



THE LIVED EXPERIENCE OF RURAL & INDIGENOUS GUATEMALAN FATHERS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES

SEBASTIAN ROMERO BSN, RN

SPECIAL THANKS

- Community Leaders
 - Silvia
 - Josefina
 - Alejandra
- Organizations
 - Fundabiem, Panajachel

SPECIAL THANKS – DISSERTATION COMMITTEE

Chair: Sara Simonsen, PhD, CNM, MSPH, BCN, FACNM

Lauri Linder, PhD, APRN, CPON, FAAN, FAPHON

Brenda Luther, PhD, RN

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Ana Sanchez-Birkhead, PhD, APRN, WHNP-BC

BACKGROUND – GUATEMALA

Poverty

79%

Guatemala's Indigenous population living in poverty (Central Intelligence Agency, 2020; Verza, 2018)

40%

Guatemala's Indigenous population living in **extreme** poverty (Central Intelligence Agency, 2020; Verza, 2018)

Social Programs

16%

Population over 65 years of age who have Social Security coverage (Rofman & Oliveri, 2012)

1 in 10

Over 65 years of age living in rural communities have coverage (Rofman & Oliveri, 2012)

Medical Deserts

1.3

Physicians per 1,000 in Guatemala in 2020 (The World Bank, n.d.)

2.2%

Yearly gross domestic production (GDP) on health initiatives (Ola, 2021)

Work Migration

264k

Total apprehension of Guatemalan immigrants at the U.S. border in 2019 (Bermeo et al., 2022)

15.3B

Amount of USD send back to Guatemala in the form of remittance in 2021 (Nugent, 2022)

BACKGROUND – FATHER LITERATURE

Families with a father present are associated with:

- Higher language levels and symbolic play development in children with autism and lower maternal stress (Flippin & Crais, 2011)
- Improved self-control and impulsivity in children with attention-deficit/hyperactivity disorder (ADHD) (Storli, 2021)
- A higher quality of life for the child as well as improved maintenance of treatment adherence (Taylor et al. 2020)
- Lower birth complication rates during their birth and lower malnutrition rates during their childhood (Jeong, 2016).
- Higher treatment adherence rates by children with chronic illness (Berg et al., 2011; Taylor et al. 2020)

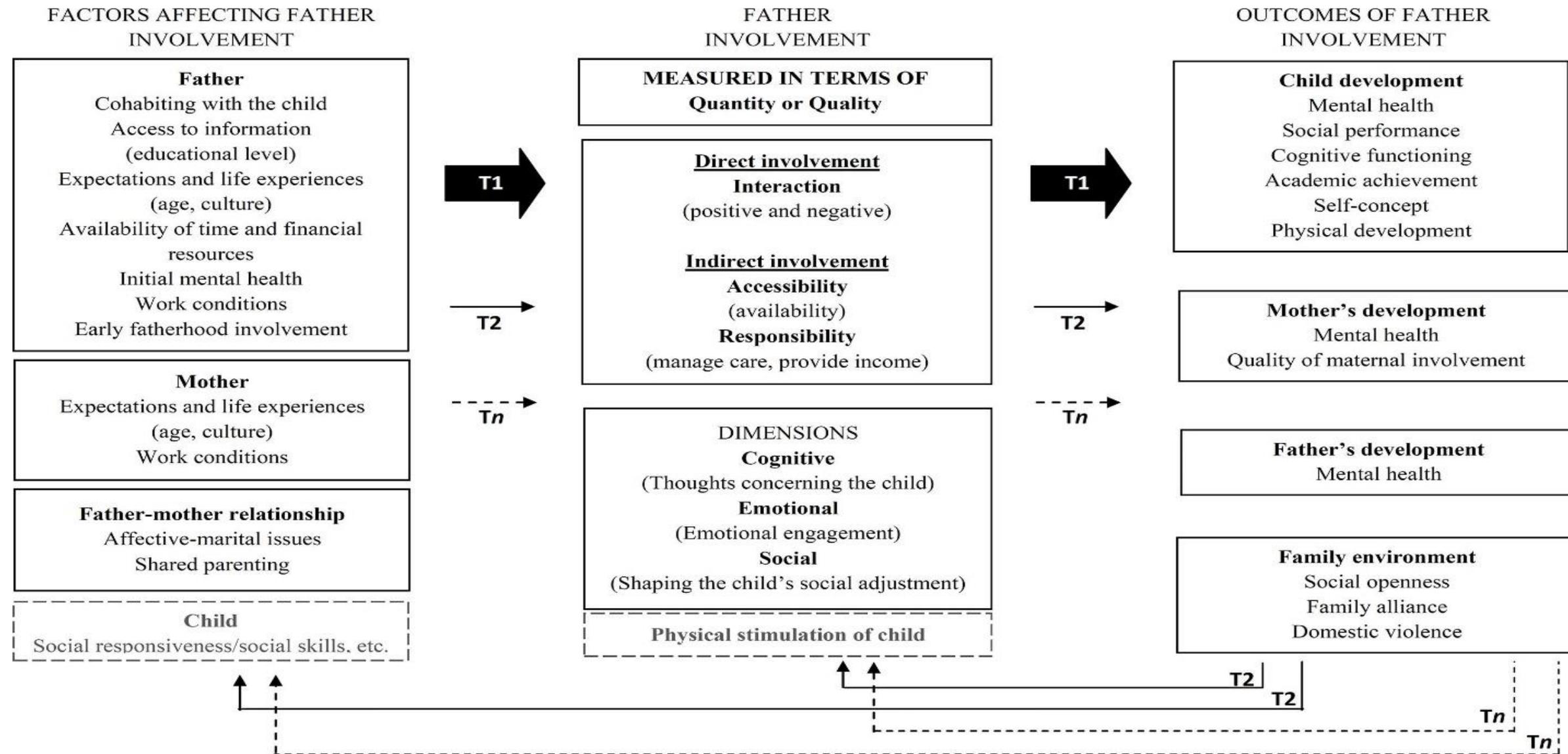
Research gap:

- A 2005 systematic review of pediatric psychology research found that 48% included only mothers, compared to 1% that included only fathers (Phares et al.).
- A 2015 study by Whitley et al. found that when referring to men's mental health, news articles were "significantly more likely to have stigmatizing content and violence as themes," while articles that focused on women's mental health were significantly more likely to quote mental health experts, discuss mental health interventions, and have recovery and inadequate resources as themes.

AIMS

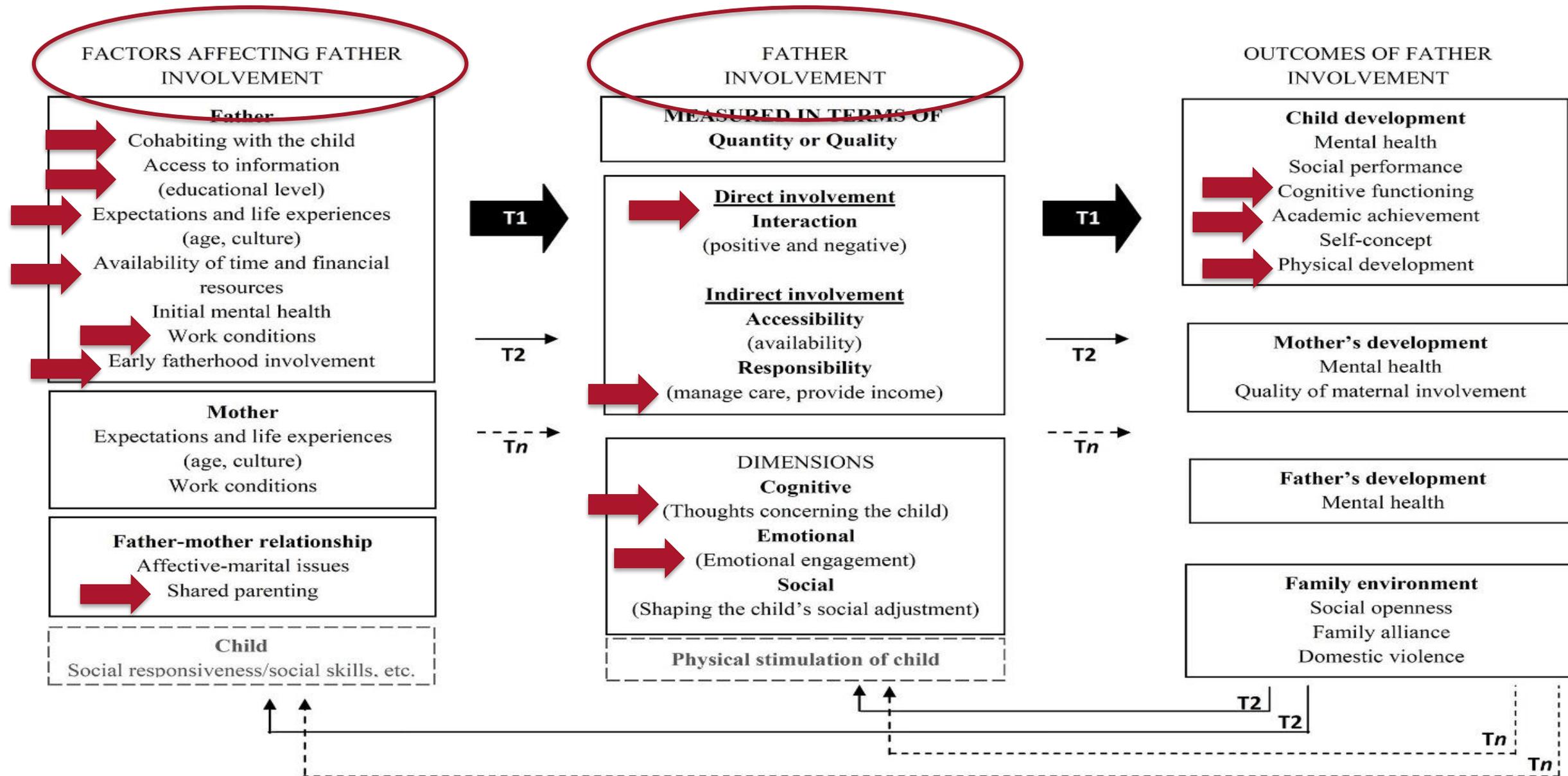
- **Aim 1:** To explore the lived experience of rural and indigenous Guatemalan fathers of children with neurodevelopmental disabilities.
- **Aim 2:** To describe the role internal factors and external factors play in shaping the lived experiences of rural and indigenous Guatemalan fathers with a child with a neurodevelopmental disability.
- **Aim 3:** To understand the role healthcare professionals and social service workers play in assisting rural and indigenous Guatemalan fathers to be effective caregivers.

BACKGROUND – THE FATHER INVOLVEMENT MODEL



Santis, L. & Barham, E. (2017). Father Involvement: Construction of a Theoretical Model Based on a Literature Review. *Trends in Psychology*, 25(3), 941-953. <https://doi.org/10.9788/tp2017.3-03pt>

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METHODS – OVERVIEW

- **Methodology:** Interpretive phenomenology (Bernard et al., 2017)
- **Data gathering method:** Semi-structured interviews (Bernard & Ryan, 2010)
- **Inclusion criteria:**
 - a) Participant must identify as Latino or indigenous or as a person of native decent (non-European descent)
 - b) Participant must be the adoptive or biological male parent of a child with a neurodevelopmental disability
 - c) Participant must speak Spanish
 - d) Participant must reside in the same home as the child
 - e) Participant's child must live in the home full-time and have a neurodevelopmental disability

METHODS – RECRUITMENT

Snowball sampling

- An effective form of recruiting due to the size of the communities
- All participants were asked if they knew anyone who may be eligible and interested in participating in the study
- Many referrals were received, but our community leaders knew most of them

Community leaders

- Someone involved in the community and highly esteemed and recognized by many
- The majority of participants were recruited through this method



METHODS – IRB PROCESS & INFORMED CONSENTING PROCESS

- **IRB Approval**
 - Obtained from the University of Utah IRB
 - Applied for approval to interview 60 mothers or fathers
 - Exempt status was received
 - Letter of Support received from community member (Silvia Mateo)
- **Consenting process:**
 - Waiver of Documentation of Informed Consent granted by IRB
 - Consent Cover Letter given to participants
 - Community members present during consenting process
- **Incentive payments:**
 - 100 Quetzals (~13 U.S. Dollars)
 - Payment received even if the interview was not completed
 - Incentive payment recommended by community leaders
- **Photography consent:**
 - *UNIVERSITY OF UTAH RECORDING AND PHOTO RELEASE AND CONSENT FORM A*
 - Obtained at the end of the interview after payment was given

INFORMED CONSENT DOCUMENTS

Sebastian Romero Page 1 of 1
Explorando la experiencia de padres Latinos de niños con discapacidades
del neurodesarrollo: Un estudio de fenomenología
9.20.2022

Carta de Consentimiento

**EXPLORANDO LA EXPERIENCIA DE PADRES LATINOS DE NIÑOS CON
DISCAPACIDADES DEL NEURODESARROLLO: UN ESTUDIO DE FENOMENOLOGÍA**

El propósito de este estudio de investigación es comprender mejor cómo los hombres latinos experimentan ser padres de un niño con una discapacidad del desarrollo neurológico. Estamos haciendo este estudio porque queremos servirle mejor a usted y a su hijo/a, pero para hacerlo primero debemos entender lo que está experimentando.

Para participar en el estudio completarán una encuesta demográfica. Luego responderá algunas preguntas sobre su experiencia como padre de un niño con discapacidad. Estas preguntas pueden hacerle sentir incómodo, pero puede optar por no responder una pregunta o finalizar la entrevista en cualquier momento.

Si tiene alguna pregunta o si siente que ha sido perjudicado por esta investigación, comuníquese con la Dra. Sara Simonsen de la Universidad de Utah, Colegio de Enfermería por teléfono al (801) -581-8576 o por correo electrónico a sara.simonsen@nurs.utah.edu o Sebastian Romero al (214) -734-2465 o por correo electrónico a sebastian.romero@utah.edu.

Comuníquese con la Junta de Revisión Institucional (IRB) si tiene preguntas sobre sus derechos como participante en una investigación. Además, comuníquese con el IRB si tiene preguntas, quejas o inquietudes que no desea discutir con el investigador. Puede comunicarse con el IRB de la Universidad de Utah por teléfono al (801) -581-8576 o por correo electrónico a irb@hsc.utah.edu.

Debería tomar entre una o dos horas para estar en este estudio. Estar en este estudio es voluntario. Puedes optar por no participar. Puede optar por no finalizar el cuestionario u omitir cualquier pregunta que prefiera no contestar sin penalización o pérdida de beneficios. Toda la información que proporcione se mantendrá confidencial y segura al ser cargada en una carpeta en línea llamada UBOX que solo le permite al Dr. Simonsen y al Sr. Romero acceder a ella. Al devolver este cuestionario, usted está dando su consentimiento y autorización para participar y nos permite utilizar la información que nos ha proporcionado.

Gracias por estar dispuesto a participar en este estudio.

«Institution»
«IRB»
«Approved» «ApprovedDate»
«Expiration» «ExpirationDate»
«Number»

FOOTER FOR IRB USE ONLY
Version: K0218

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DE GRABACIÓN Y FOTOGRAFÍA**

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Entiendo y acepto las condiciones descritas en este documento y, por la presente, renuncio a cualquier derecho que pueda tener para inspeccionar y/o aprobar las fotos o la publicidad que pueda usarse en relación con ellos, o para aprobar el uso al que se pueden aplicar las fotos. Reconozco que soy plenamente consciente del contenido de este comunicado y consentimiento y no estoy bajo ninguna discapacidad, coacción o influencia indebida en el momento de la firma de este instrumento.

Nombre impreso de la participante

Firma de la Participante _____
Fecha

Pronombres preferidos

Firma de padre/guardián legal si es menor de 18 años _____
Fecha

 THE UNIVERSITY OF UTAH

INTERVIEW QUESTIONS – AIM 1

Aim 1 To explore the lived experience of rural and indigenous Guatemalan fathers of children with developmental disabilities.

Prompt 1 Tell me about your journey as a father of a child with a developmental disability.

- **Q1** What would you say are your responsibilities towards your child as a father?
- **Q2** What are your responsibilities towards the child's mother as a father?
- **Q4** How would you describe the relationship between you and your child?
- **Q5** What do you think caused your child to be disabled?
- **Q6** What is your biggest fear when you think about your child?
- **Q7** How did it feel to discover your son's/daughter's disability?

INTERVIEW QUESTIONS – AIM 2

Aim 2 To describe the role internal factors and external factors play in shaping the lived experiences of rural and indigenous Guatemalan fathers with a child with a developmental disability.

Prompt 2 Tell me about a time when you found caring for your child difficult.

- **Q1** What has been the most challenging thing about caring for a child with a developmental disability?
- **Q2** What are some parenting strengths you have noticed about yourself since you had a child with a developmental disability?
- **Q4** What are some parenting weaknesses you have noticed about yourself since you had a child with a developmental disability?
- **Q5** What barriers have you experienced when trying to participate in caring for your child?
- **Q6** If you could go back and talk to yourself when your child was first diagnosed, what would you tell yourself?

INTERVIEW QUESTIONS – AIM 3

Aim 3 To understand the role healthcare professionals and social service workers play in assisting rural and indigenous Guatemalan fathers to be effective caregivers.

Prompt 3 Tell me about your experience as a father working with healthcare professionals or social service workers.

- **Q1** From what you know now, what do you wish healthcare professionals and social service workers would have told you about caring for your child?
- **Q2** What do you wish healthcare professionals and social service workers would do now for you and your child?
- **Q4** What type of service do you think your child still needs/requires?
- **Q5** How serious do you think your child's illness is? How long do you think it will last?
- **Q6** What tasks are most difficult for your child to do?
- **Q7** What kind of outcomes from the services your child is receiving do you most want for your child?

OVERVIEW OF TRIP

- **Dates:** June 17th to July 3rd
- **Location:** Region around Lake Atitlan
- **Languages spoken:** K'iche, Kaqchiquel, Spanish
- **Study setting:** Rainy season, rural, low-density housing



STUDY LOCATION



WEATHER AND SETTING



PUBLIC TRANSPORTATION



DATA COLLECTION PROCEDURES

- Participants were recruited from Panajachel and surrounding villages - Chipop, Godinez, Las Canoas, Las Cruces, San Andres, Los Robles
- Interviews were audio-recorded
- Demographic survey questions were asked as part of the interview (typically at the end of the interview)
- Field notes were sometimes collected during the interview but typically shortly after on the participants' demographic survey sheets
- Interviews were conducted in the participants' homes in a private room or outside



OVERVIEW OF TOTAL PARTICIPANTS

- In total, 45 interviews were conducted
 - 18 fathers
 - 27 mothers

In total, 44 of the 45 interviews were completed in participants' homes.
This study only included responses from interviews with fathers.

FATHER INTERVIEW DURATION BREAKDOWN



Duration:

- Average length of interview: 50 minutes and 40 seconds
 - Longest interview: 91 minutes
 - Shortest interview: 32 minutes

More than 15 hours of audio recordings to code.

DATA MANAGEMENT PROCEDURES

- No identifying information was collected
 - Participant interviews were identified as Father (# of interview)
 - No addresses, names, or contact information was collected
- Recorded interviews were uploaded to Ubox
 - Audio recordings destroyed from phone
 - Audio recordings destroyed from hand-held audio recorder
- Signed *UNIVERSITY OF UTAH RECORDING AND PHOTO RELEASE AND CONSENT* forms are stored in a locked cabinet in my home office
- The transcription service used is academically compliant
 - 2048-bit SSL encryption
 - Employees sign Non-Disclosure Agreements (NDA)
 - HIPPA-compliant per academic requirements.
 - Data is destroyed 14 days after transcription completion
- Audio recordings will be destroyed at the close of the study

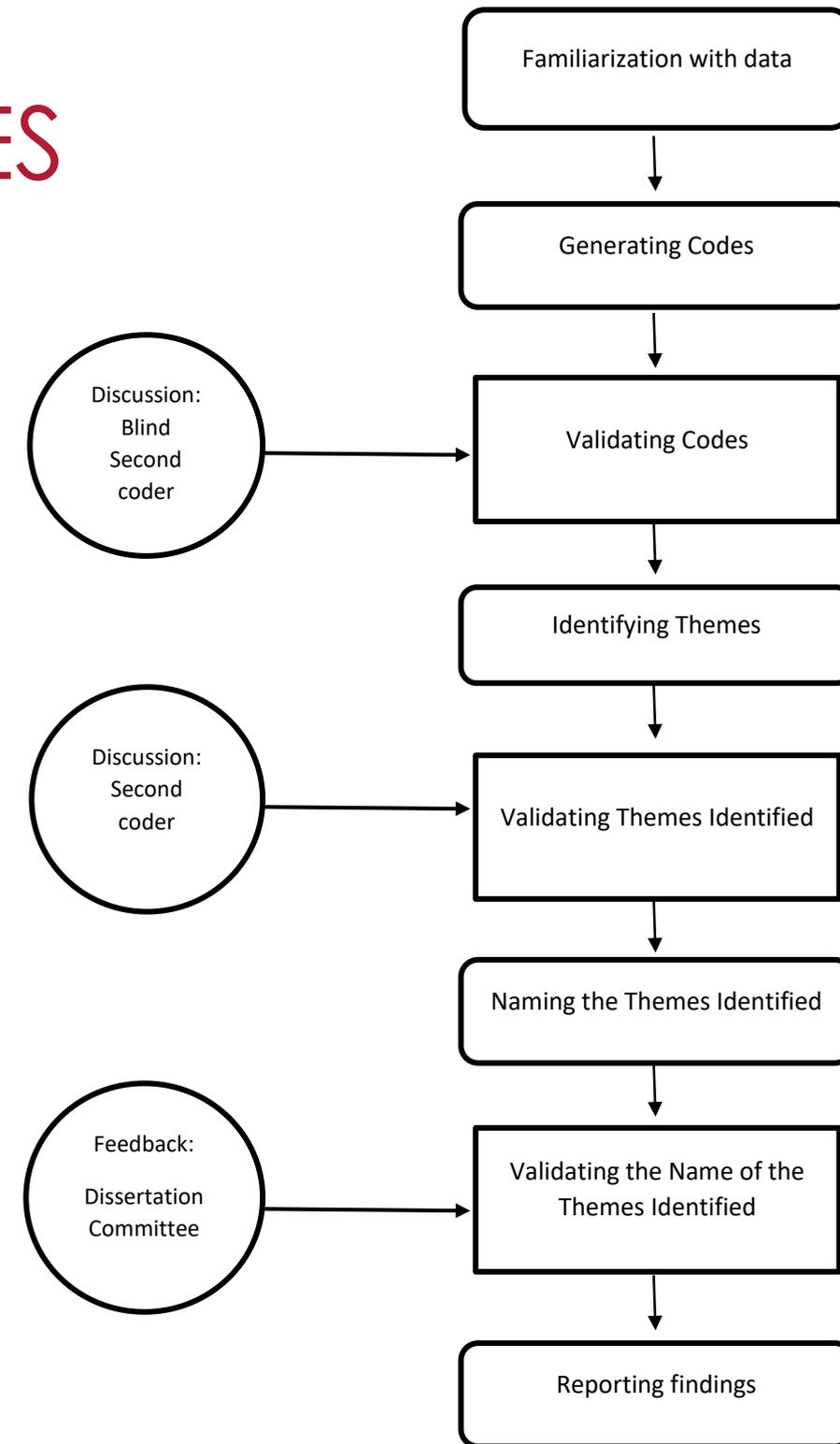
DATA ANALYSIS PROCEDURES

CODING AND THEMATIC ANALYSIS

- **Inductive coding**
 - Ground up approach
 - Exploratory aims
- **Inter-coder agreement**
 - Shared codebook
 - Blind coding
 - Four 2-hour meetings to discuss and validate codes with second coder
- **Thematic analysis**
 - Identifying themes across interviews and codes
 - Focusing on themes that pertain to study aims
 - One 2-hour meeting to discuss and validate themes with second coder

DATA ANALYSIS PROCEDURES

FLOWCHART OF THE THEMATIC ANALYSIS



DATA ANALYSIS PROCEDURES

SECOND CODER – SILVIA MATEO

- Full-time social worker & student
- Native K'iche and Spanish speaker
- Identifies as indigenous, native of Panajachel, Sololá
- Married, no children

Training

- IRB Online CIRTification (Spanish version)
- 4.5 hours of virtual training on how to code

DATA ANALYSIS PROCEDURES

TRUSTWORTHINESS OF THE STUDY FINDINGS

- **Prolonged engagement**
 - Trusted community leaders involved in the recruitment process
 - Prior service and research in the community by the interviewer (Fundabiem, Casa de Sion)
- **Reflexivity exercises**
 - Self-interview
 - Mind map
 - Journaling
- **Peer discourse**
 - Inter-coder reliability
 - Promoted reflexivity of data findings through discussion
 - Emic and Etic perspectives were employed during the data analysis
- **Validating measures used at three stages of analysis**
 - Data coding stage (discussions with the second coder)
 - Theme identifying stage (discussions with the second coder)
 - Theme naming stage (feedback from the dissertation committee)

Ahmed, Sirwan. (2024). The pillars of trustworthiness in qualitative research. *Journal of Medicine Surgery and Public Health*. 2. 100051. 10.1016/j.glmedi.2024.100051.

CODES

1. ¿Por qué yo?/ **Why me?**
2. ¿Que se puede hacer?/ **What can be done?**
3. Abandono/ **Abandonment**
4. Ayuda/ **Help**
5. Barreras al tratamiento/ **Barriers to treatment**
6. Buena experiencia/ **Positive experience**
7. Comportamiento difícil/ **Difficult behavior**
8. Concentración en el trabajo/ **Consentrating on work**
9. Crecimiento de Padre/ **Growth as a father**
10. Creencias/ **Beliefs**
11. Cuando yo muera/ **When I die**
12. Desahogo/ **Relief**
13. Deseo más grande/ **Greatest desire**
14. Deuda/ **Debt**
15. Dinámica de la familia/ **Family dynamic**
16. Discriminación y explotación/ **Discrimination and exploitation**
17. Distracción/ **Distraction**
18. Edad avanzada/ **Advanced age**
19. Indiferencia/ **Indifference**
20. Luchando/ **Perseverance**
21. Más grande, más pesado/ **Bigger, tougher**
22. Motivación/ **Motivation**
23. Mucho gasto/ **High expenses**
24. Muchos exámenes y medicamento/ **Tons of exams and medications**
25. No tiene nada/ **He doesn't have anything**
26. Oportunidades/ **Opportunities**
27. Pandemia/ **Pandemic**
28. Papel de mamá/ **Mother's role**
29. Paz y tormentas/ **Peace and tempest**
30. Pensamientos malos/ **Bad thoughts**
31. Poco a poco/ **Little by little**
32. Poder defenderse/ **Be able to defend themselves**
33. Políticas/ **Politics**
34. Preocupación/ **Concerns**
35. Recursos lejos/ **Distant resources**
36. Regalo de Dios/ **Gift from God**
37. Responsabilidad hacia madre/ **Responsibility towards mother**
38. Responsabilidad hacia niño/ **Responsibility towards kids**
39. Rumores/ **Rumors**
40. Sólo Dios sabe/ **Only God knows**
41. Susto/ **Fright**
42. Temor mayor/ **Greatest fear**
43. Terreno/ **Property**
44. Tiempo con niño/ **Time with child**
45. Todo para el niño/ **Everything for the child**
46. Trabajando juntos/ **Working together**
47. Trabajo lejos/ **Distant work**
48. Trabajo primero/ **Work comes first**

TECHNIQUES USED TO IDENTIFY CODES & THEMES

- **Repetition**

- Work Migration
- When I die
- Little by little
- When I die
- Money
- Travel

- **Metaphors and Analogies**

- *Regalo de Dios*/Gift from God
- *Luchar*/Fight/Persevere
- *Poder defenderse*/Be able to defend themselves

Indigenous typologies

- *Ni modo*/No way/No chance
- *¿Que se puede hacer?*/What can you do?
- *Solo Dios sabe*/Only God knows
- *Desahogo*/relief/ undrown

Keywords

- Barrier
- Treatment
- Sacrifice
- Hope
- Fear

Bernard, H.R., Wutich, A., & Ryan, G.W. (2017). *Analyzing qualitative data: Systematic approaches* (2nd ed.). Los Angeles: Sage.

DEMOGRAPHIC SURVEY RESULTS

FATHER PARTICIPANT BREAKDOWN – AGE & EMPLOYMENT (N=18)

Average age of father at interview: 52.9 y/o (Youngest: 24 y/o; Oldest: 78 y/o)

Average age of the father when child was born: 32.9 y/o (Youngest: ~17 y/o; Oldest: ~51 y/o)

- **9/18 (50%)** reported owning land of some sort (home or field for cultivating)
- **16/18 (89%)** reported being child's biological father, **2/18 (11%)** reported being child's adoptive father
- **11/18 (61%)** reported being legally married, **6/18 (33.3%)** cohabitating couple, **1/18 (5.6%)** widowed
- **15/18 (83.3%)** identified as indigenous, **14/18 (77.8%)** reported being able to speak Kaqchikel (One participant also spoke K'iche)
- **12/18 (66.7%)** are field workers, **3/18 (16.7%)** are salaried workers (1 security guard, 1 teacher, 1 boat driver), **1/18 (5.6%)** tuk-tuk driver, **1/18 (5.6%)** truck driver, **1/18 (5.6%)** disabled

DEMOGRAPHIC SURVEY RESULTS

FATHER PARTICIPANT BREAKDOWN – EDUCATION LEVEL (N=18)

Education

- **2/18 (11.1%)** did not receive any schooling
- **9/18 (50%)** did not complete elementary school
- **5/18 (28%)** completing elementary school
- **1/18 (5.6%)** completed middle school
- **1/18 (5.6%)** completed college



DEMOGRAPHIC SURVEY RESULTS

CHILD BREAKDOWN – AGE & DIAGNOSIS OF CHILD (N=19)

- **Average age of child with a neurodevelopmental disability: 20.1** years old (Youngest: 7 y/o; Oldest: 57 y/o)

Diagnosis

- **7/19 (36.8%)** Undiagnosed
- **2/19 (10.5%)** Cerebral Palsy
- **2/19 (10.5%)** Down Syndrome
- **2/19 (10.5%)** Spina Bifida
- **1/19 (5.3%)** Cerebral Palsy & Epilepsy
- **1/19 (5.3%)** Developmental Delay
- **1/18 (5.3%)** Developmental Delay & Poliomyelitis
- **1/18 (5.3%)** Developmental Delay & Epilepsy
- **1/18 (5.3%)** Tuberosus Sclerosis
- **1/18 (5.3%)** Can't remember

DEMOGRAPHIC SURVEY RESULTS

FATHER PARTICIPANT BREAKDOWN – SUMMARY

Father ID	Age	Indigenous	Language Other Than Spanish	Total Kids	Kids at Home	Age of Child	Diagnosis	Parent Education Level	Marriage Status	Employment	Owns Land
A	24	Yes	Kaqchikel	2	2	7	Unknown	2nd Grade	Cohabiting	Fieldworker	No
B	67	Yes	Kaqchikel	10	3	16	Down Syndrome	3rd Grade	Married	Fieldworker	No
C	43	No	No	3	2	17	Spina Bifida	2nd Grade	Married	Fieldworker/truck driver	No
D	62	Yes	Kaqchikel	6	6	13, 9	Unknown	2nd Grade	Cohabiting	Field worker	Yes
E	38	Yes	Kaqchikel	3	3	10	Can't Recall	3rd Grade	Married	Fieldworker/construction	No
F	65	Yes	Kaqchikel	9	1	34	Poliomyelitis	6th Grade	Widower	Field worker	Yes
G	73	Yes	Kaqchikel	8	6	35	Unknown	4th Grade	Married	Fieldworker	No
H	69	Yes	Kaqchikel	3	3	43	Spina Bifida	4th Grade	Married	Fieldworker	Yes
I	47	No	No	5	4	13	Down Syndrome	6th Grade	Cohabiting	Tuk-Tuk Driver	No
J	51	Yes	Kaqchikel	1	1	10	Cerebral Palsy & Epilepsy	6th Grade	Married	Fieldworker/Sand packer	No
K	56	Yes	Kaqchikel	7	1	20	Unknown	6th Grade	Cohabiting	Fieldworker/Taylor	Yes
L	57	Yes	kaqchikel	5	3	15	Epilepsy & Developmental Delay	6th Grade	Married	Fieldworker	No
M	44	No	No	3	3	15	Unknown	9th Grade	Married	Security guard	No
N	78	Yes	Kaqchikel	7	1	57	Developmental Delay	No formal education	Married	Fieldworker	Yes
O	57	Yes	Kaqchikel	9	5	14	Unknown	No formal education	Married	Disabled	Yes
P	34	Yes	Kaqchikel	3	3	14	Tuberous Sclerosis	2nd Grade	Married	Boat driver	Yes
Q	52	Yes	Kaqchikel & Kiche	2	2	13	Cerebral palsy	Bachelors	Cohabiting	Teacher	Yes
R	36	Yes	No	2	2	8	Cerebral palsy	5th Grade	Cohabiting	Truck driver	No

THEMES ANALYSIS RESULTS

EXTERNAL FACTORS OF LIVED EXPERIENCE – STUDY AIMS 1 & 2

Theme 1: Poverty (18/18)

- “Everything is money”
- Sacrifice
- Work migration

Theme 2: Culture of giving (13/18)

- Family support
- Community support

Theme 3: Lack of access (11/18)

- Challenging public transportation system
- Medical desert



THEME: POVERTY

SUBTHEME: EVERYTHING IS MONEY

Father: "I sometimes leave to distract myself from my thoughts so I don't feel trapped."

Interviewer: "What type of thoughts?"

Father: "Thoughts of, 'What am I going to do? What do I do?' There are times I am not working. I don't have a way to help them because everything is money. Everything is money. A medication, that's money. Everything is money... I am now worried about my wife, too, since she has kidney and heart problems. Long story short, I worry."

Father: "The truth is we've resigned and accepted he will stay like that because we can't do anything for him anymore. Let's say we do find someone to come and do physical therapy with him here. That brings with it a cost that we can't afford."

Interviewer: "Do you think that is your greatest barrier to getting him treatment?"

Father: "For me, that is what is stopping us...perhaps it can be done, but the obstacle is economical—a barrier that will be a huge wall because we can't do it."

Father: "Yes, it's her blood, and she would need to see a specialist. I spoke with the Sololá doctor, who said, "Yes, sir, I can see her." They told me the child is expensive, approximately 3,000 to 4,000 Quetzals (approximately 385 USD to 514 USD). I don't have any possibility of giving them that amount of money."

THEME: POVERTY

SUBTHEME: SACRIFICE

Interviewer: "How often could you visit your daughter?"

Father: "About every month, or every month and a half. We couldn't go often; sometimes, two months would pass."

Interviewer: "How long could you stay and visit?"

Father: "Half an hour. We would wait an hour, see her, and then leave. Yes, little time."

Interviewer: "How'd you do it? What were you thinking during that time?..."

Father: "It's tough because, like I said, I would go with my wife, or if not, I would go alone. I would leave in the morning, be at the waiting room at 2 pm or 3 pm, 30 minutes with her, and then "everyone out." From there, we'd be back next month. Sometimes, I'd put myself out there and ask around for money so I could take my wife to see her. She would see her mom and me. That's how we would spend the visits—we'd look at each other for some time. **How nice it would have been to have an hour or half a day.** No, it's just a little time. Let's say it's like a hospital visit—a brief amount of time. Since we also had to come back, the bus would leave us if we were late, and we didn't have money to pay for a hotel. We had to come back. We'd see her for a bit. We would talk with her and then have to start heading back...Back then, the last bus would leave at 4 pm. If you got left, you got left. What does one do? Where can one stay? Like I told you, we didn't take any extra money. We didn't have any."

Interviewer: "You said you did it so your daughter could learn to walk?"

Father: As I mentioned before, whenever opportunities presented themselves, we would take them... I told them, 'I want her to walk, even if it's a little, but she has to walk.' We would see the sacrifice she was making. **She would drag herself. All her clothes would tear, and her legs would bleed from scraping against the rocks. When that opportunity came, we said, 'Thank you, God.' That is why we were grateful to the Lord for the opportunity we received.** Before then, she was just there. It was impossible. We couldn't do anything, but we said, 'If there's ever a chance she could learn to defend herself, we'd do it.' The fact is, she achieved that."

Interviewer: "Did you ever think twice about sending her there?"

Father: "No, I didn't think twice."

THEME: POVERTY

SUBTHEME: WORK MIGRATION

Father: "If given the opportunity, I would go to work because I like to work. I can work in the field; I can do everything. Work over there, help my family get ahead here..."

Interviewer: "Why would you like to go over there?"

Father: "To look for a better life. So that they can have something here and she can have her medicine. My wife would no longer have to work. I can work over there, and she can have all the medication she needs to the letter of the law. If she got sick, a cold, a cough, we would pay for it."

THEME: POVERTY

SUBTHEME: WORK MIGRATION

Father: "I have seen some devices they will put on kids in other countries. That is what I want, there may be some here, but they are too expensive. My hope may be too high, but as long as he can walk one day, I will be satisfied... If I have to, I will go to the other side and suffer. If God allows it and he can one day walk, I know it will be worth our sacrifice. That is what I think."

THEME: CULTURE OF GIVING

SUBTHEME: COMMUNITY SUPPORT

Father: "Sometimes, I leave the house to look for my friends. Sometimes I tell them, 'Lend me some money.' Sometimes they say, 'I don't have any.' I become even more discouraged. Sometimes they say, 'I don't have any,' but sometimes some say, 'Here you go, have a little something, help yourself with this,' and they will give me something. With that, I come back happier. I tell my wife, 'They gave me this. What do we need? What do you want to eat?'"

THEME: CULTURE OF GIVING

SUBTHEME: FAMILY SUPPORT

Father: "The other [boys] did not continue studying for the same reasons, maybe some economic reasons. If they had kept studying, we would be even more financially stretched. We would then focus more on their schooling and neglect [my other son] a little. We spoke with them, and I told them, 'Well, if you will study, I will sacrifice myself to see how we manage.' But they said...' No, Dad, with the little you've given us, sixth grade, we are fine.' That's how they are now, the other two boys, and with the help of God, we'll see how we push forward."

THEME: LACK OF ACCESS

SUBTHEME: INACCESSIBLE COMMUNITY INFRASTRUCTURE

Father: "When he was little, we would still take him out, we would take him places, but how he is now, we can't do it. The other day, we took him out with his wheelchair. Thank God that they fixed the path. We can take him in his wheelchair. The only thing is that someone has to go in front [of the wheelchair] and someone behind to hold it; we can go down the hill that way....He is heavy now the way he eats. When it comes to his appetite, he's healthy. He'll eat anything. He's large, so he's heavy. That is why one can't."

THEME: LACK OF ACCESS

SUBTHEME: MEDICAL DESERTS

Father: "Yes, I am worried... my main fear is that he has a shunt [in his head], and when it gets occluded, we have to run out the door. As I said, treatment is only found in Guatemala [City], in Xela. From here to there, it's expensive. We can't take our time. When he gets sick, that's it. God be with him. We have to leave at whatever hour it is. We can't wait because that's death... That's my greatest fear because we have to run out the door. We can't wait. Unfortunately, we have those doctors in Guatemala [City] but not in Sololá. We cannot help him here. It is what it is."

THEMES ANALYSIS RESULTS

INTERNAL FACTORS OF LIVED EXPERIENCE – STUDY AIMS 1 & 2

Theme 4: Self-perception as provider (18/18)

- Work comes first
- Too old to provide
- When I am gone
- Property and shelter

Theme 5: View of struggle (17/18)

- Ni modo/There is no way
- Bad thoughts attract bad things
- Luchar/Persevere



THEME: SELF-PERCEPTION AS PROVIDER

SUBTHEME: WORK COMES FIRST

Father: "The one who has suffered more is my wife...I listen to her cry sometimes [over the phone], the desperation, because my daughter sometimes struggles to eat. My wife will sometimes call me and say, 'I can't do it anymore.' I can't do anything [to help her] because I have to work to give them, perhaps not the best things, but the necessary things. With [my daughter], all we have are expenses, which is up to me to cover. Every day I am not with them, I lose time with them because I need to work. If I don't work, I won't be able to give what I have been able to do so far. They have food. I talk with my wife about travel expenses for them, medical expenses, and those kinds of things so she can get better. The one who has suffered the most is my wife. Me too, but there is nothing I can do because, without money, there is nothing anyone can do right now. Every day I am away, I lose moments of them growing. That is the sacrifice I am making—not seeing them grow. As my wife says, there are important moments in their lives that I am missing due to my work. She will tell me, 'find another job,' but realistically, the jobs offered here don't cover our expenses with our daughter."

THEME: SELF-PERCEPTION AS PROVIDER

SUBTHEME: TOO OLD TO PROVIDE

Father: "I would not worry about money because I would go and work wherever I needed, but my daughter needs to get better. It's not possible that she will stay how she is now...My age won't last. I was more able to do things when I was younger, but now it's much more difficult...back then, I was young and could find a way to make money."

Interviewer: "Now you can't?"

Father: "[Back then] I could go and ask for work, and they would give it to me, but now they give me work, and I can't do it. I no longer have an income."

Interviewer: "Is it difficult to find work at an older age?"

Father: "It's difficult here because if you find work, it is very fatiguing. When you're young, you get tired, rest for a bit, and then you are good. Now I forget what I do. When you get old, you can do less and get fatigued."

THEME: SELF-PERCEPTION AS PROVIDER

SUBTHEME: TOO OLD TO PROVIDE

Father: "I am aware that one day the others will grow, but [my son]; I am not sure how he will be when he grows older or myself when I'm older. If this opportunity works out, when I am older, I will be able to provide for him. If not, he will suffer more when I grow old, too. Those are my thoughts right now. If the opportunity presented itself, I would take advantage of it so that I could [provide for him] when I was older. That is what [my wife and I] have thought."

THEME: SELF-PERCEPTION AS PROVIDER

SUBTHEME: WHEN I AM GONE

Father: "Those are the concerns. What I want most is that, with God's help, he will succeed and be able to care for himself. He will be someone who no longer needs us to care for him. Not to make it easier for us but because, as I said, we will not be around his whole life. How good would it be if we were? That is the more important barrier for me, and that he will be healthy. Those are my two concerns, that he will care for himself and be healthy."

THEME: SELF-PERCEPTION AS PROVIDER

SUBTHEME: PROPERTY AND SHELTER

Interviewer: "What do you most want for your child?"

Father: "I want to build them a house, each their small home. That way, if I am not here one day, I leave them with a place where they can at least live. Lately, we have lived here and there. They don't have stability. But like I tell [my wife], if God provides a way for us to buy a property, at least we could leave her with something so we can rest peacefully."

THEME: VIEW ON STRUGGLE

SUBTHEME: THERE IS NO WAY OUT

Father: "You know what, the reality is that there are days when I am alone at work. I don't have any company. I don't have anything, just work. There are times that thought comes into my mind, and I start thinking about him. What am I going to do? What other options do I have? Almost all of his exams have said that he will not walk. He will always be like that. Sometimes, I say, 'It's better that I don't think about it' because just thinking about things, the first thing that happens is you get a headache from thinking so much as if there is no way out. You think, think, and rethink, 'What am I going to do?' 'What must I do?' You definitely don't find a way out."

THEME: VIEW ON STRUGGLE

SUBTHEME: BAD THOUGHTS ATTRACT BAD THINGS

Father: "I may think those things, but then I tell myself, 'God willing, perhaps it won't come to that.' I try to relax and not think about those things so I don't get sick. When someone is just thinking, he can overstress, and something can happen to him. It is as simple as walking in the street and tripping on something. That's not what anyone wants to happen. Or someone can be leaving work and going to see their family. There have been cases where it's happened like that. Someone is overstressed, and they can get into an accident. Those things can happen, from overthinking how the family is doing to. So I say, 'I better stop thinking about it and do what I must do.' Once I am [back home], I think about the family again."

THEME: VIEW ON STRUGGLE

SUBTHEME: *LUCHAR/PERSEVERE*

Father: "I got her when she was already one year old; she was little. From there, I remember how I worked with her, with medications and therapies, and taking her to the doctor when she seized. I would take her and bring her back. Until now, we have kept working with her... I would put her [on the front basket] of the bicycle and take her all the way up there [for her therapies]. I would be pushing, just sweating. People would always ask, 'don't you get tired?' Of course, but what am I going to do? Either way, she is my daughter; I have to fight."

STRENGTHS & LIMITATIONS

Strengths

- Understudied population
- Sample size of a difficult-to-reach group
- Inter-coder reliability was strengthened by using a second coder from the community of interest with firsthand experience of culture and norms.

Limitations

- Difficulty generalizing the findings to other populations
- Brief recruitment time
 - County, state, and federal elections were held on June 25, 2023
 - Rainy season often leads to a busier work season since field workers are tending to crops

STUDY FINDINGS

COMPARED TO OTHER SIMILAR STUDIES

A Qualitative Study of Men's Experience of Being a Father in Families with Childhood Disability (Vatne et al., 2023)

- Study sample: Seven fathers from Norway who were recruited through convenient sampling
- Data collection method: Semi-structured interviews
- Themes on *Factors Perceived to Influence Father Behaviors* included: 1) multidetermined behavior, 2) personal factors, 3) family factors, 4) social factors

Fathers in the Care of Children with Disabilities: An Exploratory Qualitative Study (Uribe-Morales et al., 2021)

- Study sample: Seven fathers from Spain who were recruited through the local school system
- Data collection method: Semi-structured interviews
- Themes: 1) *Shared responsibilities*, 2) *Sometimes difficult to fit*, 3) *Either you separate or you join*.

"Es un regalo de Dios la verdad": "Hispanic" Fathers Lived Experiences of Child with an Autism Spectrum Disorder (Bobadilla, 2023)

- Study sample: Six Hispanic fathers from the United States who were recruited from families the researcher already knew
- Data collection method: Semi-structured interviews
- Themes: 1) **Spirituality and God**, 2) Non-verbal connection, 3) late involvement, and 4) **extended family's involvement**

The intersection between masculinity and health among rural immigrant Latino men (Daniel-Ulloa et al., 2017)

- Study sample: 20 Latino fathers from North Carolina who were recruited from the local clinic contact list of people who had come in for an HIV test.
- Data collection method: Semi-structured Interviews
- Themes: 1) **masculinity and the role of family provider**, 2) **sources of stress**, 3) family responsibility and health, 4) coping with stress

FUTURE DIRECTION

- **The lived experience of rural and indigenous mothers of children with neurodevelopmental disabilities**
 - 27 interviews ready to transcribe and code
- **Phenomenology research on the impact of work migration on fathers and families of fathers who have migrated and have a child with a disability**
 - Interview the mother in Guatemala and the father in the U.S.
 - I am aware of two potential participants
- **Phenomenology research on the lived experience of rural Guatemalan fathers who are not involved in the life of their child with a disability**
 - Interview the mother and father
 - I am aware of two potential participants
- **Interventional research on improving the delivery of care to rural Guatemalan communities**
 - Telehealth model of care
 - Home health model of care

POLICY IMPLICATIONS

- **Policies allocating funds to incorporate the home health model of care for delivering routine therapies to these families**
 - Travel is costly and inaccessible for many of these families
- **Immigration policies that protect immigrants from exploitative practices**
 - Immigrants (even those seeking asylum) often pay high fees to be smuggled across the U.S. border
 - Current policies do not do enough to mitigate the possibility of financial exploitation from human smugglers
- **Temporary work visas for blue-collar workers**
 - The U.S. faces a historic labor shortage of blue-collar workers
 - Current policies place preference on white-collar workers
- **Heavier expat restrictions to protect natives from displacement**
 - Foreign money entering the Guatemalan housing market is driving costs upward for natives

QUESTIONS?

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Thank you!

