



‘La Vida Normal’: Young people adapting to Type I diabetes in Bolivia

Chronic Illness

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Abstract

Objectives: To identify challenges and coping strategies of young people with Type I diabetes (T1D) and their families in Bolivia through qualitative analysis of interviews with beneficiaries of Centro Vivir con Diabetes (CVCD), a diabetes health center supported by the International Diabetes Federation Life for a Child (LFAC) program.

Methods: Eighteen young people aged 14–33 and at least one caregiver participated in semi-structured interviews in five cities in Bolivia from May to June 2016. Interviews were recorded, transcribed, and analyzed using inductive thematic analysis.

Results: Participants described needing guidance at diagnosis and facing stigma in communities. Young people expressed that life with T1D was ‘la vida normal’ (a normal life), although interpretations of normalcy varied. For some, ‘la vida normal’ meant resistance to T1D; for others it indicated acceptance.

Discussion: Access to interdependent spheres of support allowed young people to form a new normal around T1D. Receiving supplies through the CVCD/LFAC partnership maintained family connection to clinical care, CVCD education helped families share in T1D management, and peer support mitigated stigma for young people. Programs like CVCD that combine supply-based aid

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with clinical education for whole families, create effective support for young people with T1D in low- and middle-income countries.

Keywords

Type 1 diabetes, normalcy, stigma, young people, adaptation

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Introduction

A diagnosis of Type 1 diabetes (T1D) is life-changing no matter where in the world a child lives; he or she must cope with physically and emotionally painful challenges, and the entire family must adapt.¹⁻³ For families in low- and middle-income countries (LMICs), the diagnosis can be particularly devastating due to limited availability of T1D treatments.⁴⁻⁷ Bolivia, an LMIC, is the lowest income nation in South America, with 38.6% of its population living below the international poverty line.⁸ As of 2014, Bolivia's annual health expenditure per capita was \$427, compared to \$656 in neighboring Peru to the North and \$1749 in Chile to the West.⁹⁻¹¹ Support by the Bolivian government for health is limited and there is no coverage for T1D treatment or supplies for children.^{6,12,13} Within this context of extreme resource scarcity, supporting young people with T1D and their families requires an understanding of their challenges and coping strategies.

Numerous studies have documented the impact of the caregiver-child relationship on T1D management and outcomes in high-resource settings,¹⁴⁻¹⁶ yet complex issues that families living with T1D in LMICs face are largely unexplored.^{4,5,12} Additionally, research on T1D in Bolivia is particularly scarce; Duarte et al. provided the first T1D incidence study, finding a total incidence of 2.7/100,000 children < 15 y/y, with a mortality rate of 2.3/1000 patient years.¹² With the exception of Ghana and

Tajikistan, to our knowledge there are no previous studies examining psychosocial factors related to T1D management in Bolivia or other LMICs.^{4,5,12}

Context

Bolivia is a landlocked nation in South America with a wide variety of climates and ecosystems.⁸ The Altiplano, home to the majority of the nation's population, is a high-altitude, arid landscape.⁸ Throughout the country, 36 recognized indigenous groups make up a large percentage of the population (estimates nearing 50%),¹⁷ and Bolivia recognizes Spanish and 35 other languages as official.⁸

Life for a Child (LFAC) is a non-profit program of the International Diabetes Federation, headquartered in Sydney, Australia. It aims to ensure that young people (ages 0-25) in LMICs have access to the supplies most vital to their survival through partnerships that empower local organizations in their home countries. LFAC provides insulin, test strips, and other diabetes supplies and education to young people in 42 less-resourced nations around the world.¹⁸

LFAC has partnered with Centro Vivir con Diabetes (CVCD) to support young people in Bolivia since 2005.¹² LFAC sends supplies to the main CVCD center in Cochabamba where families collect them each month. Staff at CVCD-Cochabamba ship supplies to staff at the satellite center

in La Paz and to volunteers in cities where there is no physical CVCD location.¹²

In addition to managing distribution of LFAC supplies, the main CVCD center in Cochabamba and the satellite center in La Paz provide patients with regular medical care, educational sessions, Hemoglobin A1c (HbA1c) testing, and foot examinations. Whole families are invited to educational ‘charlas’ (talks), which offer opportunities for peer support. Young people at all sites have access to peer support and follow-up from trained CVCD staff or volunteers, many of whom have T1D themselves. Additionally, CVCD runs educational camps that are open to young people from all cities when funding is available.

Aim

We conducted a qualitative study with youth and young adults with T1D who currently or had previously received supplies and support from the collaborative CVCD/LFAC program.⁷ Our aim is to address a gap in the research on the relationship between youth adaptation to T1D and family support in LMICs, and further investigate positive coping and self-management strategies in young people with T1D.

Methods

Study design

The interviews analyzed and presented here were part of a capacity-needs assessment of the CVCD program conducted by LFAC from May to June 2016. As a category, capacity-needs assessments differ in their goals.^{19,20} In a literature review of needs assessments for those living with chronic conditions, Beran identified a need for assessments that examine the comprehensive “range of needs” that must be fulfilled to facilitate self-care,

rather than medical, psychological, or other realms of needs in isolation.²⁰ Our assessment aimed to achieve this breadth, identifying strategies to strengthen LFAC support for young people with T1D in Bolivia through an exploration of available clinical resources and support networks, and the perceived needs of these individuals and their medical providers in each region. To explore these questions, we conducted 26 semi-structured interviews with children, youth, and adults aged 4 to 42, along with their caregivers and other family members, seven interviews with CVCD medical professionals, and three interviews with CVCD program volunteers.

In this manuscript, we present analysis of the 18 interviews with youth/young adults with T1D aged 14 to 33 and their families (see Table 1). We chose to analyze this subset of interviews to better understand how young people were adapting to T1D in the context of their unique support networks. These participants were able to speak from a life stage of negotiating independence with caregivers and adopting more tasks of self-management.^{21,22} Additionally, the literature warrants increased study of this age group, as it is well documented globally that the summation of unique challenges during adolescence and young adulthood results in worsening blood glucose levels.^{12,22–28} This study was approved by the institutional review board of the University of North Carolina at Chapel Hill (study #16–2540) and the Board of Centro Vivir con Diabetes in Bolivia.

Sampling

All young people who received support from CVCD were eligible; however, we aimed to recruit a diverse sample in terms of age, gender, and family socioeconomic status in order to explore how resources

Table 1. Participant demographics (pseudonyms used).

Young person with T1D	Gender	Age	Years since diagnosis	Caregivers interviewed
Alejandro	M	15	6	Mother
Sara	F	18	12	Mother
Ana and Bernita	F, F	16,17	3,6	Mother, Sister
Evita	F	19	5	Mother
Angela	F	17	12	Sister
Maria	F	17	5	Mother
Jorge	M	33	23	Father
Victor	M	20	8	Mother, Father
Beatriz	F	21	14	Mother, Father
Hector	M	18	14	Mother
Pilar	F	20	8	Mother
Irene	F	16	1	Mother, Father
Guadalupe	F	16	4	Mother
Felipe	M	17	9	Father
Gerardo	M	21	3	Mother, Father
Adriana	F	19	10	Mother
Carlos	M	15	8	Mother

and needs varied based on personal characteristics of participants. As the medical social worker for CVCD, second author MCC used purposive sampling based on previously gathered information to achieve this diversity. MCC contacted potential participants and explained interview goals; all young people and caregivers who were approached agreed to participate.

Data collection

The interview guide for young people and caregivers was drafted by KS with input from LFAC and CVCD team members. The guide focused on access to resources and support, with sections dedicated to challenges of diabetes management and to experiences with peer support, health care, and managing diabetes in school. The guide led with questions for young people like, “Tell me a little bit about life with diabetes...” and “Is managing diabetes important to you? Why or why not?” Questions tailored to caregivers included,

“Is there anything that makes it particularly hard to care for your child?” and “How does having a child with T1D affect you? Affect the rest of the family?” Although some questions were specific to each party, the interview experience was designed to be conversational and many questions in the guide were answered by both caregivers and young people.

Interviews took place in participants’ homes in four cities in the Altiplano: La Paz, Oruro, Potosí, and Sucre, and one city, Cochabamba, in the Cordillera Central. Interviews were conducted in Spanish by KS, a Spanish-speaking researcher who has lived with T1D since 2005, and MCC, who is native to Bolivia and has intimate knowledge of its cultures and customs.

At the beginning of each interview, it was explained to families that participation was voluntary, that interviews would be recorded, and that their answers would not impact the care or resources they received. Informed assent to participate in interviews was obtained from all participants under the

age of 18 and informed consent was obtained from all participants over 18 years old. All interviews were conducted with young people and at least one of their caregivers together, except for two in which young people were not able to be present at the time of home visits, so caregivers and young people were interviewed separately. Two sisters who both had T1D were interviewed simultaneously. As a person living with T1D, KS brought a unique understanding of participants' experiences, which facilitated rapport. All interviews were recorded. Table 1 presents participant demographics using pseudonyms.

Data analysis

Following each interview, KS and MCC discussed their initial impressions of the context, including caregiver and young person dynamics, and the living situation and socioeconomic status of the family. During the data collection period, KS documented discussions with other investigators related to opportunities and challenges that families living in each region faced. These and additional field notes taken during home visits and observations within CVCD clinics complemented interview data.

Inductive thematic analysis was used to systematically code and identify salient themes in the data.^{29,30} Recordings of interviews were transcribed verbatim in Spanish. A narrative summary of each interview was drafted in English. These narrative summaries, along with deductive codes from the interview guide and field notes, informed an initial codebook. The codebook was primarily in English with some in vivo codes in Spanish. Transcripts were uploaded for analysis in Dedoose (Los Angeles, USA) qualitative analysis software. Table 2 outlines in detail the three phases of analysis aims and activities.

Results

When asked to describe life with diabetes, young people repeatedly used the phrase “es la vida normal” (“it’s normal life” in English) and the word “normal” (“normal” in English). We explored the apparent contrast between this emerging theme of normalcy and the stories of struggle, fear, and scarcity that young people and their families described in the same interviews. In this section, we present the primary challenges reported by participants and illustrate the two pathways described by young people to achieve normalcy within this context. We conclude with a description of factors that influenced young people’s interpretation of *la vida normal*. For a thematic map of results, see Figure 1.

Challenges

Need for guidance. Young people and their caregivers shared the burden of diabetes and expressed a range of fears. Many families reported feeling blindsided by the diabetes diagnosis and struggling to understand its arrival. Gerardo’s father described his family’s experience:

Obviously for me it was quite a blow, for the family. Like my son said, at first it was very hard for us to accept.

And his mother added, “*Because never, since he was young, had he gotten sick. . .*”

Caregivers were often left navigating uncertainty in multiple realms. Gerardo’s father described his family’s struggles around eating:

. . . food was very difficult. We couldn’t understand how much carbohydrates were in certain foods, the foods to balance it.

Not understanding diabetes put families at risk for delaying or avoiding treatment and care. Pilar, speaking about the time before she reconnected with CVCD, said:

Table 2. Aims and activities within each phase of analysis.

	Phase 1	Phase 2	Phase 3
Aim	Gather and organize initial impressions of the data into broad themes using interview guide structure. Identify unexpected, emerging themes falling outside of interview guide structure.	Re-code all interviews using second iteration of the codebook, which evolved during Phase 1 to include an additional 26 primary codes and 28 sub-codes.	Develop understanding of the focal theme presented here, <i>la vida normal</i> , and the factors promoting each of its primary two interpretations.
Number of primary codes used	8	34	4
Number of sub-codes used	20	48	2
Analysis activities	Four primary codes mapping onto domains within the interview guide were applied to each interview: <i>positive support, support lacking, education, and supplies</i> . Four other primary codes were applied representing themes outside of the interview guide structure that were mentioned in more than one interview: <i>fear, alternative remedies, intact family, and la vida normal ('normal life')</i> . During application of these initial codes, other salient themes were identified, as described in Phase 2.	Additions to primary codes included <i>family support, diagnosis, trauma, and darkness/uncertainty</i> , and sub-codes such as <i>problems with family, self-education, and isolation/feeling alone</i> . During this phase of coding, we identified two primary interpretations of <i>la vida normal</i> , the focal theme presented in this analysis.	Interviews were coded a third time using four codes: <i>acceptance of diabetes, resistance to diabetes, barriers to acceptance, and facilitators of acceptance</i> . Overlaying these broad codes onto already coded data to observe co-occurrence with each of the two primary interpretations of <i>la vida normal</i> allowed us to identify factors whose presence promoted acceptance of T1D and the challenge that promoted resistance to it. In this phase, the primary code fear was split into <i>youth fear</i> and <i>caregiver fear</i> , to identify ways in which concerns were shared or differed between the two parties.

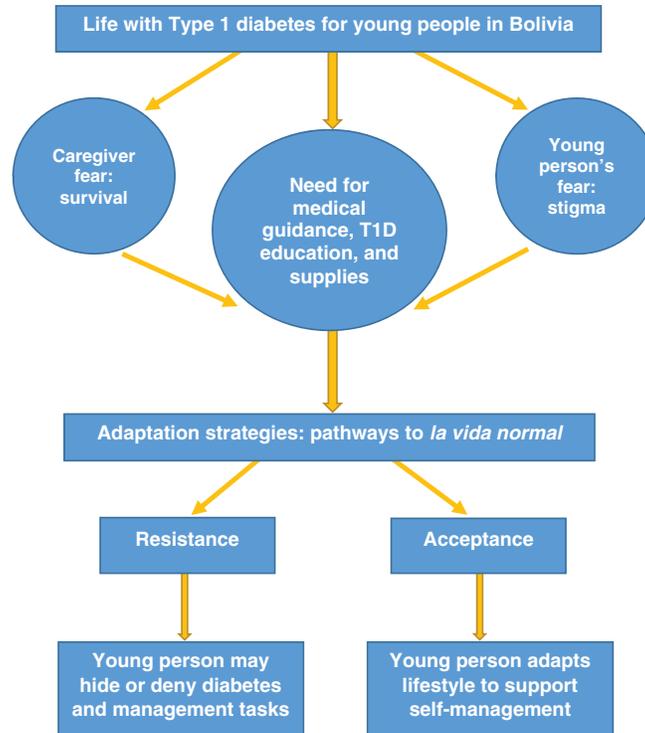


Figure 1. Thematic map of results.

Then no, I was not taking any treatment. I didn't have the entire explanation...so I stopped (treatment). Two years passed like that, and I became bedridden because I'd been admitted to the hospital and had not recovered...

Caregivers' fear: survival. Families dealt with fears related to uncertainty around diabetes, including its management and complications, which kept them in a state of distress and anxiety. Additionally, some caregivers reported negative experiences with physicians and fear related to seeking medical care. Irene's mother told us:

We are afraid to go...if she gets sick, to go to the doctors in case they say to us, 'she has this disease and she isn't able to control it.' This fear has stayed with us...

For many families, hypoglycemia was a major concern. Beatriz's mother stated starkly, "I'm terrified of lows." Victor's father described his family's response:

We leave the house and we're always on the phone, "How are you? Where are you?" like that. Because from one moment to the next he drops and it's dangerous... Now we're used to it, but at first we didn't know what to do. It scared us, but little by little we have learned.

As illustrated in the above quote, connecting to the supportive medical team at CVCD and receiving reinforcement and guidance allowed families to let go of some of their fears, even as their vigilance remained.

Young people's fear: stigma. While caregivers were preoccupied with fears related to their child's survival, young people expressed concerns related to quality of life. Many reported interactions with others who were afraid of "catching" diabetes. Maria explained, "People at my high school sometimes look at me strangely, they think that it's a disease you can catch . . .".

When asked what the biggest challenge was for young people with T1D in Bolivia, Alejandro said:

I think [it's] the people around us... they don't know about it, I think sometimes they talk bad or think that it's contagious, or something like that.

Facing social stigma was painful for young people. Hector recounted his struggles with stigma as a child:

During this time diabetes wasn't well known. There were rumors that... you could catch it from blood, things like that, so they (people at school) used to say, "Get away from him, he'll get you sick!" ... It was a little hard during this time.

Even young people who didn't mention stigma related to contagion expressed fears that T1D would affect them socially. Speaking of her diagnosis, Adriana said, "It made me very sad. I thought, 'I'll never have a boyfriend.'"

Encountering stigma related to diabetes prior to and after diagnosis increased the risk that caregivers and young people would avoid medical care and try to hide diabetes.

Adaptation strategies: pathways to la vida normal

When asked to talk about their life with diabetes, the majority of young people responded with, "es la vida normal" or, "it's just normal life." However, this response had two interpretations: resistance and acceptance, presented here through narrative case studies.

Resistance. Expressing the normalcy of life with T1D did not indicate acceptance of diabetes for all young people, as illustrated in the following narrative from an interview with Maria.

After the interview began, Maria attested to the normalcy of her life almost immediately:

*Well, my disease, I take it like a normal person. Always... I live my life normally, I behave normally, um, everything is normal, dismissing the notion that diabetes had much effect on her. In response to the question, *How does diabetes affect your life?* Maria described her interpretation of normalcy, which for her meant forgetting about diabetes:*

Hmm well I give myself a shot in the morning... I hardly think about my diabetes [laughing]. No, I forget a lot about my diabetes. You know, if I have to eat something, I eat it. I forget...

In the beginning of the interview, Maria made an effort to express that diabetes did not control her. She attested to her love of soda, *The thing that I love the most is soda*, and laughed as she told us, *If it doesn't have sugar, I prefer not to drink it*. Through maintaining these food choices, Maria strove to set herself apart from others who she saw changing their behavior in response to diabetes:

Well I know people that have diabetes and they get really worked up about it. Not me, when I go to a party I always serve myself soda. . .

As the interview went on, it became apparent that maintaining a guise of life as usual was a coping mechanism prompted by her fears of stigma. When asked what she feared most about diabetes, Maria's response was not nighttime hypoglycemia or running out of supplies, but rather, *people*.

Ultimately, Maria admitted that her difficult emotions around diabetes precipitated many decisions in her life: *I'm afraid sometimes of having a difficulty in the street . . . also sometimes I avoid going out*. She became tearful as she spoke of continually grappling with fears and doubts that had led her to question her future aspirations and the impact diabetes would have on them:

. . . Sometimes I feel strange at school, I don't know if it's because of my, sometimes it's hard for me to understand the teachers. . . It's hard for me. And I say to myself, 'Could it be my diabetes? Will I be able to go to university?' I say. 'Will I be able to?'

Maria grappled with difficult emotions related to how others perceived her and the physical impacts of diabetes that made her fearful of her abilities. For Maria and others, affirming that life with diabetes was no different than the ambiguous "vida normal" did not indicate acceptance, but rather resistance to its impacts on their lives.

Acceptance. While many young people described life with T1D as "la vida normal," not all pursued normalcy by hiding or minimizing the effects of diabetes. When asked about life with diabetes, Ariana said:

For me it's normal and it's better because on top of that we have healthier habits, in relation to exercise, our diets . . . In school, at the university, yes, it's normal in my life, I haven't had any problems. . . in relation to my studies. Yes, I've had problems, like any other youth with diabetes, but I recover well, thank God, and it's all good. Normal. For me it's a normal life. . . my friends see me and they think I don't have diabetes, I'm a normal person, so, it's all good.

Although it was still important to Ariana that her friends see her as a normal person, instead of forgetting about diabetes, she described actively managing her glucose levels with dietary and exercise choices that she had embraced as a healthier way of being:

"Well, (before) my mother always cooked a lot of carbohydrates. . . I ate a lot of bread, lots of rice, a lot of corn, a lot of cheese, and I was used to eating this way, and now. . . I eat it, but not much. Now. . . she cooks soups instead of a lot of carbohydrates, a lot of vegetables, also meat with less fat. . . I used to drink sodas but now I don't like them, now I drink a glass of fruit juice with water, or just water. Lots of fruit. Food like hamburgers and pizzas I don't eat much. . . I like them a lot, but I just eat them every once in a while. . . [laughs]."

For Ariana, her mother's willingness to change not just what was on her plate, but what the whole family ate, created a mealtime environment in which she could find normalcy while actively managing diabetes.

Factors supporting acceptance

Family sharing in care. Ariana and other young people who had begun to accept and integrate T1D into their lives spoke

Table 3. Family sharing in care.

Young person	Caregiver
Beatriz: <i>My parents have cared for me, my whole family, my aunts and uncles came to my side, even my cousin who is in elementary school.</i>	Beatriz's mother: <i>She is part of us.</i>
Interviewer: <i>"Who helps you the most with diabetes?"</i> Victor: <i>"My family...my, everyone. My brothers and sisters, and my father and my mother."</i>	Victor's mother: <i>We all worry about him. His siblings too are always calling, asking, 'how is brother?' and we're always supportive of him.</i>

often of the importance of family support. Jorge told us:

Something that I have noted also is that, well as I've been through 23 years with diabetes, the family has been fundamental to my being supported.

Many young people expressed the key role of family support, and caregivers described caring for the child's diabetes as a family responsibility (see Table 3).

Impact of CVCD support. Caregivers attributed their learning and subsequently their ability to support their children emotionally and operationally, to the education, care, and LFAC-donated supplies that they received from CVCD. Gerardo's father characterized CVCD as a sanctuary that helped his family heal from the trauma of diagnosis:

The center here in Cochabamba, at least for me, for my family, is like a temple where we go to gain more knowledge.

Beatriz's mother, who struggled with depression following her young daughter's diagnosis, illustrated how CVCD helped her overcome her initial trepidation and learn to give her daughter insulin injections: *My hand trembling, they taught me there.* She described frequent hospitalizations

related to hypoglycemia and her daughter's distress prior to finding CVCD:

Well, in the beginning there wasn't a way to check her blood sugar. And she was already having problems. Lows, convulsions. A lot. And she didn't feel that she was bad (low). As there wasn't a way to check it, we had to take her every time to the hospital, so that they could check it there...Thank God the test strips came. Her desperation has gone, I think with finding the center. And there they helped us. They have prepared us. They have explained to us. They have helped us a lot... as far as... how to live with this. They have gotten us accustomed to new ways of living... So we check it – until 11 at night we are all awake, we see how it is and then we sleep peacefully because we know she's going to wake up well.

Being able to monitor Beatriz's blood glucose at home offered the whole family peace of mind, which, in combination with education and care from the medical team at CVCD, created a powerful synthesis of support.

Learning from peers. As caregivers learned from health educators and each other at the center, education alongside similar peers helped young people overcome their fears. Alejandro described how meeting others at the center helped him feel less alone and visualize success:

I was afraid that I was the only one. But when I met others in the center, well after that we could spend time together and share experiences... now with the center, and the people I have met around this disease, now I have had more experiences and know how to manage this.

Sharing the experience of diabetes with others helped young people overcome isolation by offering them a group in which their experience was the norm. When asked how it felt getting to know others with T1D at a CVCD educational camp, Irene said:

Yikes, weird, because everyone knew how to give themselves shots and how to correct themselves and I was new ... but they are normal people... They aren't different from anyone else.

Jorge spoke of how camps offered him an opportunity to experience normalcy on a new level: *At the camps we share as diabetics, but with our families, no.*

Even when caregivers were highly engaged in diabetes care, connecting with peers offered young people an irreplaceable experience of support.

Discussion

We found that young people with T1D in Bolivia strove to achieve normalcy despite living in a context of resource scarcity, stigma, and varying levels of support. Whereas for some, expressing that life with T1D was “la vida normal” meant that they had adapted their lives to include its management, for others, it indicated resistance to changing in response to diabetes. For example, Ariana was able to achieve *la vida normal* by completely reimagining normalcy to incorporate T1D. In contrast, achieving the sense of normalcy that Maria desired required her to minimize

the effects of diabetes and negate the need to modify her habits for its management.

It is not unexpected that some young people denied the effects of T1D or engaged in behaviors to hide or minimize its effect on their lives. Other studies have supported the resentment, anger, and depression that often accompany diagnosis and life with T1D, especially for young people.^{31–33} Emotional distress and elevated glycaemia can operate in a vicious cycle, each exacerbating the other.^{34,35} Additionally, experienced and perceived stigma has been associated with poorer glycemic outcomes.³⁶ While it was outside of the study’s scope to explore how experiences of stigma varied for individuals based on ethnic background, it is likely that in an ethnically diverse nation like Bolivia, some individuals were more vulnerable to marginalization than others due to existing inequities.^{17,37}

Research has demonstrated that receiving appropriate medical, family, and peer support, both operational and emotional, fosters acceptance of T1D management tasks in youth.^{2,38,39} Among adolescents, the ability to prioritize diabetes correlates to improved blood glucose control.^{40,41} Wiebe et al. found that “diabetes goal planning” was associated with improved self-management in adolescent participants, which in turn had a positive effect on HbA1c outcomes.⁴⁰ We were not able to compare clinical outcomes with qualitative findings for young people in this study; however, Duarte et al.¹² demonstrated that young patients of CVCD were achieving average HbA1c levels similar to those of comparable age living in the United States.²³

A child’s short and long-term health with T1D depends on access to a network of support, including family, community, health care expertise in T1D, and health care systems.^{2,12,42,43} Beran has drawn on Maslow’s needs theory⁴⁴ to develop a hierarchy of needs specific to T1D, which

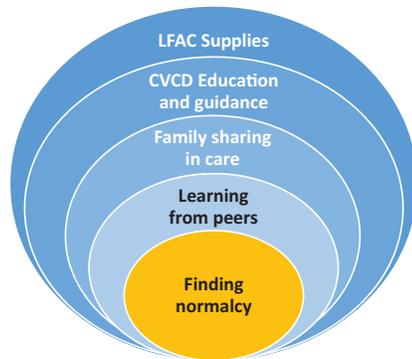


Figure 2. Interdependent spheres of support.

includes those necessary for survival and those, higher up, necessary for ‘self-actualization.’⁴⁵ In our study, participants’ descriptions of the partnership between CVCD and LFAC echoed a similar phenomenon, which we display in Figure 2 as a system of interdependent spheres of support, each enabling and strengthening the next.

The monthly collection of supplies from CVCD ensured that families stayed connected to health care and education delivery. Caregivers described this as a force that empowered them to “seguir adelante” (“continue on” in English) in adapting home life to suit their child’s needs. In this way, supplies from LFAC and education from CVCD worked synergistically. The type and amount of family support available to young people hinged on the emotional and functional support that caregivers were able to access. In turn, having an adaptive home environment in which the family shared in T1D care helped young people find stability, while peer support lessened the weight of diabetes for all.

Caregivers carried a large burden of management tasks and were the first line of support when young people grappled with frustrations, anxiety, or fears related to diabetes. Numerous studies support the centrality of the family and specifically of key

caregivers (typically mother and/or father) in determining young people’s adherence to self-management behaviors.^{2,38,46,47} Rostami et al. conducted a qualitative study with adolescents with T1D in Iran and reported that, “receiving tangible, informational, and emotional support from the family and society, advanced youths’ goals related to normalcy.”² Similarly, for families living with T1D in Bolivia, when young people displayed a positive attitude towards active self-management, caregivers had led the way; making changes to what the child and family ate, administering shots to young or newly diagnosed children, and ensuring that children performed glucose checks.

While accessing comprehensive support through CVCD allowed caregivers to gain the emotional strength and practical skills to help their child, connecting to peer support enabled young people to feel understood on a core level and helped them to accept diabetes. Support from peers has a demonstrated influence on the well-being and clinical outcomes of young people with T1D;^{48–50} Rostami et al. found this to be the case even when those peers were not living with T1D themselves.²

The process of learning to manage and accept diabetes is lifelong, and subsequently, young people need varying amounts and types of support as they progress into adulthood.²² *Resistance* and *adaptation* were not mutually exclusive; one individual could engage with both over time.⁴³ Indeed, other studies have supported the multitude of factors, including personality and age at diagnosis, that influence a young person’s ability to manage and accept diabetes.²² In this study, we saw access to medical, family, and peer support as key determinants of whether or not young people engaged in resistance: denying, hiding, or minimizing the effects of T1D, or acceptance: making changes in response to and creating a “new normal”⁵¹ around it. When young people were able to access complimentary spheres

of support, prioritized diabetes management could become *la vida normal*, because their entire network was sharing in the care.

Limitations

Our study had several limitations affecting its generalizability. We were only able to sample from youth who were enrolled in the CVCD/LFAC program, which means we did not engage with families who fell above the socioeconomic threshold to qualify for support or those who were unable to connect to care for other reasons. This was partially mitigated by CVCD's wide inclusion criteria based on a family's perception of their need; furthermore, CVCD strives to identify and reach all children diagnosed with T1D in the regions where it has a presence. We did not collect detailed demographic information or design the study to allow for comparison based on ethnic background or socioeconomic status, and further research in these areas is warranted. A limitation of analysis is that only one researcher was involved in coding; however, cross-checking of the interpretation and presentation of results occurred numerous times among the study team.

Conclusion

In conclusion, diabetes support programs like CVCD can encourage families in LMICs to stay connected to care, and create an essential network of support by addressing the educational and emotional needs of young people with T1D and their families. Further research is required to understand how to best mobilize spheres of support within contexts of stigma and scarcity to empower young people and their families to accept and adapt to T1D.

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Contributorship

GO advised development of the project aims and data collection methods and materials. KS created data collection materials, which were further refined by ED, MCN, and MCC. KS and MCC managed sampling and data collection. KS wrote the manuscript. CB contributed to analysis and manuscript revisions. GO, EK, BJA, and AM advised progression of the manuscript and contributed to manuscript revisions. ED, MCC, and MCN contributed to manuscript revisions.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

This study was approved by the institutional research board (IRB) of the University of North Carolina at Chapel Hill, IRB #: 16-2540 and by the Board of Centro Vivir con Diabetes (CVCD) in Bolivia.

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Guarantor

GO

Informed Consent

Verbal informed assent was obtained for all participants younger than 18 years of age, and verbal informed consent was obtained for all participants over 18 years of age. In addition, all participants signed a media authorization form specifying that interviews could be used for purposes not limited to articles for publication.

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