A qualitative study of pathways to care among adults with diabetes in rural Guatemala

By

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Abstract

Introduction: The burden of diabetes mellitus is increasing in low- 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.

Methods: 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 HbA1c screening for diabetes in both sites. Based on results from the first six months of the population study, semi-structured interviews were performed with 29 adults found to have a 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.

Discussion: 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 multi-sectorial and occur through strengthened government primary care and innovative private and non-governmental organization care models.

Key Words: Diabetes mellitus, healthcare access, care-seeking, healthcare decision-making, pathways to care, indigenous health, Guatemala

Key Message:

Adults living with diabetes in rural Guatemala experience fragmented diabetes care across multiple health sectors, including public, private, and non-governmental sectors. Multi-sectoral strategies that consider cost and perceptions of quality are needed to improve access to and continuity of diabetes care in Guatemala and other LMICs.

Key Findings:

- Care maps constructed from interviews with adults living with diabetes in rural Guatemala demonstrated fragmented, discontinuous diabetes care across government, private, and several other health sectors
- Semi-structured interviews also illuminated cost and perceptions of low-quality services in public facilities as barriers to diabetes care

Key Implications:

- Longitudinal investment to strengthen the national primary health care system is an important long-term strategy to improve access to affordable, continuous diabetes care
- In the interim, innovative care models at private and non-governmental organizations may help improve continuity of diabetes care in Guatemala and other LMICs

Introduction

Low- and middle-income countries (LMICs) face an increasing prevalence of diabetes[1] with limited health system resources for disease prevention, screening, or management.[2–4] Demographic investigations about non-communicable diseases (NCDs) in LMICs have examined healthcare access and treatment modalities among individuals with diabetes, revealing 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 healthcare privatization and erosion of public health systems,[10,11] with individuals with diabetes utilizing private and non-governmental health resources.[3,12–19] Understanding individuals' pathways to, sources of, and decision-making regarding diabetes care 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 characterize sources of mental healthcare and referral patterns in low- and middle-income countries.[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 percent[22] and an over 50 percent 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 centers, 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] and due to longstanding historical inequalities and more recent civil war (1960s-1990s), 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 literature about trajectories of NCD care in LMICs.

Methods

Sampling and Recruitment

This qualitative study was a planned sub-study 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 population study utilized 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 the assessment for risk factors for chronic kidney disease. We defined a diagnosis of diabetes as a hemoglobin 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 centers, as needed. Population study staff then referred subjects with diabetes interested in participating in an interview to qualitative study team members.

From November 2018-June 2019, the qualitative study team approached all 42 participants who enrolled in the population study between June 2018 and February 2019 who had a HbA1c ≥ 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. 29 agreed to the interview, with 13 in the first site and 16 in the second site. 10 individuals declined to participate, and three were traveling at the time of the proposed interview.

Data collection

Trained interviewers conducted semi-structured interviews with 29 participants, which 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 enrollment in the population study. Interviews lasted 20-60 minutes 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 1 interviewer was present, the interviewer typed detailed notes and directly transcribed short quotes during the interview. In cases where 2 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 2 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. Qualitative analysis was facilitated by the software NVivo Pro, Version 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 health care 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 color. 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 utilized each type of health resource and the proportion of participants who used different types of health resources simultaneously.

Table 2. Descriptions of Healthcare Sectors

Sector	**Description**
Government: Ministry of Health	Health posts, health centers, and hospitals open to general public with no consultation fees operated by the Ministry of Health (MOH)
Government: Social Security	Social Security system open only to those employed in the formal sector (*Instituto Guatemalteco de Seguridad Social, IGSS*)
Private	Privately run, non-government health care site
Non-governmental	Non-governmental organization 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, commercialized product (e.g. Omnilife, Herbalife, Neurobion)
Ethnomedical	Locally-grown plants and herbal remedies
Household	Treatment or care from a member of participants' social network (family member, friend, neighbor, etc)

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 United States, 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 U.S. researcher and one indigenous researcher or interpreter.

Institutional context and ethics

This study approved by the Institutional Review Boards of Partners Healthcare, Boston; the Institute for Nutrition of Central American and Panama (INCAP), Guatemala; and Wuqu' Kawoq | Maya Health Alliance (MHA), a non-governmental organization which provides health services to indigenous populations in Guatemala. All subjects provided written consent to participate in the population study and provided verbal consent to participate in the qualitative interviews. 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 at: https://doi.org/10.7910/DVN/3EO2PD

Results

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, including 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%, 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.

Figure 1. Composite Care Map – Site 1

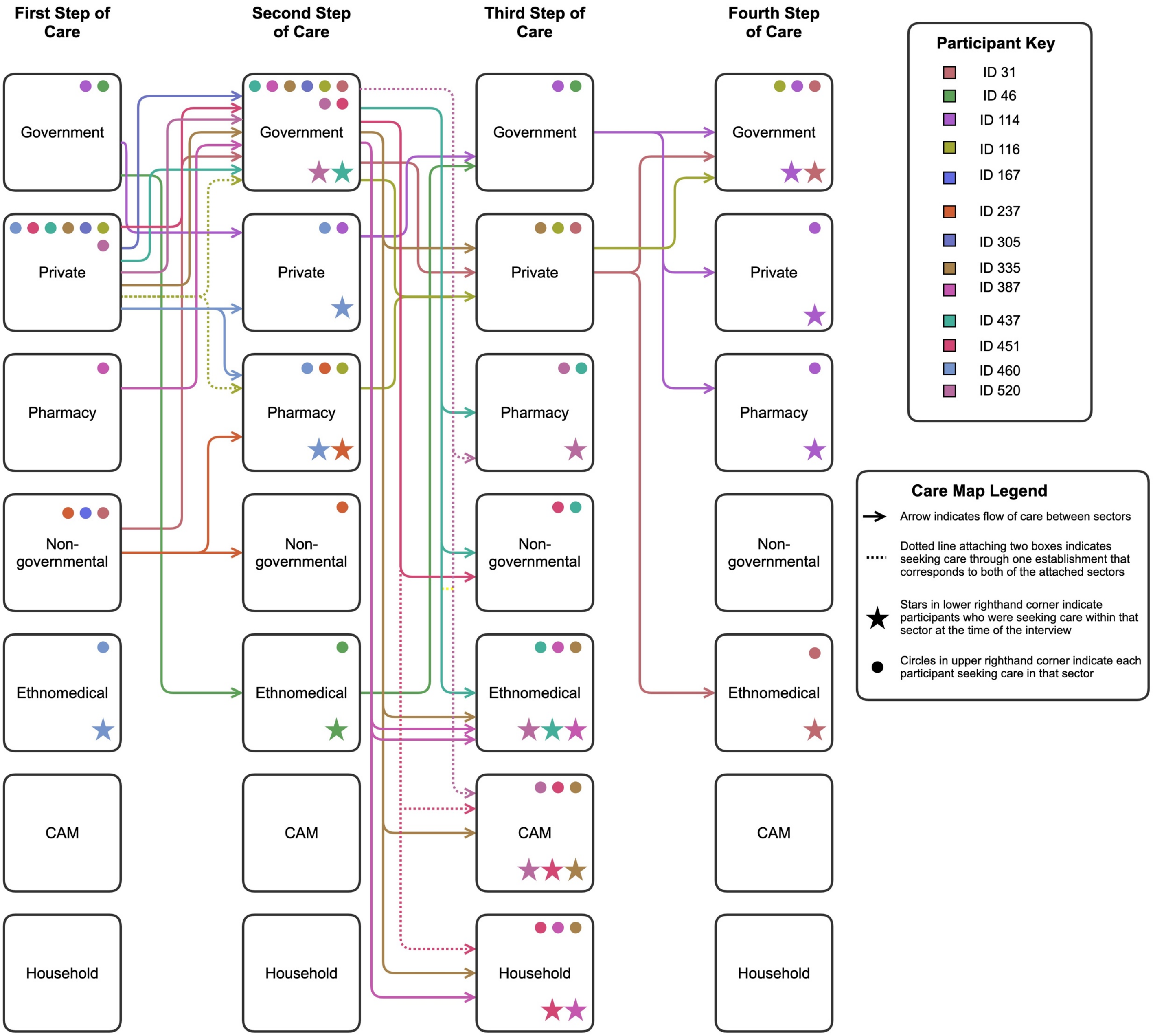


Table 3. Trends in Diabetes Care-Seeking

	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)
CAM	6 (21)
Ethnomedical	15 (52)
Household	7 (24)
Care seeking behaviors:	
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)
Traveled outside of their town to seek care	18 (62)

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)
CAM	4 (14)
Ethnomedical	10 (34)
Household	6 (21)

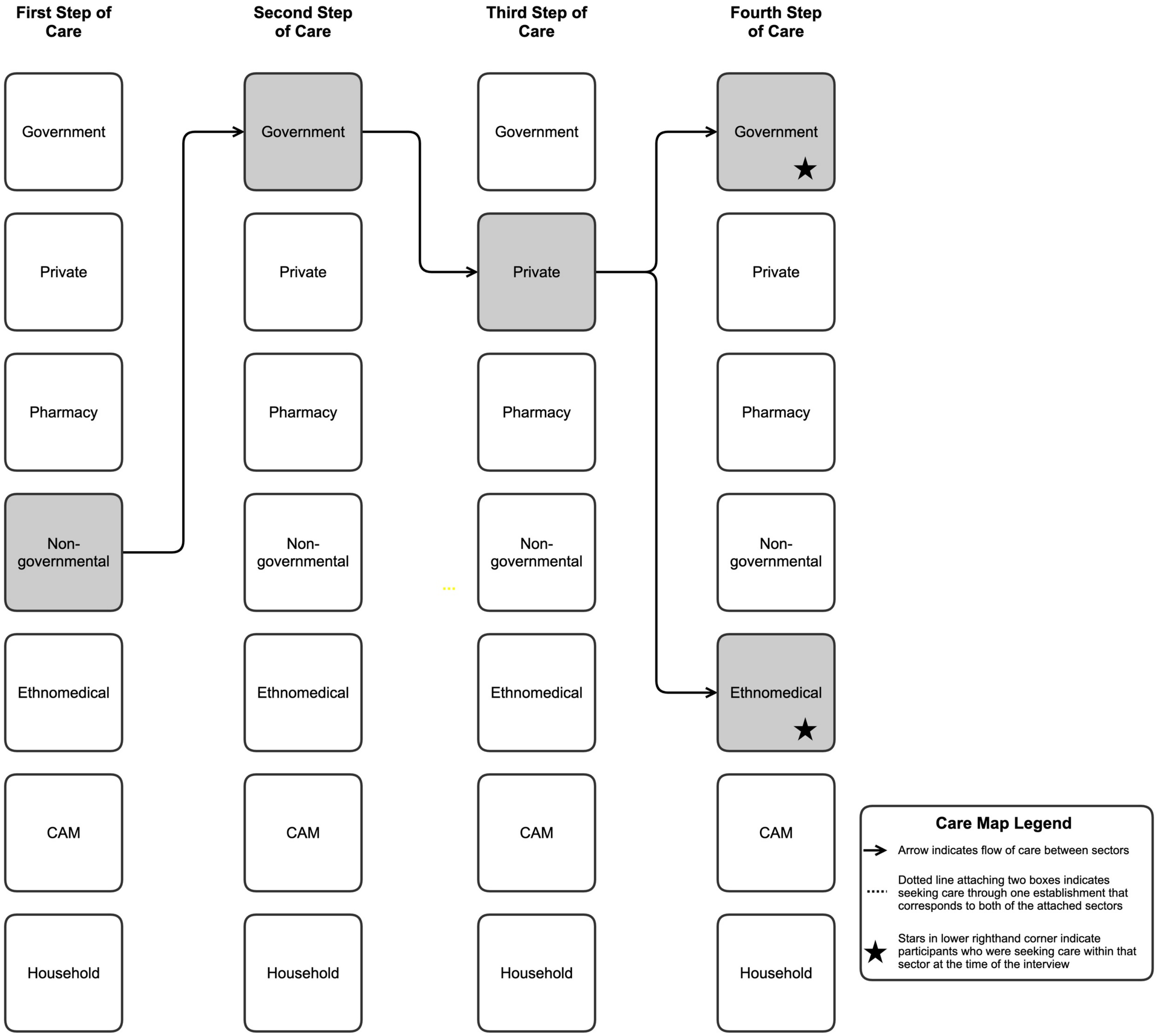
*Due to simultaneous care-seeking, percentages do not add to 100%.

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 center, 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 simultaneously, rather than in a linear sequential fashion (79%). For instance, participants used natural treatments or commercialized alternative products concurrently with biomedical medications and 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.

Figure 2. Participant Care Map, ID 31

This care map demonstrates simultaneous care seeking by a 67-year-old female from Site 1 over a period of 3.5 years.



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, 58 year-old female)

2 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:

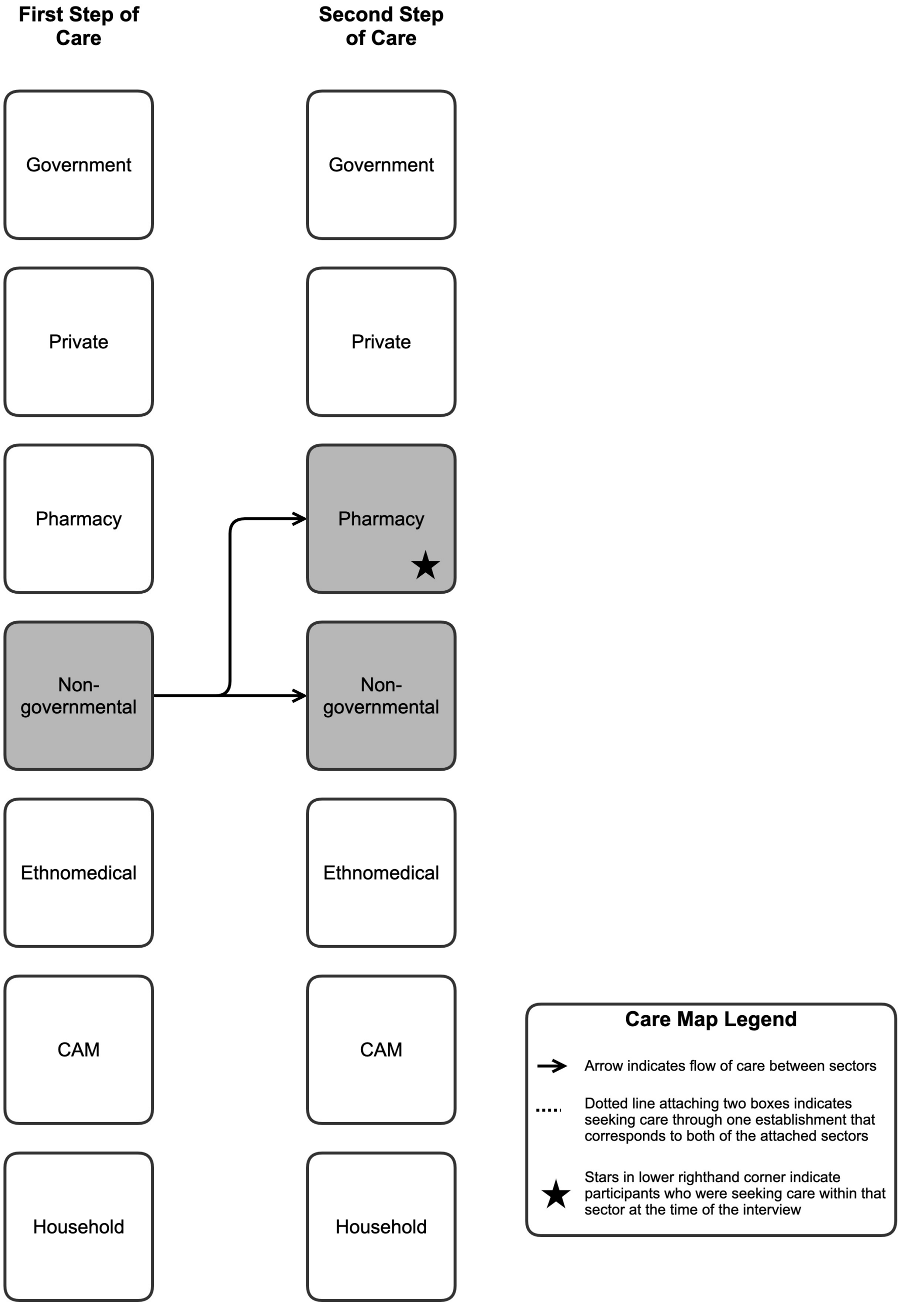
> "The doctor only told me, 'When you feel bad, come here,' but I don't have another appointment. That [feeling symptoms] is not going to happen if I follow the diet and the medications. I only take the same prescription to the pharmacy for more medication." (ID 1071, 45 year-old female)

While all participants who used the pharmacy did so to buy medication, 24% also used the pharmacy as a source of medical care, e.g. 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 utilized the pharmacy as her only source of medical care in this way.

Figure 3. Participant Care Map, ID 237

A 59-year-old female from Site 1 used the pharmacy as a regular source of medical care over the course of 3 years of diabetes care-seeking.



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, 56 year-old male)

> "In the health center, there are only trainees, no older doctors, therefore they don't know anything. They don't have experience." (ID 305, 67 year-old female)

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, 47 year-old female)

> “I did not want to go to the hospital because I was afraid to hear what they would say. Sometimes I go to the [MOH] health center and they scold you, they scold you and they judge you.” (ID 451, 48 year-old female)

Perceptions of low quality deterred three participants from seeking care in their local MOH health centers 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, 55 year-old male)

> “I went to a private doctor, because the health center and the hospital are very neglected.” (ID 1273, 56 year-old male)

Despite inability to afford private sector care, 1 participant refused to go to his local MOH health center due to perceived poor-quality care (ID 1266, 49 year-old male).

When 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, 58 year-old female)

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, 54 year-old female)

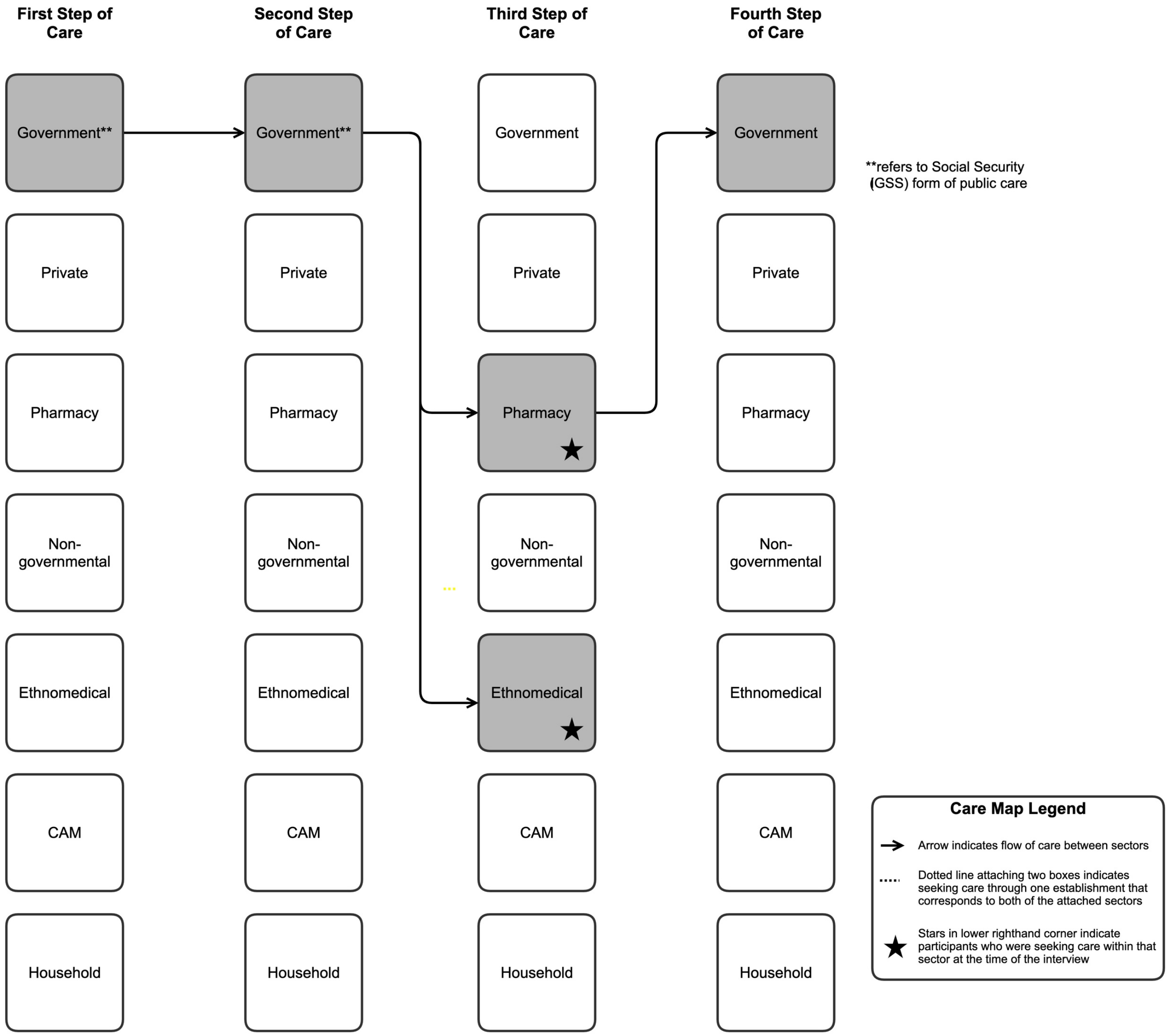
Participants described 2 major strategies to minimize care costs. First, participants sought free or cheaper sources of care (41%), including through NGOs, medical missions, or pharmacies. Second, participants continued to take previously prescribed medications--purchased from the pharmacy, as described 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, 48 year-old female)

The care pathway in Figure 4 demonstrates how cost, strategies to minimize 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, upon facing significant diabetes complications, including foot infection leading to amputation, he felt forced to pursue urgent care at the public MOH hospital (ID 1266, 49 year-old male).

Figure 4. Participant Care Map, ID 1266

A 49-year-old male from Site 2 sought diabetes care over 12 years.



Cost sometimes trumped participants' preferences of providers. For instance, 3 participants who 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, 1 participant hoped to continue with a "magnificent" doctor in a nearby city but could not afford the approximately 25 USD fee per appointment (ID 116, 52 year-old male).

Table 5 provides additional representative quotes for each theme.

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, 44 year-old female) "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, 52 year-old female) "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 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, 51 year-old female)
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, 56 year-old male) "The quality of care is low. They don't change my dose of metformin even though my sugar is still high." (ID 116, 52 year-old male) "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, 45 year-old female)

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, 56 year-old male) "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, 49 year-old male) "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, 47 year-old female)

Discussion

This qualitative study of diabetes care-seeking in rural Guatemala provides important insights into the fragmented nature of NCD care and 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, characterized by limited provider continuity, utilization of pharmacies for clinical care, and acute episodic care-seeking for diabetes complications—all making participants more vulnerable to diabetes-related morbidity and mortality. Indeed, diabetes care continuity is associated with HbA1c reduction and lower rates of hospitalization and mortality, as demonstrated in high-income settings.[33–36] Research exploring diabetes care-seeking in Guatemala,[26,38] India, and sub-Saharan Africa similarly reveal fragmented trajectories across different health sectors,[12,39,40] with initiation of care-seeking following development of symptoms rather than after routine asymptomatic screening.[39,41] In Guatemala, this trend reflects increased healthcare privatization,[25] unequal distribution of health care workers and resources in urban and rural areas,[24,42] and frequent changes in government leadership leading to staff turnover in local health clinics[42]—challenges faced in other LMICs, as well.[10,43]

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 optimize resources and shift tasks to non-physicians are feasible in LMICs, and, whether they occur through public health systems, non-governmental organizations, or in multi-sector partnerships, can improve longitudinal and continuous diabetes care while reducing costs.[44] Nurse-led interventions have shown promising results in improving diabetes care access and outcome measures in Guatemala[17] and sub-Saharan Africa.[19,45,46] 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 Asia,[19] and have improved care engagement when coupled with mobile health messaging in Honduras and Cambodia.[16,47] Community healthcare workers (CHWs) also represent an important resource. In one study in Guatemala, a diabetes program 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.[48] Notably, however, a study based in the United States found that individuals with diabetes perceived programs in which CHWs provided the main intervention as settling for lower-quality care.[49] Program 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.[12,39,41,50] While increasing availability of free public health care 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,[51] 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.[52] Non-governmental organizations 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 Guatemala[29] and in sub-Saharan Africa[39] and India.[12] In global health literature on care quality, these perceptions fall under the domains of effectiveness, equity, and person-centeredness of care.[53] 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-centeredness 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 behavior, which has been associated with improved diabetes outcomes in a variety of settings.[54] As studies about diabetes care quality in LMICs have largely focused on poor care alignment of clinical care with recommended evidence-based standards,[55,56] patient perceptions of health service quality represents an important direction for future research.

Limitations

Our study faces 4 limitations. First, pathways to care are based on retrospective self-reported health seeking behaviors over the course of several years, which are subject to recall and reporting bias. Participants were not always able to provide an exact time course of health seeking behaviors and may have omitted health resources. Second, by recruiting participants through a population study evaluating for elevated HbA1c, individuals with uncontrolled DM are overrepresented 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 generalizable 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 female, 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.[57]

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 health care 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.

List of Abbreviations

LMIC – low- and middle-income countries

NCD – non-communicable disease

MOH – Ministry of Health

IGSS - Instituto Guatemalteco de Seguridad Social

HbA1c - Hemoglobin A1c

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Role of Authors

[Author 1 MN] was involved with study design, data collection and analysis, and drafted the manuscript. [Author 8 AC] conceptualized the study design, oversaw data collection and analysis, and drafted the manuscript. [Authors 3, 4, 5 ST KW SK] were involved with study design, data collection and analysis, and provided critical revisions of the manuscript. [Authors 2, 6 DF PG] were involved with study design, data analysis, and critical revision of the manuscript. [Author 7 PR] conceptualized the study design, was involved with data analysis, and critically revised the manuscript.

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