“She’s Trying Her Best, Even Though She Gets on My Nerves”: Diabetes and the Caregiver-Child Relationship in Jamaica

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Diabetes affects ~ 1.2% of Jamaicans between the ages of 15 and 24 years.1 For young people, diabetes care begins in the family; parents’ involvement can improve weight management, blood glucose monitoring, glycemic control, and adherence.2–4 These positive outcomes are most likely in cohesive families whose members communicate well, agree on individual responsibilities, behave supportively, and solve problems together.5–7

There are many sources of diabetes-related conflict, however. Arguments over food, blood glucose testing, and exercise are the most common.8–11 At the root of tensions are the negotiation of children’s autonomy as adolescents; differing opinions on each party’s role; children’s irritation at parents’ frequent reminders, lack of knowledge, and scepticism of their ability to manage diabetes; and parents’ frustration with nonadherence.5,9,11–15 These struggles have serious repercussions; conflict compromises family cohesion, adherence and control, intra-family communication, and the quality of life (QOL) and physical and psychosocial functioning of parents and children.5,7,16–18

There are limited data on Jamaican youth living with diabetes. A cross-sectional study found that young people’s QOL was most affected by issues related to diabetes control, anxiety, and worry.19 Researchers also found that most of these youth had poor glycemic control, even with access to specialist services and subsidized medications.20

The present study, based on focus groups with youths and their caregivers, is the first of its kind. Most of the published Jamaican diabetes research has been quantitative and has focused on adults, investigating risk factors, self-care practices, and the burden of disease and its complications.21–23

Although quantitative research measures associations between behaviors and attitudes and health outcomes, qualitative research allows in-depth exploration of the dynamics of these behaviors and attitudes. The aim of this study was to investigate the caregiver-child relationship in the Caribbean context to learn more about how management of adolescent diabetes can be improved to allow providers to give more sensitive and appropriate care. We are not aware of any Jamaican research on diabetes that 1) is qualitative or 2) considers the perspectives of caregivers.

Study Methods

The data relevant to this article emerged from eight concurrent focus groups: four with 19 children aged 12–16 years and four with their 19 caregivers. The average and median ages of the children were 14 and 15 years, respectively. Half of the focus groups were held in rural locations. Aside from two rural participants (a sister who lived with the child and their mother and an aunt who was the sister of the child’s late mother), all caregivers were parents, and only one of them was a father. Most children (68%) were girls and had type 1 diabetes (74%).

Recruitment was conducted in collaboration with physicians working in diabetes clinics, endocrinologists, and diabetes educators.
Clinic admissions lists were used to identify potential participants. Patients’ caregivers were asked if they and their child would be willing to participate. If they responded positively, their child was contacted. Parents signed consent forms for themselves and their child, and the children signed an assent form.

Diabetes-appropriate refreshments, glucose monitoring kits, testing strips, and insulin were available at the sessions. A nurse was also onsite. All participants were given the equivalent of U.S. $11 toward transportation costs.

Focus group discussions were conducted using a topic guide with open-ended questions. Participants were asked, among other things, about their experiences with their caregiver or child. Sessions were recorded and professionally transcribed. The study was approved by the Ethics Committee of the researchers’ university.

Transcripts were analyzed using thematic analysis. Quotes were assigned topic codes (e.g., “monitoring,” “non-compliance”) using the qualitative data analysis software Atlas.ti (Atlas.ti Scientific Software Development GmbH, Berlin, Germany). Broad themes (e.g., “affective support” and “avoiding conflict”) were then established. Cross-comparison, cross-case, and within-case analyses identified negative cases (i.e., examples from the data that contradict the patterns identified).24

Study Results
Caregivers offered affective and instrumental support, much of which was appreciated. However, their assistance and their child’s noncompliance could create tension. Each party had developed different ways to avoid conflict. Caregivers gave mixed assessments of changes in their relationship with their child over time, but older children emphasized the desire for more control over their diabetes management.

Affective support
Caregivers declared devotion to their child and the determination to shepherd them through the challenge of living with diabetes. One mother declared, “I want to be there for him, and I am going to be there; I not giving up.” Some admitted they spoiled their child because preferential treatment was the only way to ensure the child’s survival. As one woman said, it was “better to have him that way [spoiled] than dead,” and as a result, she gave more time and attention to this son than to her other children. However, other caregivers stressed that equal treatment was important both for the child and his or her siblings, saying, “I don’t want him to feel beyond them or above them.”

In response to their child’s sadness and worries about diabetes, caregivers offered physical affection and emotional support, saying it was important to “hug them and make them know that you love them, and it’s not the end of the world.” Many tried to empathize with their child; one mother refrained from reprimanding her child for poor exam results because the child had to “deal with so much things: insulin, injecting themselves, feeling tired, everybody is enjoying cake at the party [but] they can’t eat it.”

Keeping their child’s spirits up was important because the child’s psychological state could affect his or her health. Therefore, one mother had to “run as much joke as possible [joke around as much as possible]. If I don’t, [she says] ‘Mummy, you don’t love me.’ And she build a quarrel [starts an argument]. And dat even send up the sugar [increases her blood glucose level].”

This mother’s words suggest the importance of this type of support to the children, although the children themselves mentioned it less often than their caregivers. An exception to this relative silence was one girl, who explained how she had overcome her initial fear of diabetes: “Mi mada [my mother] always tell me, ‘Don’t worry, don’t worry.’”

Instrumental support
Caregivers also supported their child in practical ways. Generally, they oversaw their child’s care regimen. Specifically, they prepared appropriate food, provided sufficient insulin and equipment, and reminded the child about insulin injections and blood glucose testing. Most children with type 1 diabetes injected themselves, but caregivers taught site rotation to minimize “bruising” and helped them test their blood glucose.

Caregivers also disclosed their child’s illness to others and introduced their child to other people with diabetes. This assistance was appreciated by many and could have positive psychological effects. It made one girl, for example, feel “on top of the world.”

Conflict between caregiver and child
Notwithstanding these reports, even the participants who initially reported smooth relationships—because their child was fully compliant or their caregiver offered practical help and reassurance—had stories of tension.

Conflict over food, testing, and injections. There was a constant battle over dietary rules. One girl understood her parents’ concern but could not resist temptation, saying, “They want you to live, and you want yourself to live, too, but . . . it’s so hard to restrain from the food.” Children cited practical reasons for not testing or injecting themselves such as a lack of time or the associated pain or bruising. Some caregivers ascribed noncompliance to laziness; more empathetic adults saw it as their child’s desire to fit in.

Conflict over monitoring and reminders. Awareness of their child’s noncompliance, as well as the mechanics of the disease itself, meant that some caregivers “watch[ed] [the child] like a baby . . . 24 hours [a day].” The children sometimes chafed under this attention; what caregivers called “watching,” “reminding,” or “persisting” felt “over-protective,” “over-dramatic,” or like “pressure” to their children. “[My mother] stress over certain things,” one child responded. “I would jog for an hour or so, then she used to be like, ‘No, you still have on weight. You need to start doing 2 hours.’ So it like she a pressure me and me a pressure myself [it’s like she pressures me, and I pressure myself].”

Conflict over disclosure. Most caregivers told staff and food vendors at school and people in their community that their child...
had diabetes. A mother disclosed her daughter’s illness to her sports coach and team because she “may have a difficulty, and it is important for them to know what to do.” Her daughter, who had only told three teammates, disagreed: “I never wanted everybody to know . . . because people are fas’ [nosy] and you know people don’t keep their mouths to themselves so you goin’ find dem telling odda people [they will tell other people].” Children agreed that the problem with wide disclosure was stigmatization or, at the very least, that “some will treat you different.”

Communication problems. Many adults said their child ignored instructions, whereas many young people complained that their caregiver ignored their claims to competence. A mother’s only problem with her daughter was “not hearing; [she] ignore you sometimes.” At the same time, a girl said her mother “doesn’t really listen to me. . . . If [she says], ‘You not supposed to have that,’ I’m like, ‘Mummy, but I feel all right,’ or, ‘My sugar level is a little bit down.’”

Physical discipline. Some parents reported hitting their child to convince him or her to comply. This was cause for debate in the session:

Participant 1 (P1): Most time [usually when] he has to go to his [doctor’s] appointment, his father has to beat him. Because he needs to be controlled.
P2: Beating him not gonna change anything.
P3: No, that is not gonna change anything.
P1: But, we talk, we plead . . . .

Threats. Parents and children said that the former often threatened the latter with the consequences of noncompliance. One girl said her mother told her, “If you don’t tek it [take insulin] you goin’ [to be] dead.” Caregivers’ recriminations had brought some children to tears. “I tell her she can just talk to me and not so loud because when she speaks very loud, I get really sad and start crying and go somewhere by myself.” Nonetheless, many caregivers believed that threats worked.

“Sometimes, you have to curse dem [them] to make dem look [make them pay attention]. You see the next evening when she come and you test, it much better.” Threats could also lead to hiding, however. A girl who felt “sluggish, sleepy, and . . . itch[y]” after eating too much sugary food told her mother when asked that she was scratching an insect bite. The children also reported hiding their cheating. One girl said she knew that if her family found out she bought sweets at school, “They will take it away and beat me, [so] I hide. I just tell them I’m going to the bathroom and eat my sweetie.”

Avoiding conflict Caregivers developed strategies to avoid conflict. Instead of “pressuring” her son, but fully aware that, “If I leave it up to him, him [he] will never” test his blood glucose levels, a mother said gently, “Come here, baby, I want a reading from you now.” They also tried to cheer their child up when conflict seemed likely. “Just talk to them and make them happy,” said one caregiver. Caregivers allowed their child to eat unhealthy foods in moderation and rewarded compliance. Realizing that a complete ban on sugary drinks had not worked, one mother permitted her child to have one per day. Another mother told her son, “There’s a guideline; there’s a border [you’re] not to cross. Di problem start [the problem starts] when you go overboard.” Caregivers ensured this was a safe compromise by checking food labels for sugar content and checking their child’s blood glucose levels. So that they would not “rebel and won’t take the medication,” caregivers promised their child desired items.

Children sometimes relied on extended family members to avoid conflict with their primary caregiver. For example, when irritated by her mother, one girl confided in her grandfather. Children often depended on other family members for appealing food (if sweet foods, usually in moderation).

Children could also use emotional manipulation to avoid condemnation. According to her mother, one girl “play pon di emotion when mi try scold her: ‘You can lick me and kill me cause mi soon dead anyway’ [plays on my emotions when I try to scold her: ‘You might as well hit me and kill me because I’m going to die soon anyway’]. Indeed, the mother walked away from the argument.

The relationship over time Participants differed over whether the relationship became easier or harder with age. Some caregivers said their work became easier as their child assumed more responsibilities, became accustomed to the tasks, and understood why compliance was necessary. Some children said they were more receptive to instructions or needed them less with age. One 16-year-old girl living with diabetes since the age of 10 whose mother initially beat her to ensure compliance currently reported taking her medication as “part of the daily routine.”

Caregivers and children differed over age as an indicator of competence, however. A mother said, “I don’t think we should let her have her way because I don’t see she reach the stage where she a go tek [she is ready to take] the insulin on her own.” Her daughter strongly disagreed. To the vocal approval of her fellow 16-year-old participants, she said, “I can control myself, most of the time. But they are doing it like, ‘She a still one likkle pickney. She nuh know wah she a do, so mi haffi watch her’ [‘she’s still a little girl. She doesn’t know what she’s doing, so I have to watch her’].”

Indeed, some caregivers confirmed that the growing desire of their child to fit in with peers and rebel against adult control increased tension. The lone father in the study said his daughter’s blood glucose level would “skyrocket” because “when dem [they are] out with dem [their] peers, dem [they] tend to forget dat dem [that they are] diabetic.” The mother of a 14-year-old said, “You can’t stop [noncompliance], especially when they reach teenager stage because they have attitudes.”

Some caregivers recognized that they had to forge a more equitable relationship. Interaction with their child was, “the same amount of
work, but a different approach. With a child you'll say, 'Don't do that or else...' With a teenager, 'Don't do that because this is what is going to happen.'"

Discussion
This is the first qualitative study of the relationship between young people with diabetes and their caregivers in Jamaica. Both parties' perceptions of their relationship can best be summed up by one girl's appraisal that, "She's trying her best, even though she gets on my nerves." There did not appear to be any significant differences in relationship issues according to rural versus urban residence, sex of the child, or type of diabetes.

Children generally believed that they had support from their caregivers, a perception important for good diabetes management.2,26 As other studies have shown, the type of support most reported was instrumental, although emotional support, particularly reassurance, was valued.14,27,28 Caregivers believed, as in other studies elsewhere, that instilling positivity was important.8,28 The presence of emotional support is encouraging because parental warmth, empathy, and adherence have been linked in the literature.2,5,7,14,29 Children have also demonstrated some empathy, which can contribute to smooth relationships by increasing tolerance of caregivers' unwelcome behavior.15,28

However, it is also clear that conflict was an ever-present threat and frequent reality for some families. Children appreciated help, but only how and when they wanted it.30 Unlike elsewhere, exercise was not a significant point of contention, although children were seldom active. As in other contexts, food and blood glucose testing were great sources of conflict.4–13,28 As Weinger et al.28 found, caregivers focused more on the future, whereas children fixated on the immediate concern that diabetes was a sometimes physically painful intrusion and marker of difference.

Participants' narratives revealed poor communication. Anderson3 argued that "the relevant question is not 'How much parental involve-

ment [in diabetes management]?' but 'How is this involvement communicated?'" Shouting, criticism, threats, and physical discipline in response to nonadherence sometimes secured immediate compliance but could also cause stubbornness and arguments,26 which fueled the cycle of bad communication. Unfortunately, threats are common in other contexts as well, because caregivers perceive them as their "only tool to motivate their children."12

Children are often punished physically in Jamaica by older family members and people in positions of authority.11 Although traditionally accepted in Jamaican society, changing mores have made physical discipline controversial in recent years. The debate among participants about the appropriateness of hitting children, even as a last resort, reflects this ambivalence.

Unhealthy communication has ramifications for children's psychological and physical health. Good communication predicts adherence and control, whereas caregivers "freak[ing] out"15,28 can lead to depressive feelings, low self-efficacy, poor adherence, and poor glycemic control.32–35

These findings are borne out in the present study, although the link to glycemic control can only be considered speculative. Sometimes reduced to tears, children hid adverse symptoms and noncompliance from their caregivers for fear of further recrimination and usually did not reveal the psychological impact of the scolding. The inability to express feelings openly hinders control;13 communication problems therefore could reverse the aim of the caregivers' communication. This is "miscarried helping,"28 in which a caregiver's sincere attempts to help leave a child feeling ashamed and harangued.

Studies have shown that caregiver-child collaboration is necessary for healthy relationships and outcomes.4,18,30 However, in many instances in the present study, collaboration was lacking. The most common example of teamwork was a caregiver teaching site rotation for insulin injections. Some caregivers indicated that, over time, collaboration became an increasingly important element of the relationship. They made greater efforts to explain the reasons for their instructions as their child grew older. Nonetheless, most caregivers' accounts suggest that they usually did not consult with the child. Wide disclosure of their child's illness was unilateral, and children were expected to do as they were told. Children's defiance and manipulation of their caregivers' affections to break rules suggest that collaboration was not always a priority for them, either.

As elsewhere, collaboration was hindered by differing opinions on the ideal level of caregiver involvement.5,11,34 Under dispute was the degree of caregiver vigilance rather than the tasks undertaken. The children did most self-care, while parents played an oversight role, a typical shifting of responsibility in adolescence.7,11,18,37 However, "hyper-vigilance"15 could be too much for the children. Close monitoring can facilitate adherence,2,38 but it can also feel like an intrusion.14,15,17,28 Nonetheless, some Jamaican caregivers, just like caregivers elsewhere, were sceptical of their child's self-care abilities.1,13,14 They were aware of what studies have reported: that maturity, not age, is key to successful self-care.39

Only the caregivers avoided conflict in ways that could improve the relationship. They managed their expectations by allowing occasional indulgences and rewarding and incentivizing good behavior, thus removing potential sources of conflict.10,13 The mother who tested her son's blood glucose communicated with him in a way that allowed frictionless completion of an important task.

Various studies show that adolescence creates difficulties in care and the caregiver-child relationship,4,8,40 although a study by Vingisalo et al.41 is an exception. The present study suggests that such difficulties are not inevitable. For example, the length of time a child has lived with diabetes might reduce conflict because the years bring
greater understanding of the illness. Furthermore, caregivers’ acknowledgment of their child’s growing autonomy through adaptation of communication styles can reduce “attitudes.”

There are limitations to this study. First, qualitative research does not produce generalizable data. Second, the number of participants is smaller than originally anticipated, primarily because of outdated contact information on admissions lists. Finally, caregivers with the most difficult relationships might not have wanted to disclose such problems to strangers; the data may therefore be unduly positive.

Nonetheless, the study provides important information on behavior that facilitates and stymies the caregiver-child relationship in Jamaica. Certainly, for the best relationship outcomes, both parties should move away from poor communication, manipulation, unilateral decision-making, and valuing immediate manipulation, unilateral decision-making, and valuing immediate over long-term benefits and toward open discussion and collaboration. This is in keeping with other studies’ recommendations for joint problem-solving, clear role delineation, and nonjudgmental communication.5-7,11

Although this study cannot prove conclusively that an improved relationship inevitably leads to better diabetes management, it does indicate that it is crucial for Jamaican health care practitioners to pay close attention to caregiver-child dynamics. The results suggest that health professionals involved in diabetes care should investigate the points and degree of conflict and cooperation, as well as the effects of conflict on both parties. Diabetes educators should also teach effective communication and conflict-resolution skills. Ultimately, health care practitioners should facilitate trusting and supportive caregiver-child relationships. Psychosocial and behavioral interventions deemed effective elsewhere and tailored to the Jamaican context could prove helpful.

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References

Lifestyle and Behavior


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