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Care-seeking patterns for common pediatric illnesses: A mixed methods study in rural Guatemala

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Abstract

Background: Despite impressive economic growth, Guatemala continues to experience high levels of poverty and a disproportionate disease burden of preventable childhood illnesses. A mixed-methods study was conducted to determine care-seeking patterns and barriers to care for common pediatric illnesses in rural communities.

Methods: Household surveys and formative assessments were conducted in four districts/sub-districts to elicit information on care-seeking practices and barriers for child illness.

Results: Facility-based care for symptoms of Acute Respiratory Infection (ARI), diarrhea, and fever, was reported by <25% of caretakers, with <5% reporting prompt care-seeking. Treatment with antibiotics for ARI symptoms was reported by 47.8% of caretakers while 77.8% reported Oral Rehydration Therapy (ORT) treatment for diarrhea. Community health workers/health posts were the primary source of care (75%), with 17.6% of caretakers reporting facility care. Children from wealthier quintiles had twice the odds of facility-based care than the poorest families (OR 2.78, 95% CI 1.32-5.83). Other factors significantly associated with care-seeking were younger children and 2 or more comorbidities. Qualitative findings indicated that the major barriers to appropriate and timely care-seeking were cultural preferences for traditional treatment, perceived illness severity, lack of spousal consent, geographical and financial access to facilities, distrust of health providers, and long wait times.

Conclusion: Treatment decision making for pediatric care is a complex and dynamic process influenced by multiple factors. As global efforts accelerate for universal health coverage and people centered care, investments for community-oriented healthcare is of paramount importance.

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Introduction

Guatemala has demonstrated an impressive economic growth rate in recent years, boasting the biggest economy in Central America.¹ Despite development investments, the country continues to experience stark disparities with extreme poverty levels and a disproportionate disease burden for women and children, with one of the world's worst rates for chronic child malnutrition.² Over half (59.3%) of the population live below the poverty line, with 9.5% living in extreme poverty (<\$2 USD/day).² The disparities worsen for rural and indigenous populations with 76.1% of the rural population and 79% of the indigenous population living below the poverty line.^{2,3} Decades of civil unrest and other factors have decimated the health infrastructure, with chronic health workforce deficits, and high crime rates and targeted gang violence limiting access to healthcare, particularly in rural areas.^{4,5} Political unrest and human rights abuses have also contributed to the unstable healthcare landscape in Guatemala.^{6,7}

The health system in Guatemala continues to face a myriad of challenges, especially related to chronic workforce deficits. Current estimates indicate a physician population ratio of 0.9/1,000 population, of whom 71% are located near the capital.^{1, 3} Though health policy mandates free primary care services, providers continue to practice a fee for service model. Catastrophic spending for healthcare is apparent among the rural poor, in addition to incurring costs of transport and medicines.⁸ An appraisal of the health system indicated several factors contributing to poor performance, which included inadequate financing resulting in insufficient essential medical commodities, lack of an effective service delivery mechanism for rural populations, inequitable workforce distribution, and political factors preventing the execution of health policies.⁹ The stark contrast between urban and rural health worker densities (25.7 health workers per 10,000 population in urban areas compared to only 3.0 per 10,000 in rural areas), the dearth of clinicians fluent in indigenous languages, and the disparities in accessing skilled birth attendants (73% among Ladinas but only 36% among indigenous women) highlight the barriers to access among rural and indigenous populations in Guatemala.⁹

The country was successful in reducing the under-five child mortality rate from 81/1,000 live births in 1990 to 29/1,000 live births in 2015, just falling short of the Millennium Development Goal target of 27/ 1,000 live births.¹⁰ As in other low and middle income economies, diarrhea (19.3%), fever (25.6%), and pneumonia (10.6%), contribute to the major disease burden in children in rural Guatemala.¹¹ Globally, malnutrition is a major contributory factor for more than half of under-five deaths.¹² The recent estimates for stunting based on the Demographic Health Survey (DHS), was 46.5% in Guatemalan rural areas for children under-five.¹¹

The Bellagio Child Survival Study Group postulated that 63% of childhood deaths could be averted if coverage for effective interventions could be achieved.¹³ Barriers to prompt and appropriate care-seeking from trained health providers was identified as one of the key global research priorities for preventing mortality from pneumonia.¹⁴ The majority of caretakers whose children experience illness neglect to seek timely and appropriate care from trained health providers.^{15–17} Earlier studies in Guatemala showed that formal care-seeking from government facilities and private doctors was 19.8% for symptoms of constant cough, 49.7% for pediatric pneumonia, 21.8% for diarrhea, 30.6% for severe pediatric diarrhea, and 25% for fever; poverty was shown to be a key predictor for care-seeking, followed by ethnicity and education.^{18,19}

Patients' perceptions of access, quality of care, and affordability as well as their ability and willingness to pay for services drive utilization of the system. Access to care is a complex dynamic of various health system components including health policy and financing, geographic location of services, and availability of trained personnel and essential commodities.²⁰ As the health system in Guatemala faces formidable challenges for universal coverage, complementary strategies for community oriented healthcare are essential to ensure effective service utilization. Evidence from other contexts has illustrated that community based interventions with volunteers can effectively improve appropriate prevention and utilization of health services and care-seeking behavior.¹⁰⁻¹²

The primary health structure of the Guatemalan Ministry of Health includes health posts and convergence centers, which are designed as the first point of contact and facilitate the access of health services in rural areas. Most health posts have an auxiliary nurse or health technician who screen the population for epidemiological risks and treat common diseases like diarrhea or Acute Respiratory Infection (ARI). In the past, two different types of national programs were implemented through Community Health Workers (CHW) in Guatemala, but these systems are no longer fully functional due to lack of resources. Several non-governmental organizations have supported community-based services including CHW to complement the government health services and be a liaison for the auxiliary nurse or health technician at the health post and the community. World Vision, a Christian relief and development organization, enhances community capacity by equipping community health volunteers and community health councils to support basic preventive and curative care at the community level, and ensure appropriate referral and service utilization at the facility level. As part of an ongoing multi-country study to examine the effectiveness of integrated community interventions on maternal newborn and child health we conducted a baseline mixed methods evaluation. The findings on facilitating factors and barriers to curative care seeking were to inform project strategies in the future.

Methods

This multi-country research study was conducted by the Johns Hopkins University, in collaboration with the National Institute of Public Health, Cambodia, Moi University, Kenya, Institute of Economic and Social Research at the University of Zambia, and Institute of Nutrition of Central America and Panama, Guatemala.

In most countries where World Vision operates, health and developmental programs are implemented through comprehensive Area Development Programs (ADP), which are integrated multi-faceted interventions focusing on health, nutrition, water and sanitation, food security, education, and child sponsorship/protection. These ADP are distinctive geographic areas covering a population ranging from 19,000 to 25,000 people. For the study, four ADP from each country were selected and matched on selected demographic and health characteristics including disease burden, poverty, and access to formal healthcare among other factors. Two ADP were assigned to the intervention arm and two to the comparison arm of the study. Communities in the intervention sites received a package of interventions including health promotion by CHW, and social accountability mechanisms using Community Voice and Action and Community Scorecards, to strengthen community to health facility linkages, enhance

community knowledge of health facility entitlements, and support facility performance.²¹ Facility and community management councils were established or existing councils/committees were strengthened through training and supportive supervision based on the Global Fund's Community Systems Strengthening Framework²².

Results from the baseline survey in Guatemala are reported in this paper. ADP selected for the study are illustrated in Table 1. Ethical clearance for the study was obtained by the Johns Hopkins Bloomberg School of Public Health's Institutional Review Board and the research review board at the Institute of Nutrition of Central America and Panama.

Table 1: Selected ADP Study Sites in Guatemala

Study Arm	ADP Sites	
	Nuevo Amanecer	Comapa
Intervention		
Comparison	Tinamit Junam	Apas

The baseline evaluation in Guatemala was conducted from October to December 2013. Communities were sampled in proportion to population size, using a multi-stage sampling strategy and eligible households were selected from each sampling unit. In each household one eligible woman between the ages of 15-49, and up to three children under-five were selected randomly. Sample size was estimated to detect a significant difference in differences in the decline in nutritional outcomes in children under-five, with a two-sided alpha of .05 ($\alpha = 0.05$) and power of 80% ($1 - \beta = 0.80$), factoring 5% for non-response rate and design effect of 1.2. Illness episodes two weeks prior to the interview and subsequent care-seeking practices were elicited from caretakers of children under-five.

Formative assessments using 32 focus group discussions and 49 key informant interviews were conducted with community health committee members, CHW, male and female community members, village leaders, program staff, and health facility supervisors in the ADP.

Study teams trained on survey field procedures, informed consent, and ethical protocols, conducted the baseline assessments using modified instruments from the standard DHS.²³ Interviews were conducted with the head of households to obtain information on sociodemographic characteristics, food security, etc. Caretakers of children were subsequently interviewed to obtain information on child illness care-seeking behaviors, feeding practices, immunizations, etc. Standard procedures were followed for translation of instruments, field testing, and other survey procedures to ensure quality control and participant confidentiality.

All caretakers of eligible children (age 0-59 months) were interviewed on symptoms of cough, rapid breathing, diarrhea, blood in stool, and fever experienced by children in the previous two weeks, as well as illness and preventive care-seeking patterns. ARI was defined as cough and difficult breathing, diarrhea was defined by caretaker's report.

Data Analysis

Data was entered, cleaned and verified using REDCap.²⁴ Data analysis was performed with STATA V14.2²⁵, using descriptive statistics, chi-square, t-tests, and univariate and multivariate logistic

regressions for the factors associated with child care-seeking. Cases with missing data for selected independent variables were excluded from the regression models. Using principle component analysis, we constructed the wealth quintiles with a combination of 12 household assets (television, radio, bicycle, etc.), type of roofing, drinking water source, and type of sanitation. Collinearity was tested for the independent variables used in the regression models. For the qualitative analysis, the coding followed standard procedures of inductive and deductive themes and data were classified into sub themes based on the content.

Results

We conducted 3,048 household surveys, which showed that 81.8% of the households were headed by males, with an average family size of 5.3 members per household (Table 2). Three fourths of the child caretakers were between 20-36 years; 13% were adolescents. Only two thirds of the child caretakers were married, and 61.7% had a primary or secondary level education; 34.2% had no formal education. Of the 3,512 children included in the study, one third were under the age of one year.

Table 2: Selected Socio-demographic Characteristics of Study Participants

	N	%/mean
Household Characteristics (n=3,048)		
Head of household		
Male	2,461	81.8
Female	547	18.2
Mean family size	3,048	5.3
Child Caretaker Age		
15-19 years	396	13.0
20-36 years	2,298	75.7
37-49 years	344	11.3
Child Caretaker Marital Status		
Married	2,058	67.6
Single/divorced/widowed	987	32.4
Child Caretaker Education		
No formal education	1,039	34.2
Primary/secondary	1,874	61.7
More than secondary	126	4.1
Child Characteristics (n=3,512) ^a		
Child Gender		
Male	1,783	50.8
Female	1,728	49.2
Child Age		
0-11 months	1,083	32.3
12-23 months	993	29.7
24-59 months	1,272	38.0

^aUp to three under-five children per household were eligible for enrollment

Reported Illness and Care-seeking Practices

Based on the child caretakers report, 35% of the children had an illness episode in the previous two weeks with 14.2% reporting symptoms of ARI, and 17.8% reported diarrhea (Table 3). The most commonly reported symptom was fever (22.1%), with 15.1% reporting comorbidities in children in the previous two weeks.

Table 3: Caretaker Report of Child Illness Episode in the Past Two Weeks and Care-seeking Practices

	N	n	%
Reported illness in past two weeks (n=1,230)	3,512	1,230	35.0
ARI (cough with difficult breathing)	3,426	487	14.2
Diarrhea	3,483	620	17.8
Diarrhea and blood in stool	605	62	10.2
Fever	3,468	766	22.1
Comorbidities (two or more illnesses)	3,391	511	15.1
Sought facility-based ^a care for illness			
ARI (cough with difficult breathing)	275	45	16.4
Fever	446	74	16.6
Diarrhea	331	52	15.7
Sought immediate care (within 24 hours)			
ARI	261	6	2.3
Fever	391	11	2.8
Diarrhea	318	11	3.5
Reported appropriate treatment			
Antimalarials for fever	766	33	4.3
Antibiotics for ARI	487	233	47.8
ORT for diarrhea ^b	591	460	77.8
Source of care (any condition)	1,230	708	
Government clinic	708	14	2.0
Government hospital	708	38	5.4
Private clinic/hospital	708	72	10.2
Health post/CHW house	708	533	75.3
Pharmacy	708	47	6.6
Other (Municipality, relative, shop)	708	11	1.6
Source of care (for ARI)	487	280	
Government clinic	280	1	0.4
Government hospital	280	15	5.4
Private clinic/hospital	280	29	10.4
Health post/CHW house	280	199	71.1
Pharmacy	280	27	9.6
Other (Municipality, relative)	280	4	1.4
Source of care (for fever)	766	453	
Government clinic	453	8	1.8

Government hospital	453	23	5.1
Private clinic/hospital	453	43	9.5
Health post/CHW house	453	336	74.2
Pharmacy	453	29	6.4
Other (Municipality, relative, shop)	453	7	1.6
Source of care (for diarrhea)	620	337	
Government clinic	337	5	1.5
Government hospital	337	16	4.7
Private clinic/hospital	337	31	9.2
Health post/CHW or midwife house	337	256	76.0
Pharmacy	337	18	5.3
Other (Municipality, relative)	337	5	1.5

^a Facility-based care; clinic or hospital (public and private)

^bORT: Oralite, Oral Rehydration Salts, homemade sugar-salt solution, porridge/soup/rice water/coconut water, yogurt, fruit juice, tea, milk

^c Some caretakers reported seeking care for child illness, but were not aware of the type of facility they attended.

Less than a fifth of the caretakers whose children experienced symptoms of ARI, fever or diarrhea sought care at a private or public clinic or hospital. Prompt care-seeking (within 24 hours) was only reported by 4% of the caretakers. A majority of caretakers reported seeking care at a health post or with a CHW (ARI, 71.1%, fever, 74.2%, diarrhea 76%). Seeking care from local stores or pharmacies was reported by 9.6% of caretakers whose children experienced ARI, 6.4% for fever, and 5.3% for those with diarrhea. Other caretakers also reported receiving care from municipalities and relatives.

Oral Rehydration Therapy (ORT) for diarrhea, which included oral rehydration salts and home-made fluids, was reported by 77.8% of caretakers, 47.8% reported antibiotic treatment for symptoms of ARI, and only 4.3% reported treatment with antimalarials for fever.

Care-seeking by Wealth Quintile

Illness and care-seeking patterns by household wealth quintiles are described in Table 4. There were no significant differences between wealth quintiles for reported illness for any condition (ARI, diarrhea, fever, or comorbidities). However, there were significant differences for facility care-seeking between the poorest and wealthier quintiles (ARI, $p<0.001$, Fever, $p<0.009$, Diarrhea, $p<0.018$) with higher percentages of caretakers in the wealthiest quintiles (15-18%) accessing facility-based care compared to 3-5%, in the poorest quintiles. Likewise, a higher percentage of caretakers from wealthier quintiles sought care at public or private clinics or hospitals (3-10%), compared to the poorer quintiles (0.7-2.6%). Over half of the caretakers from the poorer quintiles reported seeking care at a health post or a CHW, compared to only 32.5% in wealthier quintiles ($p<0.001$). Since very few caretakers ($<4\%$) sought prompt care, there were no apparent differences between the quintiles.

Table 4: Illness Care-seeking Patterns of Child Caretakers by Wealth Quintile

	Q1 (lowest)	Q2 (lower)	Q3 (moderate)	Q4 (high)	Q5 (highest)	Chi- square p value
	n (%)	n (%)	n (%)	n (%)	n (%)	
Reported illness in past two weeks	n=783	n=716	n=771	n=604	n=638	
ARI	109 (14.4)	116 (16.6)	93 (12.4)	86 (14.6)	83 (13.2)	0.198
Diarrhea	124 (15.9)	124 (17.5)	133 (17.4)	115 (19.2)	124 (19.6)	0.398
Fever	172 (22.3)	172 (24.4)	153 (20.1)	131 (22.0)	138 (21.8)	0.395
Comorbidities (≥2 illnesses)	107 (14.2)	121 (17.7)	104 (14.0)	96 (16.4)	83 (13.3)	0.130
Sought facility-based care for illness (N=122)						
ARI (n=45)	3 (2.8)	10 (8.6)	13 (14.0)	4 (4.7)	15 (18.1)	0.001
Fever (n=74)	9 (5.2)	13 (7.6)	18 (11.8)	11 (8.4)	23 (16.7)	0.009
Diarrhea (n=52)	4 (3.2)	7 (5.7)	12 (9.0)	11 (9.6)	18 (14.5)	0.018
Sought immediate care (within 24 hours)						
ARI (n=6)	-	2 (1.7)	1 (1.1)	1 (1.2)	2 (2.4)	0.634
Fever (n=11)	-	3 (1.7)	3 (2.0)	1 (0.8)	4 (2.9)	0.247
Diarrhea (n=11)	3 (2.4)	-	2 (1.5)	3 (2.6)	3 (2.4)	0.501
Source of care (any illness symptom)	n=164	n=164	n=140	n=117	n=123	0.261
Government clinic	2 (0.7)	2 (0.8)	3 (1.2)	-	7 (3.0)	0.032
Government hospital	7 (2.6)	4 (1.5)	8 (3.2)	6 (2.8)	13 (5.6)	0.112
Private clinic/hospital	4 (1.5)	14 (5.3)	17 (6.8)	14 (6.6)	23 (10.0)	0.002
Health post/CHW house	138 (50.9)	131 (49.3)	105 (41.8)	84 (39.8)	75 (32.5)	0.000
Pharmacy	8 (3.0)	15 (5.6)	10 (4.0)	10 (4.7)	4 (1.7)	0.185
Other (Municipality, relative, shop)	1 (0.4)	3 (1.1)	2 (0.8)	3 (1.4)	2 (0.9)	0.791

Note: N does not sum to the total as some children with co-morbidities sought care from different sources, and some caretakers were not aware of the type of facility/hospital

Factors Associated with Pediatric Care-seeking

We performed bivariate and multivariate logistic regressions to determine factors associated with facility care-seeking and both facility and CHW or health post care-seeking (Table 5). Significant predictors of facility-based care-seeking included child age, comorbidities, wealth quintile, and location. Marital status, maternal education, maternal age, and child gender were not significantly associated with care-seeking when controlled for other factors. Older children (2 years and above), were less likely to receive facility care than younger children (<2 years of age) (OR 0.41, 95% CI 0.24-0.70, $p<0.01$). Caretakers of children with comorbidities were more likely to seek care (OR 1.87, 95% CI 1.24-2.82, $p<0.01$) compared to children reporting only one illness symptom. Children from the highest wealth quintile had almost three times higher odds of receiving care at a hospital or clinic when compared to children from households in the poorest wealth quintile (OR 2.78, 95% CI 1.32-5.83, $p<0.01$). When compared to children living in Apas, children in Comapa had significantly lower odds of facility-based care (OR 0.27, 95% CI 0.12-0.60, $p<0.01$). Though the odds of care-seeking were slightly lower in Nuevo Amanecer (0.99), and Tinamit Junam, (0.91), the difference was not significant.

Table 5: Association between Household, Respondent and Child Characteristics and Health Facility and CHW Illness Care-seeking

Characteristics	Care-seeking at a clinic/hospital OR (95% CI)	Care-seeking at a clinic/hospital/ CHW house /health post OR (95% CI)
Head of household (<i>Ref, female</i>)		
Male-headed	1.04 (0.56 – 1.96)	1.67 (1.09 – 2.55)*
Maternal age (<i>Ref, <24 years</i>)		
≥24 years	0.71 (0.46 – 1.08)	0.94 (0.71 – 1.23)
Marital status (<i>Ref, single/divorced/widowed</i>)		
Married	1.51 (0.94 – 2.41)	1.06 (0.80 – 1.40)
Maternal education (<i>Ref, no education</i>)		
Primary/secondary	0.94 (0.59 – 1.50)	1.09 (0.82 – 1.45)
More than secondary	0.89 (0.24 – 3.35)	1.31 (0.53 – 3.20)
Child Gender (<i>Ref, female</i>)		
Male	1.18 (0.79 – 1.77)	0.92 (0.71 – 1.18)
Child Age (<i>Ref, <24 months</i>)		
≥24 months	0.41 (0.24 – 0.70)**	0.84 (0.64 – 1.11)
Comorbidities (<i>Ref, one symptom</i>)		
Two or more illness symptoms	1.87 (1.24 – 2.82)**	3.00 (2.31 – 3.89)***
Wealth Quintile (<i>Ref, poorest</i>)		
Poor	1.25 (0.58 – 2.72)	1.34 (0.91 – 1.99)
Moderate	1.64 (0.77 – 3.46)	0.95 (0.64 – 1.42)
Richer	1.30 (0.58 – 2.91)	0.92 (0.60 – 1.40)
Richest	2.78 (1.32 – 5.83)**	1.23 (0.80 – 1.90)
Location (<i>Ref, Apas</i>)		

Comapa	0.27 (0.12 – 0.60)**	1.16 (0.75 – 1.79)
Nuevo Amanecer	0.99 (0.54 – 1.81)	0.42 (0.27 – 0.64)***
Tinamit Junam	0.91 (0.46 – 1.82)	0.38 (0.24 – 0.61)***
Constant	0.07 (0.03 – 0.18) ***	0.67 (0.40 – 1.12)
Pseudo R2	0.0984	0.0944
N	1,131	1,131

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

In the second model, where CHW and health posts were included in the appropriate care-seeking framework, gender of household head, comorbidities, and location were significant predictors. Caretakers living in male-headed households were more likely to seek care compared to those in female-headed households (OR 1.67, 95% CI 1.09-2.55, $p < 0.05$). Caretakers of children with comorbidities were three times more likely to seek CHW or facility care (OR 3.00, 95% CI 2.31-3.89, $p < 0.001$) than those with only one illness symptom, and caretakers of children living in Nuevo Amanecer and Tinamit Junam were less likely to seek care than children living in Apas (OR 0.42, 95% CI 0.27-0.64, $p < 0.001$; OR 0.38, 95% CI 0.24-0.61, $p < 0.001$, respectively).

Reported Barriers to Child Illness Care-seeking from Formative Assessments

To determine the barriers to care, as well as enablers to appropriate and timely care-seeking, we used focus group discussions and key informant interviews with various community stakeholders. Highlights of key findings related to care-seeking barriers are summarized in Table 6.

Table 6: Select Findings from Formative Surveys on Barriers to Facility Care-Seeking

Theme	Illustrative Quotes
Family and Community Level Barriers	
<i>Sub Theme: Preference and Rationale for Traditional Healers and Remedies</i> - Existing capacity and knowledge and availability of home remedies at community level - Convenient to access, effective, culturally accepted - Symptom specific care-seeking (i.e. diarrhea cases should use traditional remedies first) - Strong family and community influence to	Community committee member, Apas: “...home remedies are made, depending on the disease because there are always people in our communities who are dedicated to caring for children.” Community member, Apas: “...as women what we do is to look for herbs or garlic and see something to give them and see how they are doing; you have to give them the flower of the dead, you grind them with garlic; epazote.” Community member, Tinamit Junam: “most make homemade medicines, because as I say it is very difficult to go to the health center.” CHW, Tinamit Junam: “There are women who can cure children like when they have a fever, they bathe them in lemon water, or those who have diarrhea can rub them, give them medicine, if they see that they do not heal then

use traditional medicine	<i>they take them to the health post..."</i> Community official, Tinamit Junam: Parents <i>"lack the intuition"</i> to take their children to the health facility when they are sick. Community official, Comapa: Families are <i>"well settled"</i> into their customs Community official in Nuevo Amenercer: Some families are <i>"closed-minded"</i>, believing children should be treated at home with homemade remedies
Sub Theme: Husbands Restrict Facility Care - Decision making by husbands determine source of care, women require permission from husbands, resulting in delays - Incidents of men beating wives for taking children to health facilities - Men believe that women will not complete household duties if they go to the health center	Community committee member, Comapa: <i>"Sometimes the one who decides in the house is the husband because the money is handled more by the husband."</i> CHW, Nuevo Amenercer: <i>"Always the ladies have to consult the husband and depending on whether the husband says yes they do."</i> Community member, Apas: <i>"Sometimes one talks with a friend they see a problem with your children and they guide you on what you have to do. Next you talk with your mother or family member, but first you go to your husband. He then suggests what has to be done with the sick child, and then one can act."</i> Community member, Apas: <i>"... the first thing that a man can say is that you do not have time to lose... there are others who do not let the women take their children to vaccinate because they say the child cries a lot with that vaccine, and it gives them a fever like an animal."</i>
Sub Theme: Limited Geographic Access and Transport - Expensive transport, mothers can't walk to facilities - Closure of health extension services exacerbate the situation	Health facility staff, Tinamit Junam: <i>"There is an ambulance but the family has to pay and it is expensive, there are some who can give it and who cannot because there are families that do not really have the money..."</i> Community committee member, Comapa: <i>"The difficulty is transportation because if there are no medicines or something to give them and they will not go in the vehicle, then they risk going on foot. And always almost always they go on foot."</i>
Sub Theme: Lack of Knowledge on Danger Signs and Appropriate Treatment	CHW, Nuevo Amenercer: <i>"...I asked her- Is the baby well? [She said] Yes, the baby is fine - but he was not well because since birth he was vomiting, and they didn't tell</i>

▪ Caregiver disbelief in vaccinations ▪ Caretaker lack of awareness of danger signs for immediate care ▪ Mothers do not use food supplements for children, give it to animals	<i>me that. The nurse got there...[the mother] told [the nurse] the baby was perfectly fine, and after eight days he died."</i> Health facility staff, Tinamit Junam: <i>"... children under five are given Chispitas supplementation but it is complicated because we have seen them thrown away."</i>
Health Facility and Provider Related Barriers	
Sub Theme: Facility-related Barriers ▪ Absence of doctors, and distrust in nurses' ability to provide treatment, lack of medicines and 'materials' ▪ Preference for private doctors as the treatment and care is better ▪ Adverse outcomes after taking the child to the hospital ▪ Confusion on registration cards ▪ Only one patient per family is examined	Community member in Comapa <i>"...I had the case of my sister-in-law that the baby was not sucking, and the midwife did not explain ...three days later we took her to the hospital and she died because she got a disease throughout her little body."</i> Female community member in Nuevo Amanecer: <i>"I do not go to the health center because I prefer a midwife or a private doctor. They take tests and see if one is okay or not. They explain to one how one is."</i> CHW, Tinamit Junam: <i>"... doctors are missing, there are only nurses who know only about vaccines, but with a serious illness they do not know how to give medicine or something else, and they do not have all the material here, that's why I prefer to take them with a private doctor."</i> Staff, Comapa: <i>"Last year my two nephews got sick and they only treated one of them , the one who was worse . Supposedly they don't see two members of the same family. My other nephew went the next day."</i> Female community member, Comapa: <i>"...they force one to take the card, but wherever is not in the child's card, they do not attend."</i>
Sub Theme: Lack of Medication and Supplies at Health Facilities ▪ Frequent stock-outs of necessary medicines, especially vaccines, leading to multiple visits, discourage caregivers	CHW, Nuevo Amanecer: <i>"Maybe in these last months the medicine has become scarce because sometimes we send children to be vaccinated and there are no vaccines or the mothers do not have money and they go to the health center to get the medicine and sometimes they only give a prescription"</i> Community committee member in Tinamit Junam: <i>"...they told us there were no vaccines; they didn't have the one</i>

to return Costs of care, affordability	<i>the child needed. Then they told us to return on a specific date, so we went back, and the same...My daughter is a year and a half, and the vaccine that she was supposed to receive when she was one year old, she hasn't received because there are none."</i> Health facility staff, Nuevo Amencer: <i>"in recent years we have not lacked medications, but in other years we did, and people got mad and say –why come if there are no medications?"</i> Community member, Apas: <i>"Right now, there are quite a few children, for example those who have completed their four years have not been given their four-year-old vaccine, because there are no supplies"</i> Community member, Tinamit Junam: <i>"a syrup is given and the rest give the prescription to buy. If you do not have money, you cannot buy it"</i> Female community member, Comapa: <i>"When there is no medicine they give the prescription to buy, even if we are poor we have to get the money and buy it."</i> Community Committee Member: <i>Parents who must take their children to the hospital for an emergency have several unexpected expenses, such as transportation, medicines, diapers, food, and baby's bottles.</i>
Sub Theme: Long Waiting Times Resulting in Preference for Private Doctors Early visits, waiting in queue for long hours, therefore preference for private doctors even if it's more expensive care. Borrowing money to afford private doctor, if child requires emergency care, as health facility has long waiting times	Male community member in Nuevo Amanecer: <i>"We go to the health center, we have to get up early to grab a number and wait in line until nine or ten, and one goes with a sick child and what we need is to be attended quickly and that is what is not done in the health center so that's why my wife says that it is better that we look for a private doctor."</i> Male community member in Tinamit Junam: <i>"It depends on how your economic condition is going. Because one who feels he can pay for a private doctor will not go to the health center because he knows that he will receive better care...it is fast and you go back to home. At the health center, you get your number and have to wait your turn and it gets more complicated."</i> Female community member in Tinamit Junam: <i>"The nurse</i>

	<i>arrives at 8:00 a.m. in the morning and at 3:00 p.m. in the afternoon she has not finished seeing patients. In other words, to go to the health center the person has to give up for a full day to be able to go to a consultation”.</i> Female community member in Tinamit Junam: <i>“There are women who start queuing at 5:30 in the morning and the health center does not start attending until 8:30, and they are hungry and cold.”</i> Female community member in Tinamit Junam: <i>“that's why many women do not go, they say better I do not go because a lot of time is going to be wasted. It requires patience and others say better I do not go and return.”</i> Community member in Nuevo Amancer: <i>“...because if you do not have the resource to go to the health center and by nine o'clock and ten o'clock they do not take care of you, they send you to the hospital or tell you to come tomorrow and what if the child is serious? One has to go and find a solution, the person has to go to the private doctor or borrow money to go.”</i>
Sub Theme: Fear of Mistreatment by Health Personnel ■ Poor patient experience related to provider behavior; scolded for not accessing care on time, seeking care for ‘healthy’ children	CHW, Comapa: <i>“...several women tell me –I won’t take my child to the Center anymore...they scolded me.”</i> Female community member, Comapa: <i>“... if a child is healthy they do not give you anything, sometimes they scold us if we take healthy children, only the sick are taken care of...”</i> Community members: Families receive negative comments like <i>“if the child is sick, why didn’t you come earlier.”</i>

Cultural and Family Barriers

Factors related to social norms, existing community capacity, and knowledge for curing common illnesses were frequently reported as reasons for not seeking facility care. Traditional medicine was mentioned frequently as an effective and preferred method to treat many pediatric conditions, especially diarrhea. The use of traditional treatments was often recommended as the first line of care by family and community members, as it was culturally effective and convenient to access compared to a hospital or health facility. Lack of spousal consent by husbands was reported by some women as the reason for delayed care-seeking as the husband was the major decision maker in the family. The opportunity cost of taking children to the health facility was also mentioned, as this meant neglecting other duties. The care-seeking pathway described by a caretaker in the Apas community illustrates the value given to a husband’s decision; *“sometimes*

one talks with a friend, they see a problem with your children and they guide you on what you have to do. Next you talk with your mother or family member, but first you go with your husband. He then suggests what has to be done with the sick child, and then one can act."

Lack of knowledge and awareness of danger signs and the perceived ineffectiveness of modern medicine were also cited as reasons for caretakers not to take their children to health facilities. Women mentioned vaccination side effects as a reason for not accessing care at the health center. Limited geographical access, due to distance of health facilities, or lack of adequate transport were mentioned frequently as other barriers to care. The most important finding from the discussions was that caretakers failed to recognize danger signs in children requiring immediate facility care, thus delaying timely diagnosis and treatment for treatable conditions.

Care-seeking Barriers Related to Experiences with the Health Facility and Health Providers

Numerous factors related to the experience in health facilities and perception of providers were quoted by the community members. Geographical access, inconvenient hours, long waiting times, lack of trained providers, ineffective or unavailable medicines, adverse health outcomes, and repeat visits due to lack of services or medicines, were frequently mentioned by the focus group participants. One community member in Tinamit Junam stated, "...they told us there were no vaccines; they didn't have the one the child needed. Then they told us to return on a specific date, so we went back, and the same...My daughter is a year and a half, and the vaccine that she was supposed to receive when she was one year old, she hasn't received because there are none."

Lack of trust of health providers based on past experiences emerged as a strong rationale for avoiding care from public hospitals and clinics, and preferring care from private clinicians even if it were more expensive was reported. There were multiple reports of women being scolded for waiting too long to bring their child, or being chastised for bringing a healthy child to a clinic, or bringing two sick children at the same time.

Discussion

The literature is replete with studies on the determinants of pediatric care-seeking, with several reporting findings from Guatemala.^{18,19,26-29} The current research was conducted as a baseline measure to identify barriers to care in rural communities and to design community oriented intervention packages to effectively address the barriers at both the health system and community level. Although several studies have previously reported in care-seeking practices for pediatric illness, few included qualitative components.²⁷⁻³¹

Our findings on reported incidence of ARI (14.2%), diarrhea (17.8%) and fever (22.1%), are similar to those reported earlier and in the recent DHS (ARI 11.8%, diarrhea 19.3%, fever 25.6%).^{11,27} Care-seeking from formal facilities, both private and public was lower than 17% for all three conditions of ARI, diarrhea and fever, with 70% reporting care from CHW and health posts. These figures are much lower than those reported for rural DHS statistics (formal care-seeking; ARI 51.6%, diarrhea 42.9%, fever 48%).¹² However, it is important to note that often the areas where ADP are located are remote with extremely poor populations. In a recent study in Guatemala, care-seeking from government facilities and private doctors for children with severe pediatric pneumonia was much higher at 49.7% and 30.6% for severe pediatric diarrhea in

Comitancillo and San Lorenzo.²⁸ An earlier study reported lower levels of care-seeking for constant cough (19.8%), diarrhea (21.8%), and almost 25% for children with symptoms of fever.¹⁸ Homebased or self-care was reported at 5% for severe pediatric pneumonia cases, 7% for severe diarrhea cases, and 19% of influenza-like illnesses.²⁸ Almost one-third of children with influenza-like illnesses and one-third of severe pediatric diarrhea cases were treated by pharmacists or drug vendors.^{27,28} Local stores were more frequently sought as the first point of advice for severe pediatric pneumonia (24%) than the formal health sector (20%).²⁷ These findings provide strong evidence for strengthening the capacity and competency of CHW, as well as ensuring appropriate support systems and supervision. The prevalent practice of seeking shopkeepers and pharmacies for treatment of illnesses highlights the need for complementary strategies to equip these providers with the standard treatment protocols for common illnesses that contribute to the major disease burden.

Prompt care-seeking and treatment is critical to ensure that the child receives essential care by trained providers. Less than 5% of caretakers reported immediate care-seeking from public or private facilities, for all three conditions, again highlighting the need for health promotion strategies at the household and community level, for caretakers of children to recognize danger signs, and improve access to trained providers. In this study, ORT was reported by 78% of caretakers for children experiencing diarrhea. However, appropriate treatment for ARI with antibiotics was only reported by 48% of caretakers, and antimalarials by less than 5% of caretakers of children with fever.

Wealth quintiles constructed based on common household assets, access to safe water and sanitation, and roof type, indicated that the caretakers from the wealthiest quintiles had significantly higher levels of facility care-seeking and those from the poorest quintile sought care mostly from CHW and health posts. Though the Integrated Community Case Management strategy has been embraced by most ministries of health, the CHW infrastructure has major limitations in these rural communities, due to the difficult terrain, security incidents, and lack of effective support from the healthcare system, which includes access to essential supplies, commodities, and supervision. Hence, efforts must be made to equip these CHW with adequate training and supplies, in order to ensure equitable access to quality healthcare services.

Based on other studies on child illness care-seeking we included several household and individual characteristics in the bivariate and multivariate logistic regression models. In the first model which included public and private clinics and hospitals for formal care-seeking, odds of care-seeking were significantly higher for children younger than two years, experiencing comorbidities, wealthier quintiles, and those living in Apas. In the second model, where CHW and health posts were included, odds of care-seeking were significantly higher for male headed households, children with comorbidities, and the community of Apas. Mother's employment status, beliefs about disease etiology, education, child age, perceived severity of illness, and type of illness, have all been shown to be predictors of formal pediatric care-seeking in Guatemala^{18,26–28,30}

Similar to our study findings from the qualitative assessments, decisions about care-seeking were made only after consultation with the father or the grandmother in previous studies.^{26,29}

Grandmothers were more likely to recommend traditional or herbal remedies for treatment of illness.²⁹ Qualitative studies have shown that herbal remedies are considered effective treatment and are preferred as they can be easily obtained from local stores.²⁷

The mixed methods design provided additional insight on the reasons for delaying care-seeking. Most caretakers reported treatment with home remedies or traditional medicines before seeking external sources of care. Many female caretakers had to obtain permission from their spouses before determining the type of care. More importantly, facility and provider characteristics as well as previous experience and perceptions, played a key role in caretakers' decisions to seek home remedies or care from CHW and health posts. Long waiting times, inconvenient service hours, lack of trained health personnel, rude behavior (particularly in government clinics), lack of essential medicines, costs of care, lack of transport, and long distances were all mentioned during the focus groups sessions as critical barriers to facility care-seeking. A study of availability and affordability of 27 World Health Organization essential child medicines in Guatemala, reported that only 35-47% of facilities had an adequate supply of medicines and the cost was often a day's worth of wages or more.³¹ Private pharmacies (often the only option when health facilities experience stock outs) reported much higher costs for medicines.³¹ These reported barriers related to cultural norms and health facility conditions have been described in other studies in Africa.^{32,33}

In a majority of the qualitative assessments, costs of transport, repeat visits, and inadequate treatment and medicines emerged as key barriers for facility care. The evidence from the care-seeking patterns by wealth quintile further corroborates this finding. Community members from Comapa were less likely to seek care than those from Apas, and mistreatment of health personnel was also reported frequently in Comapa. This may have influenced community member's decision and preference for CHW and health posts. The recent evidence on mistreatment by health care personnel of women in labor and post-natal care has been highlighted as a key barrier for patient centered care.^{34,35,36}

An important finding to highlight is that despite low formal care seeking levels, 78% of the children were treated with ORT for diarrhea, and 48% with antibiotics for ARI. In contexts with poorly functioning health systems, alternative treatment delivery strategies that provide better access to communities can be strengthened for appropriate treatment for common childhood illnesses. This finding is consistent with a meta-analysis of 11 studies that found on average that 25% of antibiotics for child conditions were obtained without a prescription.³⁷ However, the availability of antibiotics without a prescription is concerning as improper use of antibiotics can lead to antibiotic resistance.

Our results highlight the importance of CHW in rural areas like Guatemala, where barriers to facility-based care are numerous. In Guatemala, the majority of families with a sick child turn to a CHW for care. This further strengthens the case for community oriented service delivery, like those supported by World Vision programs. A previous ethnographic survey of CHW in Guatemala highlighted the commitment and dedication of the CHW to their communities but also expressed the need for a more formal supervision and capacity-building.³⁸ However, supporting CHW is not sufficient to address the healthcare needs of these rural populations, as

appropriate referrals are required for children who are at risk. The barriers to seeking care at a facility must be addressed in order to ensure universal access to health care in Guatemala.

The study has several limitations, including; the cross-sectional design, lack of quantitative information on the barriers to care-seeking, reliance on caretaker's report of illness, and inadequate documentation of healthcare environment factors that may have further affected care-seeking, including worsening security.

Poverty negatively impacts care-seeking behaviors, therefore continued efforts to target public health interventions toward economically vulnerable groups are necessary. Social accountability mechanisms and interventions supported by World Vision programs can help empower communities to hold their governments accountable to improving the quality and access of care at public facilities. A follow up study on the integrated package of community oriented interventions showed improvements in care-seeking and prompt care-seeking, though the proportions were still sub-optimal due to community and health system barriers.³⁹

Conclusions

The study provides some important findings on the care-seeking practices and barriers to formal care for common illnesses that contribute to major disease burden in Guatemala. The multi-factorial dynamics of care-seeking related to social, household, and health system aspects, necessitate multi-faceted and integrated strategies including household and community health promotion and treatment through community providers, social accountability strategies enhancing community engagement, and strengthening primary care systems to ensure capacity and competency of frontline health providers. A concerted effort of strategic stakeholders investing at community and health system levels will facilitate the achievement of universal coverage through people centered healthcare for improving the health of rural populations.

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Conflict of Interest

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