(28)</sup>

A study reporting recommendations for the management of NCDs in conflict areas<sup>(29)</sup> highlights that an integrated, multi- and interdisciplinary approach should be developed, ensuring the provision of quality care, involving community leaders and influential individuals. Such an approach, as reported by Magnusson et al.,<sup>(28)</sup> needs to be grounded in the right to health. This includes the prevention of NCDs and their risk factors, the improvement of access to care, and addressing the social impact of these ailments. This highlights the appropriateness of a strategy under the *health in all policies framework*<sup>(38)</sup> as carried out by the NHF.

Over the last 10 years (2009-2019), El Salvador has implemented a national health system with the aim to guarantee universal health coverage. Progress has been made, but the fragile context remains challenging, not only to ensure further progress, but also to maintain what has been realised.<sup>(26)</sup>

The Latin American current of *critical epidemiology*<sup>(31)</sup> criticises the concept of ‘social determinants of health’ on the basis of its fragmented analysis of the social reality. They advance the concept of ‘*social determination of health*’, as this approach emphasizes the determining influence of the overarching structural inequalities and the skewed power relations at all levels, which helps us to better understand the complex interactions of these layers on the social and health reality of communities and individuals.

This public health current explicitly links their analysis to organized activism for structural change,<sup>(32)</sup> advocating for an extending network of empowering community activism and organization.<sup>(33,34)</sup> Consequently, health promotion then refers to a process where individuals organize and act to increase control over factors related to their individual and collective health.<sup>(35,36)</sup>

While this approach is widely embraced in communities that engage in the *National Health Forum*, this type of organized engagement has a clearly political stand, implying a continuous struggle to maintain their influence on local health policies through social mobilisation.

While over time the number of organized communities and their impact have been increasing, their focus is mainly on rural areas, much less in the cities. Moreover, other social phenomena cause contrasting dynamics: youth gangs create high levels of social violence, related to the enormous economic divide in the country.

Political accountability mechanisms ensured through the *National Health Forum* constituted an important factor to rate higher trust in health system performance. Accordingly, our study found that quality of the management of NCDs care lies in a comprehensive approach to improve the relation between PHC and specialized environments; and relying in community-based interventions involving all community assets and taking into account the social, economic context.

## Limitations

The complexity of the sociocultural, political and economic context of El Salvador must be noted. The periods of fieldwork might have been too short to gain an overall in-depth knowledge of this context. Moreover, the high level of violence in important parts of the country limited the fieldwork possibilities. Many of these challenges were partially solved thanks to the support and accompaniment of key Salvadorian stakeholders.

This study was conducted between November 2017 and January 2019. The results of the national elections in February 2019 led to a government change, which might imply important changes in the health system analysed here.

## Conclusions

The complementary research methods and the different groups of participants (patients, health personnel and health system coordinators) all identified similar strengths and obstacles in NCDs management. The combined use of different research methods proved effective for obtaining an in-depth understanding of NCDs management strategies in El Salvador along the different levels of care (primary health care and specialized care), and could serve to guide analyses in function of policy-making in other fragile contexts.

The generation of equitable health policies that pursue accessible quality services is an essential first step to improve access and continuity of care for NCDs. But the Salvadorian experience also shows that a strong and well-organized involvement of the communities can positively influence health care access at the community level, while also promoting a prevention culture.

Participants insisted on the strengthening of healthy lifestyle initiatives adapted to their sociocultural and economic contexts.

## Declarations

### Ethics approval and consent to participate

This study was approved by the National Health Ethics Committee of El Salvador (CNEIS/2018/005\_A) and by the ethics committee of Queen Margaret University in Edinburgh. All participants were informed about the study and signed an informed consent which would be safely kept for 5 years.

### Consent to publish

All authors give their consent for this study to be published.

### Availability of data and materials

All raw material and data are available and can be accessed through the Journal BMC Health Services Research

### Funding

This study was supported by the NIHR Research Unit on Health in Situations of Fragility, through the NIHR Global Health Research Programme 16/136/100.

### Competing interests

The authors declared no conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Authors' contributions

All authors have read and approved the manuscript. N.V., M.L and M.J. elaborated the manuscript, researched the data, and contributed to the discussion; P.D.V., and K.B. contributed to the discussion, and reviewed and edited the manuscript. P.D.V. coordinated the whole study.

### Acknowledgements

This research was possible thanks to support from members of the Ministry of Public Health

Policies, the National Health Form (FNS) and the Public health policies observatory-

University of El Salvador, which facilitated access to different communities that might

otherwise be difficult to reach because of ongoing social violence.

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## Tables

*Table 1: Estimated number of population affected by NCD by region, area of residence and sex in the adult population of El Salvador (6)*

	Diabetes Mellitus (DM)	Hypertension (HBP)	Chronic Kidney disease (CKD)
NATIONAL LEVEL	487,875	1.446,381	459,114
REGION			
Occidental (Ahuachapán, Santa Ana, Sonsonate)	86,524	296,275	74,181
Central ( <b>Chalatenango</b> , La Libertad)	52,274	141,189	23,634
Paracentral (Cuscatlán, La Paz, Cabañas, San Vicente)	53,799	180,519	82,133
Oriental ( <b>Usulután</b> , <b>San Miguel</b> , <b>Morazán</b> , La Unión)	101,084	297,210	150,990
Metropolitana ( <b>San Salvador</b> )	194,194	531,187	128,176
SEX			
Male	179,708	604,184	283,905
Female	308,167	842,196	175,210

*Highlighted in black are the regions where health facilities of this study are located*

*Table 2: Patient interviews*

NON-COMMUNICABLE DISEASES suffered by patients interviewed	N
Cardiovascular disease	9
Diabetes Mellitus type 2	3
Chronic Kidney Disease	2
Total	14

*Table 3: Staff interviews*

PRIMARY HEALTH CARE STAFF	PROFESSIONAL PROFILE	N
Coordination level	Departmental Coordinator (1)	4
	Intermunicipal coordinator (2)	
	Regional coordinator (1)	
Interdisciplinary PHC team	Health educator (1)	8
	Sanitary inspector (1)	
	Medical student in year of social service (1)	
	General practitioner (1)	
	Family doctor (1)	
	Nurses (1)	
	Pharmacist (1)	
	Laboratory technician (1)	
Total		12

Table 4: Thematic categories pre-defined to conduct along the three phases of data collection

<b>Illness narratives</b>	<ol style="list-style-type: none"> <li>1) Social determinants of care</li> <li>2) Patient pathways</li> <li>3) Health systems issues (e.g. costs of care, waiting times, quality of care)</li> </ol>
<b>Mapping social connections and trust allocation</b>	<ol style="list-style-type: none"> <li>1) Public institutions (e.g. primary health care centres, public hospitals, maternity health centres, social insurance services)</li> <li>2) Private institutions (e.g. private clinics, private hospitals, private doctors, naturopath)</li> <li>3) Organisations (including local and international NGOs)</li> <li>4) Community (e.g. neighbours, community associations)</li> <li>5) Family (e.g. immediate or extended family members)</li> </ol>
<b>Semi-structured interviews with NCD patients and staff members in the PHC setting</b>	<ol style="list-style-type: none"> <li>1) Primary health care in El Salvador (including organization and coordination of care, evolution of the country's health system, accessibility and barriers to care)</li> <li>2) Chronic disease management in the PHC system (including prevention and promotion of care, pathways to care, quality of care and barriers to care)</li> <li>3) Community engagement</li> </ol>

## Figures



Figure 1

Departmental map of El Salvador

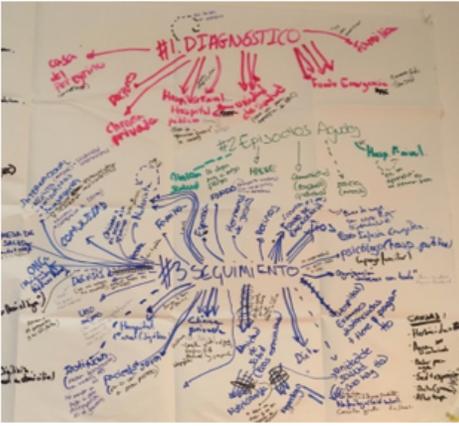


Figure 2

Workshop map of organized rural community

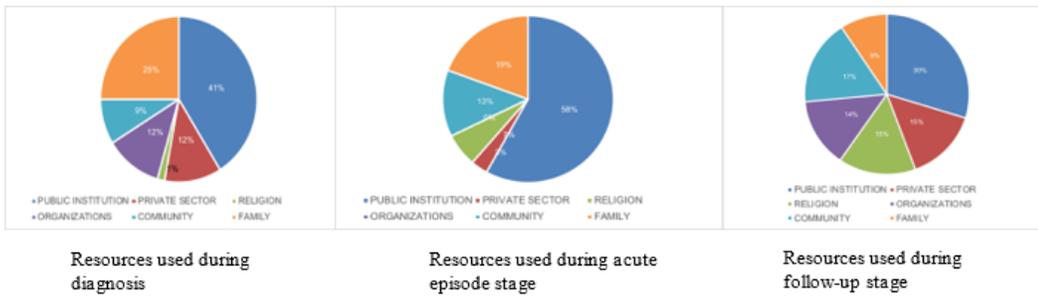


Figure 3

Resource used along the three scenario: diagnosis, acute episodes and follow-up stage

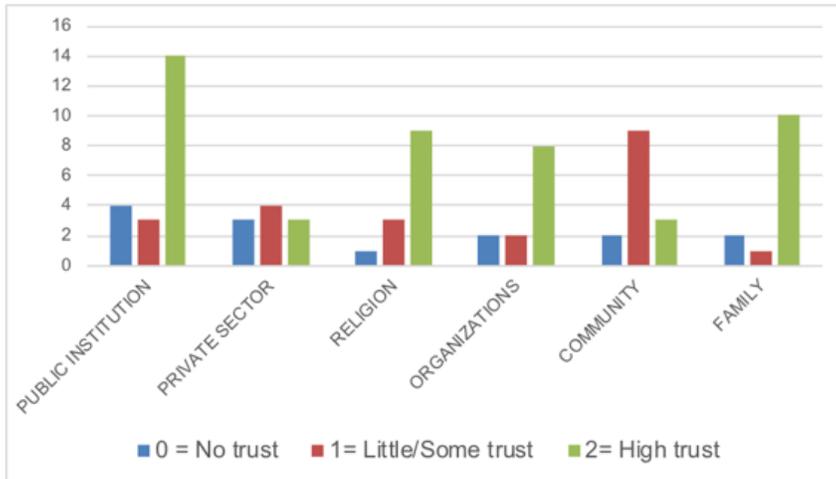


Figure 4

Levels of trust reported in resources identified by category