

BMJ Open Qualitative study of pathways to care among adults with diabetes in rural Guatemala

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ABSTRACT

Objective The burden of diabetes mellitus is increasing in low-income and middle-income countries (LMICs). Few studies have explored pathways to care among individuals with diabetes in LMICs. This study evaluates care trajectories among adults with diabetes in rural Guatemala.

Design A qualitative investigation was conducted as part of a population-based study assessing incidence and risk factors for chronic kidney disease in two rural sites in Guatemala. A random sample of 807 individuals had haemoglobin A1c (HbA1c) screening for diabetes in both sites. Based on results from the first 6 months of the population study, semistructured interviews were performed with 29 adults found to have an HbA1c $\geq$ 6.5% and who reported a previous diagnosis of diabetes. Interviews explored pathways to and experiences of diabetes care. Detailed interview notes were coded using NVivo and used to construct diagrams depicting each participant's pathway to care and use of distinct healthcare sectors.

Results Participants experienced fragmented care across multiple health sectors (97%), including government, private and non-governmental sectors. The majority of participants sought care with multiple providers for diabetes (90%), at times simultaneously and at times sequentially, and did not have longitudinal continuity of care with a single provider. Many participants experienced financial burden from out-of-pocket costs associated with diabetes care (66%) despite availability of free government sector care. Participants perceived government diabetes care as low-quality due to resource limitations and poor communication with providers, leading some to seek care in other health sectors.

Conclusions This study highlights the fragmented, discontinuous nature of diabetes care in Guatemala across public, private and non-governmental health sectors. Strategies to improve diabetes care access in Guatemala and other LMICs should be multisectorial and occur through strengthened government primary care and innovative private and non-governmental organisation care models.

INTRODUCTION

Low-income and middle-income countries (LMICs) face an increasing prevalence of diabetes¹ with limited health system

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study demonstrates the utility of care mapping in studying sources of healthcare and care-seeking trajectories for non-communicable diseases.
- ⇒ One limitation is data included retrospective self-reported health-seeking behaviours over several years and are subsequently subject to recall and reporting bias.
- ⇒ Another limitation of this study is by recruiting participants through a population study evaluating for elevated haemoglobin A1c, individuals with uncontrolled diabetes mellitus are over-represented in our sample.
- ⇒ Our study was conducted in majority indigenous populations living in rural areas and may not be generalisable to other areas of Guatemala.
- ⇒ This study struggled to recruit equal proportions of men and women.

resources for disease prevention, screening and management.^{2–4} Demographic investigations about non-communicable diseases (NCDs) in LMICs have revealed a high degree of unmet need and loss to follow-up in diabetes care.^{5–9} While valuable, these quantitative survey-based data do not provide insights into sources of care or longitudinal care trajectories of individuals with diabetes in LMICs. This information is particularly important as LMICs face increasing health-care privatisation and erosion of public health systems.^{10 11} Individuals with diabetes increasingly use private and non-governmental health resources.^{3 12–19} Understanding individuals' diabetes care pathways and decision-making in LMICs can inform health system improvements to address NCDs.

Care mapping is an interview-based process used to reconstruct participants' pathways to care for a particular illness. The technique was historically developed by the World Health Organization to characterise sources of mental healthcare and referral patterns



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in LMICs.²⁰ Care mapping is similar to but distinct from patient journey mapping, a quality improvement method that focuses on processes of obtaining care from the patient perspective.²¹ We coupled care mapping with qualitative interviews to study sources of and healthcare-seeking decisions surrounding diabetes care in rural Guatemala.

Guatemala is a Central American country with an estimated diabetes prevalence of 8.8%.²² Guatemala also has had an over 50% increase in diabetes-related morbidity and mortality over the past decade.²³ Guatemala has a mixed health system offering diabetes and NCD care through multiple sectors. The Ministry of Health (MOH) sponsors a network of public hospitals, health centres and posts, which are intended to provide citizens with free care, but face significant resource limitations and medication stockouts leading to out-of-pocket spending.²⁴ The Social Security System provides healthcare to the approximately 18% of the population with formal employment.²⁴ Given limited access to government and social security care, healthcare seekers are increasingly turning to the growing private for-profit and non-governmental healthcare sectors.²⁵ Guatemala also has a rich historical tradition of ethnomedical healing, based largely around herbal remedies, as well as an expanding market of naturopathic products, both of which are used for diabetes care.^{25 26} Notably, 45% of the Guatemalan population identifies as indigenous Maya.²⁷ Due to longstanding historical inequalities and more recent civil war (1960s–1990s), the Maya population faces structural, linguistic and cultural barriers to biomedical healthcare.²⁵ Indigenous Maya people also experience obstacles to diabetes care, including medication cost, perceived mistreatment, and limited social supports for lifestyle changes.^{26 28 29}

This qualitative study explores pathways to care among individuals with diabetes in rural Guatemala. We aim to offer insights to improve diabetes care in LMICs. Our findings offer a unique contribution to the literature about trajectories of NCD care in LMICs.

METHODS

Sampling and recruitment

This qualitative study was a planned substudy conducted as part of a population-based study assessing incidence and risk factors for chronic kidney disease in two rural majority-indigenous Guatemalan sites. The two sites were selected due to their distinct cultural, agricultural and health resource profiles. The first site is located in the highlands in close proximity to a large highway and three cities with major hospitals; it has a majority indigenous population, which cultivates maize, beans and vegetables. The second site is on the southwestern coast, where agricultural production focuses on sugar cane; the population identifies as both indigenous and of mixed descent, and hospital access requires farther travel.

The population study used a mapping technique to randomly sample households in each site, fully detailed

elsewhere.³⁰ Briefly, from June 2018 to February 2019, of 1281 eligible individuals recruited from 533 households, 807 non-pregnant adults agreed to participate in the population study. During the initial population study visit, participants received screening blood tests for diabetes as part of an assessment for risk factors for chronic kidney disease. We defined a diagnosis of diabetes as a haemoglobin A1c (HbA1c) $\geq 6.5\%$ or a prior self-reported diagnosis of diabetes. During a follow-up study visit, population study staff informed subjects of their HbA1c result and facilitated referrals to local health centres, as needed. Population study staff then referred subjects with diabetes interested in participating in an interview to qualitative study team members. Inclusion criteria for this qualitative study were: adult (age 18 years+), non-pregnant, HbA1c $\geq 6.5\%$ or a prior self-reported diagnosis of diabetes, Spanish-speaking or Kaqchikel Mayan-speaking, and participation in the population study. Exclusion criteria were: paediatric patients (age < 18 years), pregnant, no laboratory or self-reported diagnosis of diabetes, primary speaker of a language other than Spanish or Kaqchikel Mayan, not a participant in the population study.

From November 2018 to June 2019, the qualitative study team approached all 42 participants who enrolled in the population study between June 2018 and February 2019 who had an HbA1c $\geq 6.5\%$ and reported a previous diagnosis of diabetes. The research team aimed to interview approximately 12 participants from each study site, given literature indicating that this sample size typically captures the range of experiences and leads to saturation of qualitative data.³¹ Participants were approached in sequential order of receipt of laboratory results in both study sites. A total of 29 agreed to the interview, with 13 in the first site and 16 in the second site. Ten individuals declined to participate, and three were travelling at the time of the proposed interview.

Data collection

Trained interviewers conducted semistructured interviews with 29 participants. A single interview was performed with each participant. Interviews explored participants' experiences of seeking diabetes care and their pathways to diabetes care. Interviewee demographics are detailed in [table 1](#). Interviews occurred approximately 4–6 months after participants' initial enrolment in the population study. Interviews lasted 20–60 min and occurred in participants' homes. Depending on participant preference, interviews were conducted in either Spanish or Kaqchikel Maya, with the support of an experienced Kaqchikel interpreter. Based on participants' preferences, interviews were not digitally recorded. Instead, in cases where one interviewer was present, the interviewer typed detailed notes and directly transcribed short quotes during the interview. In cases where two interviewers were present, the second researcher transcribed responses and quotes in real time. All notes and transcribed quotes were reviewed after the interview for accuracy prior to analysis.

Table 1 Sample demographics

	N	%
Total	29	100
Sex		
Male	8	27.6
Female	21	72.4
Language		
Spanish	28	96.6
Kaqchikel	1	3.4
Ethnicity		
Indigenous Maya	17	58.6
Ladino	12	41.4
HbA1c		
HbA1c<7	2	6.9
HbA1c=7–10	10	34.5
HbA1c>10	17	58.6
	Mean (SD)	Range
Age	53.5 (7.4)	41–72

Data analysis

Researchers reviewed notes from the first 12 interviews and developed a codebook using an inductive strategy, in which codes arise from interview data rather than from a priori hypotheses. All interviews were coded by two study team members, and a third team member reviewed coding for discrepancies. Discrepancies in coding were resolved and themes were elucidated by consensus. After the first 20 interviews, no new codes or themes arose, indicating saturation. This was confirmed with formal analysis and review of the other nine interviews. Qualitative analysis was facilitated by the software NVivo Pro, V.11.4.1 for Windows.

The research team collectively reviewed interview notes to generate for each participant a care map, or a digital flowchart depicting each individual's pathway through

sources of diabetes care. Care maps were created to allow visual representation of each individual's use of distinct healthcare resources outlined in [table 2](#). As described in the care map legend, arrows demarcate sequential and simultaneous use of health resources, and boxes with stars in the lower righthand corner indicate the health sector a participant was using at the time of the interview. A composite care map was generated for each site aggregating individuals' pathways to care, with each care pathway noted by a different colour. This article features composite care maps separated by site and with individual pathways outlined through four steps of care, for ease of illustration given the visual complexity of care trajectories otherwise. After all care maps were created, two coders independently reviewed each care map to determine the proportion of participants who used each type of health resource and the proportion of participants who used different types of health resources simultaneously.

Researcher characteristics

In qualitative research, reflexivity refers to consideration of how researchers' identities and values influence the research process and findings. Our study team included members from both Guatemala and the USA, all of whom have previously studied perceptions of chronic disease in Guatemala. We sought to reduce the impact our identities could have on the research in two ways: (1) interviewers had no involvement in collecting biological samples or disclosing laboratory results; (2) all interviews were conducted in teams with one US researcher and one indigenous researcher or interpreter.

Institutional context and ethics

We follow the Standards for Reporting Qualitative Research guidelines to describe the present investigation.³² The interview guide, codebook, coded data and care maps are available through Dataverse.³³

Table 2 Descriptions of healthcare sectors

Sector	Description
Government: Ministry of Health	Health posts, health centres and hospitals open to general public with no consultation fees operated by the Ministry of Health
Government: Social Security	Social Security System open only to those employed in the formal sector (Instituto Guatemalteco de Seguridad Social)
Private	Privately run, non-government healthcare site
Non-governmental	Non-governmental organisation or short-term medical mission
Pharmacy	Business selling medications and/or offering consultations for medical complaints, usually for-profit
Complementary and alternative medicine (CAM)	Non-biomedical, commercialised product (eg, Omnilife, Herbalife, Neurobion)
Ethnomedical	Locally grown plants and herbal remedies
Household	Treatment or care from a member of participants' social network (family member, friend, neighbour, etc)

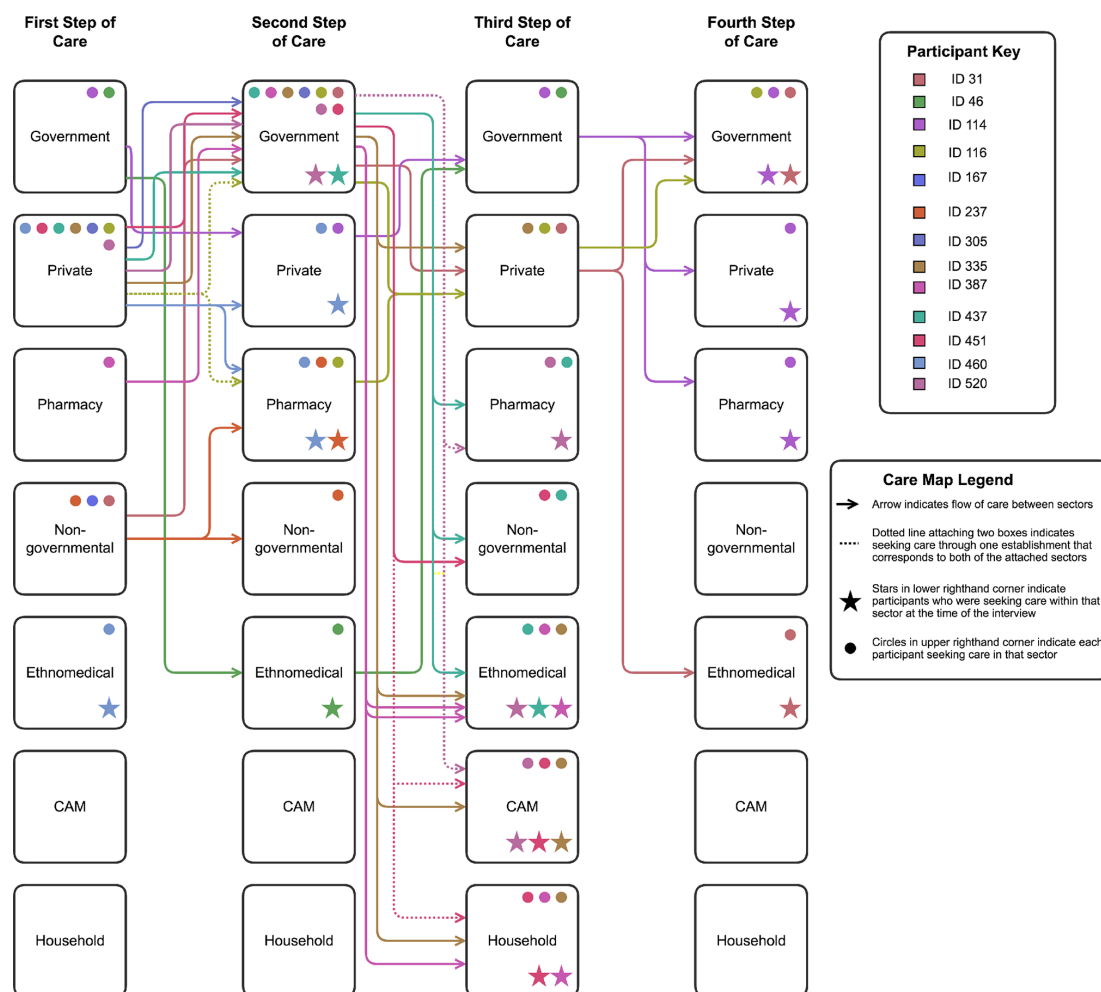


Figure 1 Composite care map—site 1. CAM, complementary and alternative medicine.

Patient and public involvement statement

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

RESULTS

Four distinct themes emerged regarding pathways to diabetes care and participants' decision-making: (1) fragmentation in care; (2) the role of pharmacies; (3) perceptions of quality of care; and (4) cost. Pervasive across all themes were participants' sentiments of challenges in accessing care as well as gaps between participant experience and healthcare provider recommendations.

Fragmented pathways to care

Participants' distinct pathways to care highlight fragmented diabetes care. The majority of participants initiated diabetes care-seeking due to perceived symptoms of diabetes or acute illness (97%). Only one participant initiated care after a diabetes diagnosis through routine asymptomatic screening at a regular doctor's visit. The time over which participants reported seeking diabetes care ranged from 3 months to 23 years.

Figure 1, a composite diagram of pathways to care from all participants from the first study site through their fourth step of care, demonstrates that individuals seek diabetes care in multiple health sectors. These include government, private and non-governmental sector biomedical care, as well as ethnomedical therapies and complementary and alternative medicine. Importantly, figure 1 demonstrates that individuals with diabetes do not follow a singular path to care. Rather, the majority of participants in both sites (site 1, 92% and site 2, 100%) accessed care in multiple health sectors. Proportions of participants who sought care in each sector are outlined in table 3. Sectors participants were using at the time of interview are specified in table 4.

Participants' care pathways also demonstrate discontinuous care. The majority of participants saw multiple providers (90%). As further described below, participants stopped care or changed providers due to cost and lack of economic resources. Even when participants sought care at the same clinical location, such as a government health centre, discontinuity in care resulted from changing healthcare staff and rotating trainees.

The majority of participants sought care with different providers and/or in different health sectors

Table 3 Trends in diabetes care-seeking

	N (%)
Accessed care in sector	
Government	18 (62)
Ministry of Health	15 (52)
Social Security	5 (17)
Private	19 (66)
Non-governmental	10 (34)
Pharmacy	20 (69)
Complementary and alternative medicine	6 (21)
Ethnomedical	15 (52)
Household	7 (24)
Care-seeking behaviours	
Sought care from more than one provider	26 (90)
Sought care across more than one sector	28 (97)
Simultaneously sought from more than one provider or sector	23 (79)
Obtained care locally	23 (79)
Travelled outside of their town to seek care	18 (62)

simultaneously, rather than in a linear sequential fashion (79%). For instance, participants used natural treatments or commercialised alternative products concurrently with biomedical medications. They did not perceive the two treatment modalities as mutually exclusive. The care pathway in [figure 2](#) reflects simultaneous care-seeking. Simultaneous care-seeking trends are quantified in [table 3](#).

Roles of pharmacy

Pharmacies played an important and unique role in diabetes care. The majority of participants (69%) used a pharmacy for consultation or out-of-pocket medication purchasing at some point in their diabetes care trajectory. A significant minority of participants (24%) used the

pharmacy to continue purchasing medications even when they were no longer regularly following with a provider. For instance, one participant explained:

Only when I feel very bad do I go to the hospital. Other than that, I just buy my pills. (ID 1112, female in 50s)

Two participants reported that the doctors they saw encouraged participants to stop seeking regular care with them, continue with medications as initially prescribed, and come back only if they had symptoms. For example:

The doctor only told me, 'When you feel bad, come here,' but I don't have another appointment. That [feeling symptoms] is not going to happen if I follow the diet and the medications. I only take the same prescription to the pharmacy for more medication. (ID 1071, female in 40s)

While all participants who used the pharmacy did so to buy medication, 24% also used the pharmacy as a source of medical care, for example, to check their blood sugar when they perceived diabetes symptoms and receive intravenous fluids or medications to manage those symptoms. [Figure 3](#) shows how one participant used the pharmacy as her only source of medical care in this way.

Perceived low-quality public sector care

The majority of participants sought care from a government facility (MOH or Social Security) at some point in their care trajectory (62%). Many participants (59%) sought free care in MOH and Social Security clinics or hospitals as their first or second stop for diabetes care in the healthcare system. However, the MOH lacks resources to consistently provide free medications and laboratory exams and hosts rotating trainees in facilities, which led to perceptions of low quality among 21% of participants:

You can't trust the health centers or the hospital because they are very neglected... Before, we went to the hospital with confidence. The hospitals served us. Now, they say to you, 'Look, you have to buy this, you have to do these exams.' (ID 1273, male in 50s)

In the health center, there are only trainees, no older doctors, therefore they don't know anything. They don't have experience. (ID 305, female in 60s)

Participants' perceptions of low-quality MOH care were also based in experiences of poor communication with government providers (21%). Some participants noted feeling ignored, talked down to or scolded and judged by both MOH and Social Security providers:

The doctor doesn't ask anything, he doesn't ask if I feel well or if I have any issues. He only gives me the prescription. He doesn't ask anything. So, it's not good in [the social security clinic]. (ID 1307, female in 40s)

I did not want to go to the hospital because I was afraid to hear what they would say. Sometimes I go

Table 4 Sector of diabetes care at time of interview*

Sector in which participants were seeking diabetes care at the time of interview	N (%)
Government	8 (28)
Ministry of Health	5 (17)
Social Security	3 (10)
Private	5 (17)
Pharmacy	13 (45)
Non-governmental	4 (14)
Complementary and alternative medicine	4 (14)
Ethnomedical	10 (34)
Household	6 (21)

*Due to simultaneous care-seeking, percentages do not add to 100%.

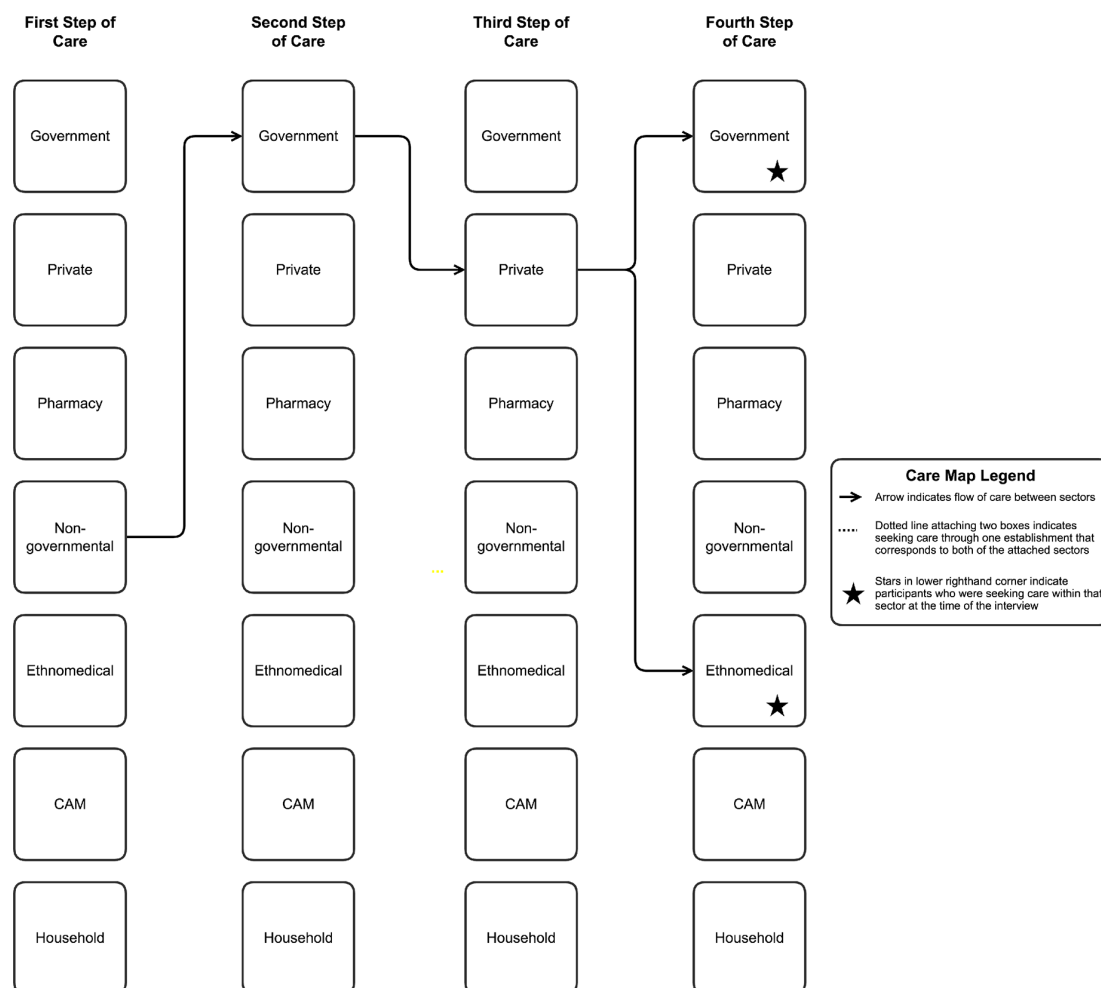


Figure 2 Participant care map, ID 31. This care map demonstrates simultaneous care-seeking by a woman in her 60s from site 1 over a period of 3.5 years. CAM, complementary and alternative medicine.

to the [MOH] health center and they scold you, they scold you and they judge you. (ID 451, female in 40s)

Perceptions of low quality deterred three participants from seeking care in their local MOH health centres or led them to the private sector:

I don't go to the health center because we think that they don't give the services we need or have the specialists. So you have to go to the other doctors directly... The health center sends you out, to a hospital, a national hospital or private hospital. (ID 460, male in 50s)

I went to a private doctor, because the health center and the hospital are very neglected. (ID 1273, male in 50s)

Despite inability to afford private sector care, one participant refused to go to his local MOH health centre due to perceived poor-quality care (ID 1266, male in 40s).

Participants occasionally (10%) referred to positive community reputations driving their care-seeking decisions. These reputations were not associated with government facilities but rather with private doctors, clinical facilities in larger cities and specialists:

I felt very desperate, so I left for Xela, because there are good doctors there. (ID 1112, female in 50s)

Cost

Cost significantly influenced participants' care-seeking. The majority of participants described a financial burden associated with diabetes treatment (66%). Some participants took loans to finance their diabetes care (21%) or relied on family members to pay for treatment costs (21%). Some participants delayed seeking care (14%) or went without medications for periods of time due to lack of economic resources (14%).

Well, there are times that we have to stop taking [medications] because we don't have the money. But, we have not taken out a loan, because loans don't go away. It is better to bear it. (ID 1246, female in 50s)

Participants described two major strategies to minimise care costs. First, participants sought free or cheaper sources of care (41%), including through NGOs, medical missions or pharmacies. Second, participants continued to take previously prescribed medications—purchased

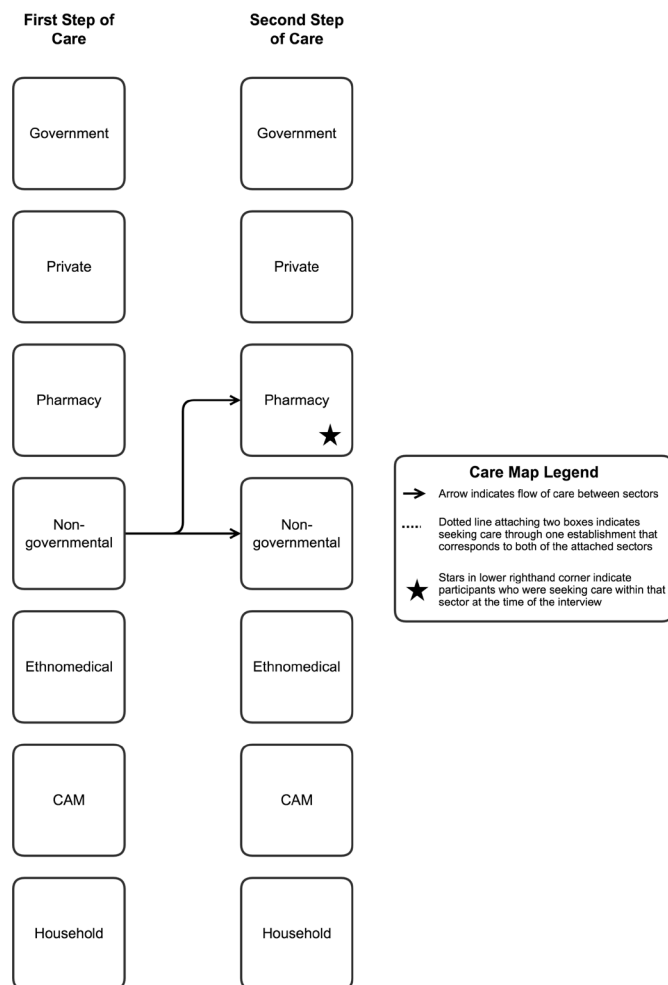


Figure 3 Participant care map, ID 237. A woman in her 50s from site 1 used the pharmacy as a regular source of medical care over the course of 3 years of diabetes care-seeking. CAM, complementary and alternative medicine.

from the pharmacy, as described above or previously obtained—without regular follow-up care (17%).

I didn't go to the [community provider] again because of the cost...I didn't go anymore, because I had the pills. (ID 451, female in 40s)

The care pathway in figure 4 demonstrates how cost, strategies to minimise expenses and perceptions of the government MOH system can impact diabetes care-seeking. This participant initially had Social Security coverage through his employer, but then lost his job and associated coverage. He had no money or insurance to pursue consistent diabetes care. While he desired to see a diabetes care provider, he refused to visit a MOH clinic due to perceived poor-quality care. He instead continued to buy metformin at a pharmacy and intermittently used plant-based treatments. However, on facing significant diabetes complications, including foot infection leading to amputation, he felt forced to pursue urgent care at the public MOH hospital (ID 1266, male in 40s).

Cost sometimes trumped participants' care-seeking preferences. For instance, three participants who

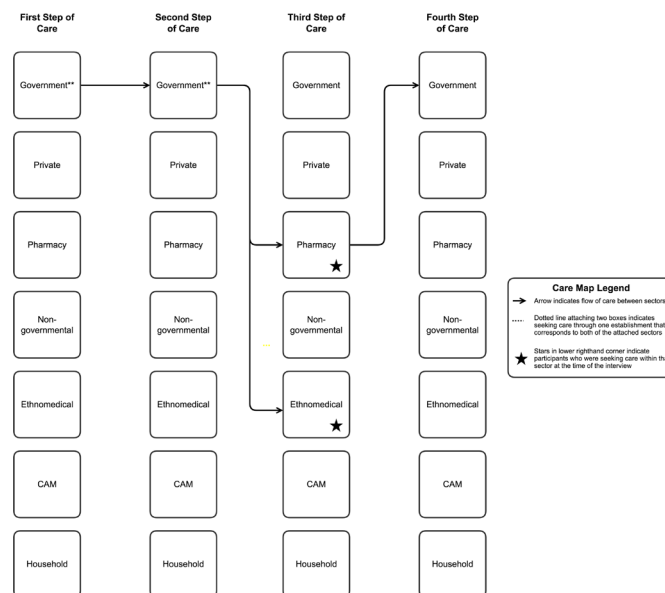


Figure 4 Participant care map, ID 1266. A man in his 40s from site 2 sought diabetes care over 12 years. CAM, complementary and alternative medicine.

expressed dissatisfaction with MOH care continued seeing MOH providers due to care being free. Others sought out perceived high-quality care in the private sector but discontinued it due to associated costs. For instance, one participant hoped to continue with a 'magnificent' doctor in a nearby city but could not afford the approximately US\$25 fee per appointment (ID 116, male in 50s).

Table 5 provides additional representative quotes for each theme.

DISCUSSION

This qualitative study of diabetes care-seeking in rural Guatemala provides important insights into the fragmented nature of NCD care. It also highlights the roles of cost and perceptions of quality in care-seeking decisions. Together, these findings have major implications for diabetes interventions in Guatemala and other LMICs.

First, care mapping illuminated the fragmented nature of diabetes care, characterised by limited provider continuity, utilisation of pharmacies for clinical care and acute episodic care-seeking for diabetes complications. Participants simultaneously and sequentially used biomedicine, ethnomedicine and commercialised complementary and alternative medicine products for diabetes care. Gaps between biomedical providers' and participants' understandings of diabetes management were common, as were participants' perceptions of poor quality of biomedical care. These features all make participants more vulnerable to diabetes-related morbidity and mortality. Indeed, diabetes care continuity is associated with HbA1c reduction and lower rates of hospitalisation and mortality, as demonstrated in high-income settings.^{34–38}

Other research exploring diabetes care-seeking in Guatemala has also highlighted fragmentation in care

Table 5 Representative quotes

Theme	Quote/notes
Pharmacy Participant accesses pharmacy without regular diabetes care or as a source of diabetes care	I only buy medicine in the pharmacy. I don't follow with a doctor. (ID 1203, female in 40s) When I feel bad, I go to the pharmacy. When my mouth feels salty [dehydrated], I go to the pharmacy and they do the [blood sugar] test. (ID 437, female in 50s) I felt very tired, barely had energy even to talk. It started for me like that for two months, or more, maybe 15 days more than that I felt like that, and that's when I said I'm going to the pharmacy. When I got there, and I explained it, they told me they detected my sugar [being high]. (ID 1294, female in 50s)
Perceived quality of care Perceptions of poor quality of care and poor communication styles in public health system	I did not trust the health centers or the hospital because they are very neglected. We have a very bad government. (ID 1273, male in 50s) The quality of care is low. They don't change my dose of metformin even though my sugar is still high. (ID 116, male in 50s) In the beginning I took the pills, but the doctor was very rude with me. He told me some strong words: "Look, lady! You are a diabetic! No bread!" And me, then what am I going to eat? But I was scared. Then the food I would eat at home made me scared. (ID 46, female in 40s)
Cost Poverty and financial limitations affect care-seeking	When I had a crisis [diabetes related hospitalization], I got into a little debt...We had to take a loan and my sons supported me. (ID 1273, male in 50s) For 10 years I have not been anywhere [for diabetes care] because everything costs money. I'd want to go to a doctor if it weren't for the cost. (ID 1266, male in 40s) I'm ashamed, because before I was not taking [medication]...Just one box of pills cost me 500Q. You know, what's in charge is the money. (ID 1230, female in 40s)

pathways. Specifically, qualitative and ethnographic studies in both this study's highland site and periurban indigenous areas have revealed phenomena of people with diabetes cycling between biomedical and ethnomedical treatments as well as between public and private sector biomedical facilities and pharmacies. Such cycling usually occurs in relation to economic circumstances, acute experiences of diabetes related symptoms and perceptions that private biomedical facilities offer a higher quality of care than public facilities.^{26 39} In Guatemala, care fragmentation reflects increased healthcare privatisation,²⁵ unequal distribution of healthcare workers and resources in urban and rural areas^{24 40} and frequent changes in government leadership leading to staff turnover in local health clinics⁴⁰—challenges faced in other LMICs, as well.^{10 41} Indeed, investigations of diabetes care in India, and sub-Saharan Africa similarly reveal fragmented trajectories across different health sectors,^{12 42 43} with initiation of care-seeking following development of symptoms rather than after routine asymptomatic screening.^{42 44}

Strengthening government primary care in LMICs will require longitudinal resource investment and represents a long-term strategy to enhance access to and continuity of diabetes care. Care models that optimise resources and shift tasks to non-physicians are feasible in LMICs, and, whether they occur through public health systems, non-governmental organisations or in multisector partnerships, can improve longitudinal and continuous diabetes care while reducing costs.⁴⁵ Nurse-led interventions have shown promising results in improving diabetes care access and outcome measures in Guatemala¹⁷ and sub-Saharan Africa.^{19 46 47} Peer-based interventions, in which community non-professionals are trained to provide continued

support and promote diabetes self-management, have improved health outcomes in sub-Saharan Africa and Asia¹⁹ and have improved care engagement when coupled with mobile health messaging in Honduras and Cambodia.^{16 48} Community healthcare workers (CHWs) also represent an important resource. In one study in Guatemala, a diabetes programme led by CHWs, who were equipped with a smartphone application to aid in clinical decision-making and supervised by a remote physician, showed improvements in HbA1c.⁴⁹ Notably, however, a study based in the USA found that individuals with diabetes perceived programmes in which CHWs provided the main intervention as settling for lower-quality care.⁵⁰ Programme evaluations in LMICs should further explore the social and cultural acceptability of CHWs' roles in diabetes care.

Second, our study highlights cost to patients as a major barrier to diabetes care, as similarly demonstrated in sub-Saharan Africa and Asia.^{12 42 44 51} While increasing availability of free public healthcare is an important goal, the expanding private health sector is assuming an increasing role in primary care delivery globally.¹⁰ As such, innovative fee-for-service models should be considered as means for improving diabetes care access and continuity in Guatemala and other LMICs. Value-based care, or using outcome and cost data to improve care delivery through performance-associated payment,⁵² can be leveraged to improve health outcomes while reducing costs for clients. For example, the Clínicas del Azúcar model in Mexico rewards low-income clients for lifestyle modifications and improved health outcomes with reduced membership fees.⁵³ Non-governmental organisations can also play roles in lowering costs through preferential purchasing

of generic medications and price negotiations with local suppliers, as described in a study from Guatemala.¹⁷

Finally, perceptions of low-quality care related to government facilities' resource limitations and providers' communication styles drove participants in our study to change diabetes providers, further affecting care access and continuity. Medication stock-outs and mistreatment by public sector providers have similarly been documented as sources of dissatisfaction with diabetes care elsewhere in Guatemala²⁹ and in sub-Saharan Africa⁴² and India.¹² In global health literature on care quality, these perceptions fall under the domains of effectiveness, equity and person-centredness of care.⁵⁴ Improvements in effectiveness and equity must occur through investment and resource management changes to make diabetes medications, providers and specialists more readily and consistently available. Person-centredness of diabetes care may be improved through provider education in motivational interviewing, a communication technique intended to elicit an individual's values and intrinsic desires to change behaviour, which has been associated with improved diabetes outcomes in a variety of settings.⁵⁵ As studies about diabetes care quality in LMICs have largely focused on poor care alignment of clinical care with recommended evidence-based standards,^{56 57} patient perceptions of health service quality represent an important direction for future research.

Limitations

Our study faces four limitations. First, pathways to care are based on retrospective self-reported health-seeking behaviours over the course of several years, which are subject to recall and reporting bias. Due to the availability of the qualitative research team and the logistics involved in performing home visits in rural areas, data were collected from each participant in a single interview, rather than longitudinally over repeated interviews. Participants were not always able to provide an exact time course of health-seeking behaviours and may have omitted health resources. Second, by recruiting participants through a population study using elevated HbA1c to evaluate for diabetes as a risk factor for chronic kidney disease, individuals with uncontrolled diabetes mellitus are over-represented in the qualitative study sample. Care trajectories are likely different for individuals who are successfully engaged in treatment with better-controlled disease. Third, our results reflect experiences of a majority indigenous population living in rural areas and may not be generalisable to other areas of Guatemala, particularly given the local strength of ethnomedicine in rural areas as well as unique political-economic, cultural and linguistic barriers to biomedical care faced by indigenous Maya people.²⁵ Fourth, the majority of our participants are women, which is likely related to recruitment through daytime home visits during men's work hours, and reflects known difficulties of recruiting men into NCD activities in the region.⁵⁸

CONCLUSION

Adults with diabetes in Guatemala experienced fragmented diabetes care and faced costs and perceived low-quality care as barriers to diabetes care. Strengthening the national primary healthcare system while innovating in private and non-governmental sectors can help improve diabetes care continuity. This study offers important lessons about improvements needed in diabetes care in Guatemala and other LMICs.

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Contributors ANC conceptualised the study design, oversaw data collection and analysis and drafted the manuscript. MN was involved with study design, data collection and analysis and drafted the manuscript. ST KW and SK were involved with study design, data collection and analysis and provided critical revisions of the manuscript. DF and PG were involved with study design, data analysis and critical revision of the manuscript. PR conceptualised the study design, was involved with data analysis and critically revised the manuscript. ANC acts as guarantor for this work.

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REFERENCES

- Cho NH, Shaw JE, Karuranga S, *et al*. IDF diabetes atlas: global estimates of diabetes prevalence for 2017 and projections for 2045. *Diabetes Res Clin Pract* 2018;138:271–81.
- Allen LN. Financing national non-communicable disease responses. *Glob Health Action* 2017;10:1326687.
- Kankeu HT, Saksena P, Xu K, *et al*. The financial burden from non-communicable diseases in low- and middle-income countries: a literature review. *Health Res Policy Syst* 2013;11:31.
- Soetedjo NNM, McAllister SM, Ugarte-Gil C, *et al*. Disease characteristics and treatment of patients with diabetes mellitus attending government health services in Indonesia, Peru, Romania and South Africa. *Trop Med Int Health* 2018;23:1118–28.
- Manne-Goehler J, Geldsetzer P, Agoudavi K, *et al*. Health system performance for people with diabetes in 28 low- and middle-income countries: a cross-sectional study of nationally representative surveys. *PLoS Med* 2019;16:e1002751.
- Manne-Goehler J, Atun R, Stokes A, *et al*. Diabetes diagnosis and care in sub-Saharan Africa: pooled analysis of individual data from 12 countries. *Lancet Diabetes Endocrinol* 2016;4:903–12.
- Stokes A, Berry KM, Mchiza Z, *et al*. Prevalence and unmet need for diabetes care across the care continuum in a national sample of South African adults: evidence from the SANHANES-1, 2011–2012. *PLoS One* 2017;12:e0184264.
- Price AJ, Crampin AC, Amberbir A, *et al*. Prevalence of obesity, hypertension, and diabetes, and cascade of care in sub-Saharan Africa: a cross-sectional, population-based study in rural and urban Malawi. *Lancet Diabetes Endocrinol* 2018;6:208–22.
- Yan LD, Hanvoravongchai P, Aekplakorn W, *et al*. Universal coverage but unmet need: national and regional estimates of attrition across the diabetes care continuum in Thailand. *PLoS One* 2020;15:e0226286.
- World Health Organization. The private sector, universal health coverage and primary health care, 2018. Available: https://www.who.int/docs/default-source/primary-health-care-conference/private-sector.pdf?sfvrsn=36e53c69_2
- Pfeiffer J, Chapman R. Anthropological perspectives on structural adjustment and public health. *Annu Rev Anthropol* 2010;39:149–65.
- Bhojani U, Mishra A, Amruthavalli S, *et al*. Constraints faced by urban poor in managing diabetes care: patients' perspectives from South India. *Glob Health Action* 2013;6:22258.
- Bigdeli M, Jacobs B, Men CR, *et al*. Access to treatment for diabetes and hypertension in rural Cambodia: performance of existing social health protection schemes. *PLoS One* 2016;11:e0146147.
- Pastakia SD, Pekny CR, Manyara SM, *et al*. Diabetes in sub-Saharan Africa - from policy to practice to progress: targeting the existing gaps for future care for diabetes. *Diabetes Metab Syndr Obes* 2017;10:247–63.
- Gyawali B, Ferrario A, van Teijlingen E, *et al*. Challenges in diabetes mellitus type 2 management in Nepal: a literature review. *Glob Health Action* 2016;9:31704.
- Steinman L, Heang H, van Pelt M, *et al*. Facilitators and barriers to chronic disease self-management and mobile health interventions for people living with diabetes and hypertension in Cambodia: qualitative study. *JMIR Mhealth Uhealth* 2020;8:e13536.
- Flood D, Mux S, Martinez B, *et al*. Implementation and outcomes of a comprehensive type 2 diabetes program in rural Guatemala. *PLoS One* 2016;11:e0161152.
- Micikas M, Foster J, Weis A, *et al*. A community health worker intervention for diabetes self-management among the Tz'utujil Maya of Guatemala. *Health Promot Pract* 2015;16:601–8.
- Esterson YB, Carey M, Piette JD, *et al*. A systematic review of innovative diabetes care models in low- and middle-income countries (LMICs). *J Health Care Poor Underserved* 2014;25:72–93.
- World Health Organization, Division of Mental Health. Pathways of patients with mental disorders: a multi-centre collaborative project, 1987. Available: <https://apps.who.int/iris/handle/10665/61855>
- Trebbel TM, Hansi N, Hydes T, *et al*. Process mapping the patient journey: an introduction. *BMJ* 2010;341:c4078.
- Barcelo A, Gregg EW, Gerzoff RB, *et al*. Prevalence of diabetes and intermediate hyperglycemia among adults from the first multinational study of noncommunicable diseases in six Central American countries: the Central America Diabetes Initiative (CAMDI). *Diabetes Care* 2012;35:738–40.
- Institute for Health Metrics and Evaluation. Guatemala, 2015. Available: <http://www.healthdata.org/guatemala>
- Pan American Health Organization (PAHO). Health in the Americas: Guatemala (summary: regional outlook and country profiles). Washington, DC; 2017. <https://www.paho.org/salud-en-las-americas-2017/?p=3338>
- Chary A, Rohloff P. *Privatization and the new medical Pluralism: shifting healthcare landscapes in Maya Guatemala*. Lexington Books, 2015: 227 p.
- Chary A, Greiner M, Bowers C, *et al*. Determining adult type 2 diabetes-related health care needs in an Indigenous population from rural Guatemala: a mixed-methods preliminary study. *BMC Health Serv Res* 2012;12:476.
- Ministerio de Salud Pública y Asistencia Social (MSPAS), Instituto Nacional de Estadística (INE), Secretaría de Planificación y Programación de la Presidencia (Segeplán), ICF International. VI Encuesta Nacional de Salud Materno Infantil, ENSMI 2014–2015. Guatemala City, Guatemala Ministerio de Salud Pública y Asistencia Social (MSPAS); 2015.
- Flood D, Rohloff PJ. "This disease is for those who can afford it": Privatization and Pluralism among Indigenous Diabetics. In: Chary A, Rohloff P, eds. *Privatization and the new medical Pluralism: shifting health care landscapes in Maya Guatemala*. Lanham, Maryland: Lexington Books, Rowman & Littlefield; : 51–68p..
- Nieblas-Bedolla E, Bream KDW, Rollins A, *et al*. Ongoing challenges in access to diabetes care among the Indigenous population: perspectives of individuals living in rural Guatemala. *Int J Equity Health* 2019;18:180.
- Miller AC, Rohloff P, Blake A, *et al*. Feasibility of satellite image and GIS sampling for population representative surveys: a case study from rural Guatemala. *Int J Health Geogr* 2020;19:56.
- Guest G, Bunce A, Johnson L. How many interviews are enough?: an experiment with data saturation and variability. *Field Methods* 2006;18:59–82.
- O'Brien BC, Harris IB, Beckman TJ, *et al*. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.
- Chary A, Nandi M, Flood D. [dataset] Data from: pathways to care among adults with diabetes in Guatemala. *Dataverse Data Repository* 2022.
- Knight JC, Dowden JJ, Worrall GJ, *et al*. Does higher continuity of family physician care reduce hospitalizations in elderly people with diabetes? *Popul Health Manag* 2009;12:81–6.
- Weir DL, McAlister FA, Majumdar SR, *et al*. The interplay between continuity of care, multimorbidity, and adverse events in patients with diabetes. *Med Care* 2016;54:386–93.
- Chang P-Y, Chien L-N, Bai C-H, *et al*. Continuity of care with physicians and risk of subsequent hospitalization and end-stage renal disease in newly diagnosed type 2 diabetes mellitus patients. *Ther Clin Risk Manag* 2018;14:511–21.
- Lin W, Huang I-C, Wang S-L, *et al*. Continuity of diabetes care is associated with avoidable hospitalizations: evidence from Taiwan's National health insurance scheme. *Int J Qual Health Care* 2010;22:3–8.
- Heianza Y, Suzuki A, Fujihara K, *et al*. Impact on short-term glycaemic control of initiating diabetes care versus leaving diabetes untreated among individuals with newly screening-detected diabetes in Japan. *J Epidemiol Community Health* 2014;68:1189–95.
- Flood D, Rohloff P. Diabetes in Indigenous Maya Communities. In: *Privatization and the new medical pluralism: shifting healthcare landscapes in Maya Guatemala*. 53, 2015.
- Avila C, Bright R, Hoadley K. Guatemala health system assessment. Bethesda, MD USAID Health Finance & Government Project, Abt Associates Inc; 2015. <https://www.hfgproject.org/guatemala-health-system-assessment-2015/>
- Global Health Workforce Alliance, World Health Organization. A universal truth: no health without a workforce, 2014. Available: <https://www.who.int/workforcealliance/knowledge/resources/hrhreport2013/en/>
- Zimmermann M, Bunn C, Namadingo H, *et al*. Experiences of type 2 diabetes in sub-Saharan Africa: a scoping review. *Glob Health Res Policy* 2018;3:25.
- Atwine F, Hultsjö S, Albin B, *et al*. Health-Care seeking behaviour and the use of traditional medicine among persons with type 2 diabetes in south-western Uganda: a study of focus group interviews. *Pan Afr Med J* 2015;20:76.

- 44 Nang EEK, Dary C, Hsu LY, *et al.* Patients' and healthcare providers' perspectives of diabetes management in Cambodia: a qualitative study. *BMJ Open* 2019;9:e032578.
- 45 Joshi R, Alim M, Kengne AP, *et al.* Task shifting for non-communicable disease management in low and middle income countries--a systematic review. *PLoS One* 2014;9:e103754.
- 46 Gill GV, Price C, Shandu D, *et al.* An effective system of nurse-led diabetes care in rural Africa. *Diabet Med* 2008;25:606–11.
- 47 Kengne AP, Fezeu L, Sobngwi E, *et al.* Type 2 diabetes management in nurse-led primary healthcare settings in urban and rural Cameroon. *Prim Care Diabetes* 2009;3:181–8.
- 48 Piette JD, Mendoza-Avelares MO, Milton EC, *et al.* Access to mobile communication technology and willingness to participate in automated telemedicine calls among chronically ill patients in Honduras. *Telemed J E Health* 2010;16:1030–41.
- 49 Duffy S, Norton D, Kelly M, *et al.* Using community health workers and a smartphone application to improve diabetes control in rural Guatemala. *Glob Health Sci Pract* 2020;8:699–720.
- 50 Brown SA, Hanis CL. Lessons learned from 20 years of diabetes self-management research with Mexican Americans in Starr County, Texas. *Diabetes Educ* 2014;40:476–87.
- 51 Lewis CP, Newell JN. Patients' perspectives of care for type 2 diabetes in Bangladesh -A qualitative study. *BMC Public Health* 2014;14:737.
- 52 Global Development Incubator, Bill & Melinda Gates Foundation, USAID Center for Innovation and Impact, The Rockefeller Foundation. Leapfrog to value report, 2019. Available: https://static1.squarespace.com/static/5db772d44638535b2114f2e6/t/5df2a7258f674e48379b81c8/1576183591245/2019_LeapfrogToValue_Report.pdf
- 53 The Center for Health Market Innovations. Clinicas del Azúcar, 2020. Available: <https://healthmarketinnovations.org/program/clinicas-del-az%C3%BAcar>
- 54 National Academies of Sciences and Engineering, Health and Medicine Division, Board on Health Care Services, Board on Global Health, Committee on Improving the Quality of Health Care Globally. The Current State of Global Health Care Quality [Internet]. In: *Crossing the global quality chasm: improving health care worldwide*. National Academies Press (US), 2018[cited 2020 Nov 28]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK535654/>
- 55 Ekong G, Kavookjian J. Motivational interviewing and outcomes in adults with type 2 diabetes: a systematic review. *Patient Educ Couns* 2016;99:944–52.
- 56 Mudaliar U, Kim W-C, Kirk K, *et al.* Are recommended standards for diabetes care met in central and South America? A systematic review. *Diabetes Res Clin Pract* 2013;100:306–29.
- 57 Shivashankar R, Kirk K, Kim WC, *et al.* Quality of diabetes care in low- and middle-income Asian and Middle Eastern countries (1993-2012): 20-year systematic review. *Diabetes Res Clin Pract* 2015;107:203–23.
- 58 Fort MP, Castro M, Peña L, *et al.* Opportunities for involving men and families in chronic disease management: a qualitative study from Chiapas, Mexico. *BMC Public Health* 2015;15:1019.