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The Subjective Experience of Cameroonian Siblings Confronted with the Intellectual Disability of One of Their Members in Cameroon

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ABSTRACT: A child's intellectual disability affects the family in general and siblings in particular. This hinders the identification process within the sibling group, which is often subject to stigmatization by those around them. It is within this context that this article explores the subjective experience of Cameroonian siblings confronted with the intellectual disability of one of their members in Cameroon. The study is based on a fundamentally qualitative clinical method, and data were collected through semi-structured interviews with three sibling groups, each including one member with an intellectual disability. These data were analyzed using thematic content analysis. The results show that the siblings' subjective experience of intellectual disability is characterized by a mixed awareness of the disability, feelings of rejection and stigmatization, feelings of pain, sadness, and tolerance, as well as a sense of sibling unity and complicity. These findings can be used to support siblings of children with disabilities in general, and those with intellectual disabilities in particular.

KEYWORDS: Intellectual disability, siblings, subjective experience, sibling relationship, Cameroon

INTRODUCTION

Cameroon is among the countries where the prevalence rate of intellectual disability (ID) in children is estimated to be twice as high as in the rest of the world (Maulik et al., 2011; Ké & Liu, 2012). According to reports from the World Bank and the WHO (2010), the prevalence of people living with disabilities is estimated at 15% of the global population and represents 10% of the total population in Cameroon (BUCREP, 2010).

More specifically, data from the statistical yearbook of Cameroon's Ministry of Social Affairs (MINAS), published in 2012, report a total of 2,450 individuals (adults and children) with intellectual disabilities, with or without associated disorders (autism, epilepsy, and others).

When a traumatic family event such as intellectual disability occurs in one member, the overall balance of the family can be disrupted, leading to disorganization that affects all members and may result in chaos. Intellectual disability, defined as a condition characterized by significant limitations in intellectual functioning and adaptive behavior—manifested in reduced conceptual, social, and practical skills (Schalock et al., 2007)—disrupts the balance within the sibling group and inhibits the identification process essential to the construction of sibling bonds.

Sibling groups who have experienced the same traumatic event may undergo what can be described as an unspeakable experience, akin to witnessing death directly. This shared historical moment creates a traumatic bond that may become intertwined with the sibling relationship (Romano, 2009, p. 295). For children who were not present and did not directly witness the event, manifestations of psychological distress have been systematically observed.

According to Romano (2009), in sibling groups with a member living with a disability, there is often a blockage in the processes of identification and individuation. The fear of becoming a victim of a similar event may hinder the development of structuring processes of separation and differentiation between children, leading either to fusion reactions ("he and I are the same") or to radical separation ("I don't want to hear about him anymore; I have nothing to do with him; he no longer exists for me") (Romano, 2009, pp. 295–296).

These consequences can lead to contradictory feelings in which jealousy, envy, fear, guilt, anger, aggressiveness, rejection, exaggerated expressions of affection, active indifference, irritation, and others are experienced either successively or simultaneously. These are all expressions of the suffering of the siblings of the affected child and also reflect the reactivation of earlier psychological issues.

Within these sibling groups, there is a blockage in the processes of identification and individuation, as identifying with this "almost same" carries the risk of becoming that injured other oneself, while separating from them entails the risk of losing oneself (Romano, 2009, p. 295). Alongside

this blockage, shame emerges as one of the major feelings experienced by siblings of a person with intellectual disability. This includes shame of being different from peers, shame of the sibling's difference, and sometimes even shame of being oneself "normal" (Bergis, 2010, p. 36).

Intellectual disability may thus become, within the sibling group, an object that mobilizes affects, feelings, and emotions. According to Dayan (2008), being confronted with a sibling who cannot be mentally represented gives rise to a deep and troubling sense of strangeness, where intimacy and familiarity should exist. André (1986) refers to this as an "adhesive identification with the psychically dead child."

If siblings are driven by the fear of resembling the child with a disability (intellectual disability), conversely, they may also experience difficulty in finding similarities with them. The child with a disability may then be perceived as a stranger whom they do not understand and sometimes struggle to recognize as their sibling: they are unable to grasp aspects of the child's intrapsychic life, how they themselves can influence them, and what they represent to that sibling. They may find it difficult to establish an intersubjective relationship, even if an interpersonal relationship can still occur (Claudel, 2012).

From this arise numerous questions regarding perception, attitudes, thoughts, emotions, beliefs, lived experience, and the meaning that siblings attribute to intellectual disability. In other words, the subjective experience of intellectual disability within these sibling groups raises many questions.

The subjective experience referred to here relates to intimate and personal feelings—the way siblings perceive, interpret, and make sense of the intellectual disability of one of their members. It concerns how siblings live with this reality while mobilizing their affects, representations, personal history, and internal resources.

According to Merleau-Ponty (1945), subjective experience is irreducible and must be understood through the lived perception of the siblings. This experience is not merely a reflection of the external world but a sensory-motor and intentional construction, rooted in the body and the world.

Following the diachronic model of subjective experience (Merleau-Ponty, 1945; Minkowski, 1933; Ricoeur, 1985), the subjective experience of siblings is not fixed; it unfolds along an evolving trajectory that begins with the announcement of the intellectual disability diagnosis. This moment constitutes a foundational temporal rupture, often associated with a disruption in the perception of the future and a transformation of the sibling bond. Under these conditions, subjective time is marked by intense emotions such as shock, sadness, incomprehension, anger, and, in some cases, guilt.

Over time, siblings gradually construct a narrative representation of the situation of intellectual disability by integrating family history, parental responses, social dynamics, and everyday life experiences. This construction is part of a process of subjectivation, within which siblings may reinterpret the disability of the affected member through new lenses (maturity, personal development, social engagement, etc.).

In Cameroon, examining the subjective experience of intellectual disability among siblings is particularly relevant, as these siblings face a unique reality and culturally specific meanings. Indeed, intellectual disability is often perceived as the result of witchcraft. As Nguimfack (2016) notes, "the strong belief in witchcraft in Cameroon and its frequent use in explaining certain facts or phenomena means that illness, in the minds of the people, always has an exogenous rather than endogenous origin."

Similarly, Tsala Tsala (1989, p. 110) reminds us that "in most traditions in Cameroon and Central African countries, illness is rarely an individual matter. It is always the direct or indirect manifestation of a cosmic disorder with immediate effects on social organization and interpersonal relationships within the group."

Thus, in Cameroon, representations of disability are shaped by beliefs and prejudices with mystical and religious symbolism (Tchokote, Tsala Tsala & Scelles, 2020). In this context, how do siblings experience the intellectual disability of one of their members?

Drawing on Merleau-Ponty (1945), Minkowski (1933), and Ricoeur (1985), we focus on the lived experience—how siblings perceive, interpret, and make meaning of the intellectual disability of one of their members. It is within this framework that this study This study explores the subjective experience of siblings confronted with the intellectual disability of one of their members in the Cameroonian context, marked by stigmatization as well as beliefs and prejudices rooted in mystical-religious symbolism.

1. METHODOLOGY

To achieve the stated research objective, we used Interpretative Phenomenological Analysis (IPA), a research method that allows for an in-depth exploration of experience, psychological mechanisms, and the meaning attributed to a situation (Smith et al., 2009).

As this is a qualitative study, we opted for a small heterogeneous sample to promote internal diversity. The sample consists of three sibling groups, each including a member with an intellectual disability (ID). A purposive sampling technique was used to select participants.

The Aba sibling group

The Aba sibling group consists of three children: one girl and two boys. The eldest, Aba, aged 18, has an intellectual disability and attends the Cameroon Center for the Promotion of Persons with Disabilities (PromHandi-Cam). Sara, the middle child, aged 16, is a high school student in grade 10. Frank, the youngest, aged 14, is in grade 7 at a local secondary school. These children were abandoned by their mother when the youngest was 2 years old and the eldest was 6 years old. At that time, the eldest already showed significant developmental delays, as he was not speaking, not walking, and was frequently ill.

The Bobo sibling group

This sibling group consists of three children: the eldest, a 20-year-old female student; Alain, aged 19, also a student; and Bobo, aged 13, who has an intellectual disability and attends a local rehabilitation center. The mother is a homemaker and the father is a taxi driver. Bobo was diagnosed with an intellectual disability at the age of 3, when his parents noticed developmental delays compared to peers of the same age.

The Bidou sibling group

This sibling group consists of five children: two girls and three boys. The eldest, Bidou, has an intellectual disability. She is 19 years old and enrolled at the Renaissance Specialized Rehabilitation Center. The second child, Zumba, is in grade 11 (science track) at a local high school; the third, Wooh, is in grade 9 at the same school as her brother. The fourth child, Shey (6 years old), is in elementary school (grade 1), and the youngest,

Aïke (4½ years old), is in kindergarten. The two youngest children were present during the interview but did not participate and appeared drowsy, as their age did not allow for sufficient analytical capacity.

We used semi-structured interviews as the data collection technique and an interview guide as the data collection tool. Group interviews lasted an average of 60 minutes. All interviews were recorded with participants' consent using a voice recorder.

The collected data were transcribed using Word processing software and analyzed using content analysis, specifically thematic content analysis, which involves identifying recurring general themes within verbal or textual expressions that appear across more concrete content. The aim of this type of analysis is to identify categories within discourse or text, corresponding to a summarized reorganization of what is expressed. To ensure empirical grounding, key words and essential excerpts from participants' discourse were retained.

2. RESULTS

The results obtained from the analysis of the collected data are organized around the following themes: knowledge of intellectual disability, stigmatization, reactions to stigmatization, sibling relationships, and sibling complicity.

2.1 Awareness of the disability

Over the years, siblings have developed a range of knowledge regarding intellectual disability. In this regard, Sara states: *"For me, it's… it's a… it's a delay compared to his age, the age he should have. That it's… that he is… that mentally…" …he is behind where he should normally be." Following this,* Frank adds*: "I think it is God who made him this way."* As for Aba, the child with an intellectual disability in this sibling group, he says: *"As for my delay, hmm, it's true that I would like to be ahead like others, but I can't."*

In the same vein, Rita, Bobo's sister, expresses herself as follows: "For me, it's the fact that he cannot do well at school like children his age. *For example, if I take the case of age that we were talking about just now, he is not someone you can tell something once and he remembers it. Well… there is a small thing… copying. If it's about copying, he can copy."*

For members of these sibling groups, although they are aware that their brother or sister is living with a disability, in many cases they do not know the name of the condition. This is, for example, the case of Charly's sibling group, who, although they had already been told the name of their sister's disability, did not pay attention to it. On this subject, Zumba says: *"We were told the name of her illness before, but I forgot. It's a very strange name, I forgot […] (Well, for me, it didn't change anything, we continued to live like that, but she is still our sister. We live like that, but I don't treat her differently)."*

For Aba, the child with an intellectual disability, this situation raises questions and incomprehension, as reflected in his words: *"For me, I don't know… hmm… I don't know why I was born like this."*

These sibling groups perceive the member with an intellectual disability as a normal person. They do not express a difference between themselves and their sibling. On this matter, Frank, Aba's brother, says: *"For me, he is like that, like a normal person."* The Bobo sibling group, for their part, highlights the abilities and skills of their brother with an intellectual disability. Zumba states: *"I'll start. Uh… he is… he is a child who really loves work. He has always loved working, he has always liked… uh… using his hands. So… even in studies, he has always been… so we feel that if he were 'normal'—in quotes, as people say—if he were normal, he would really be good at school. Because when we studied, he would always come with his notebooks; he always wanted to study with us."* Following this, while also emphasizing their brother's abilities, Wooh adds: *"I think she has already said a lot, but I can also say that I noticed he is resourceful. He can just be there and make his own toys by himself."* Regarding the Bidou sibling group, Shey, the younger brother, states at the very beginning of the interview*: "She is not sick.".*

This reflects how these siblings perceive their older sister's situation. For them, she is completely normal like all of them; they only note that she has fewer abilities compared to them. On this subject, Zumba explains: *"I can say that she is not sick because she just doesn't have the same capacity to understand or grasp what we are told. Otherwise, she is not different. Because she can do what we do, she can go where we go, she can watch TV like me. The difference is that she doesn't have the same capacity to understand certain things as we do. She understands what we understand, but there are some things she cannot understand.".*

As their sibling develops, these sibling groups discover abilities that are unique to them. In this regard, the Bobo sibling group (Rita and Alain) describe their brother's understanding as follows: *"And sometimes he himself knows… he senses when we are lying to him."*

Rita adds: *"Yes, because he is not stupid. He is quite intelligent."*

Alain supports this by saying*: "Or maybe it's just wisdom? I think he is becoming wise."*

The discovery of the sibling's disability often occurred under unexpected circumstances. Indeed, siblings were sometimes informed in atypical situations. For some, it followed an illness or a critical condition affecting their brother or sister.

In the case of the Bidou sibling group, the discovery of the sister's disability occurred through observation and information, as Zumba explains: *"I knew because she didn't go to school. I was told that she had a learning difficulty, that she could not properly grasp what she was taught. That's why she stopped going to school."*

For Wooh, the discovery occurred during conflicts with her older sister, as she explains*: "For me, I found out because our mother told us. I think I was still in primary school. That's when I found out […] Whenever we argued, during small conflicts, she would remind me: 'Be careful, she is your older sister and she is not like you. She didn't ask God to be like that, and she is sick.'"*

2.2 Feelings of rejection or stigmatization

In African cultures, disability is often perceived as the embodiment of wrongdoing, a transgression of ancestral norms, or the persecution of a group by a malevolent third party. This perception frequently leads to the stigmatization of individuals living with disabilities…

On this subject, Sara, Aba's sister, states: *"In… in this neighborhood, apart from this neighbor, everyone behaves, I can say, fairly well with him. There is also the new neighbor who behaves a bit… hmm. But when we are both outside, there are people who speak very badly, there are people who speak very badly, and there are people who feel sorry for him because it shows, and there are people to whom it means nothing."*

This is also reflected in the words of Zumba, Bidou's younger brother, who says:*"Yes! People look at her strangely, and sometimes they even insult her."*

Similarly, Rita, Bobo's sister, adds:*"He was stigmatized by the other children in the neighborhood when he played. For example, there were marbles—during the holidays, we would gather in front of our house to play hopscotch and other games. There were the older kids' group and the younger kids' group like him."*

Faced with the stigmatization experienced by their sibling, brothers and sisters adopt various reactions. These reactions reflect their discomfort with the attitudes directed toward their sibling. In this regard, Alain, Aba's brother, expresses his anger as follows:*"It often makes me angry. It really makes me angry."*

In contrast, Zumba, Bidou's brother, states:*"It doesn't affect me. Silence. Because being like her… it's just… it's not something she chose. It's just a way of being. And when people say those things, I tell myself that if she had the ability to understand what it means… that's why I don't even try to deal with that kind of thing. That's how I see it."*

Following them, Sara, Aba's sister, explains:*"Me… it makes me… I often cry when people make fun of him. But our father often tells us that God is in control, that he didn't steal to be like this, that we shouldn't care about what people think… Sometimes I'm sad, sometimes I confront people, sometimes I stay silent. Sometimes I even cry because sometimes it's bearable and sometimes it's unbearable… and sometimes it just passes."*

Regarding this issue, Alain, Bobo's brother, adds:*"I felt really bad. I understood that he wouldn't be able to do certain things like us, like progressing normally at school. It really, really hurt me."*

Unlike the members of Aba's sibling group, who tend to adopt passive reactions to stigmatization, members of Bobo's sibling group display active responses aimed at stopping such behavior. Rita explains:*"I would scold the other children. I would tell them it was the last time."*

In the same vein, Wooh, Bidou's sister, states:*"When people around us show contempt toward her, we reprimand them. Yes, we reprimand them. Because an adult… well, it's mostly children. An adult cannot just stand there, look at someone like that differently, and insult them. No one chooses to be born this way. It's mostly children, but we correct them and tell them that she is our older sister, and just because she is like that doesn't mean you should despise her."*

2.3 Sense of relational unity and sibling complicity

Many children, when confronted with a peer with a disability, experience difficulty investing in that relationship, as the disability can create a sense of unsettling strangeness. In such cases, disability may obstruct the process of identification and affect their sense of self.

However, among the participants in this study, the relationship between siblings is similar to that found in sibling groups not affected by disability. Regarding the sense of sibling unity, Sara from the Aba sibling group explains:*"For me, it's normal, because sometimes siblings are kind to each other, sometimes they get angry, sometimes they are happy together… When we play, we are often together… We get along normally. During the holidays, since we didn't travel and there weren't many people around, we spent time watching things or playing in the room. It's normal, honestly."*

Similarly, Wooh, Bidou's sister, states:*"For me, in the future, her presence will not be a problem, because she is also a person like us. Maybe… when we become adults, she will be older, and we will take care of her. One of us may stay with her, and we can also help her attend training programs."*

If sibling complicity is rooted in a sense of belonging to the same group, it also implies recognizing the boundary between the sibling group and others (Scelles, 2003). Functionally, this complicity is often expressed through shared interests, including bending rules together, creating their own rules, and sharing secrets.

In Bobo's sibling group, there is strong complicity between the two boys, as their older sister Rita explains:

"The two of them are the closest… They've even changed now that they're older. Recently, they were playing, and I told them, 'Aren't you ashamed? At your age, you're still doing what you did as kids!' They like play fighting, throwing punches—real punches that hurt—and then they burst out laughing. They are really happy. So yes, they are very close, especially when it comes to jokes and playing."

Alain adds:*"I play a lot with him, I tease him a lot. If I don't see him, I go out and when I see him, I start play fighting… we play a lot… And there are also little things, like when our parents say not to turn on the TV, we still do it. Then I tell him, 'No one should say anything.' That's how it is."*

3. DISCUSSION OF RESULTS

Many studies have examined the psychological well-being of siblings of individuals with intellectual disabilities. Most highlight the presence of anxiety, depression, and feelings of guilt and shame (Williams et al., 2003; Gortais, 2002). Difficulties in expressing structured feelings of jealousy and aggression have also been noted (Scelles & Houssier, 2002).

In contrast to these studies, the results of this research do not highlight feelings such as shame or guilt among participants. Scelles (2010) identifies the frequent presence of guilt and shame experienced in isolation, often because parental attention is focused on the child with a disability.

The results reveal strong complicity between the child with a disability and their siblings. This aligns with findings by Poujol and Scelles (2014), who observed the predominance of positive affects such as happiness and the highlighting of sibling complicity. This displayed complicity may serve as a form of reparation for parents, who feel reassured seeing their children get along well. It may also reflect an intrafamilial injunction—an unspoken prohibition against expressing aggression toward the sibling with a disability—or even an awareness among children with disabilities of latent hostile feelings directed toward them (Korff-Sausse, 2006).

Consistent with these studies, the results of this research reveal a strong sense of complicity among siblings in families where one member has an intellectual disability.

Summers (2005) describes the impacts of disability on siblings in terms of psychological stress, family functioning, and eco-cultural adaptation. Eco-cultural adaptation refers to changes in family routines, work habits, and social practices following the birth of a child with a disability. In line with this, the results of this study highlight several modifications in family routines. Siblings develop new rituals to adapt to the situation. The findings of this study are consistent with this perspective, as siblings have made numerous adjustments to adapt to intellectual disability (ID).

3.1 The feeling of distress within the sibling group

According to Powell and Gallagher (1993), siblings of a child with a disability may be made vulnerable by excessive emotional intensity, poor emotional regulation, or repression of experienced emotions. They may experience not only sadness, distress, anxiety, and fear, but also anger, shame, disgust, and even contempt regarding their situation.

The child with a disability does not appear as a rival of equal standing to other siblings. The limitations they present may make them a source of anxiety (Potamianov, 1984), and the relational dynamics of "rivalry–competition–aggressiveness" that typically structure sibling bonds may be disrupted (Jalenques & Jalenques, 1992).

In the same vein, the results highlight the expression of feelings of shame and guilt within sibling groups. Over time, however, these feelings seem to lose their negative impact on daily life through a process of habituation.

Guilt occupies a central place in the inhibition of the sibling complex, as noted by Gardou (1997). Siblings may feel guilty not only for being in good health but also for experiencing jealousy toward the child with a disability or for expressing aggression toward them (Schauder, 1999). Self-blame can be understood as a response to distress in situations beyond one's control. This pervasive guilt often intertwines with shame and may even stem from it.

In public settings, siblings may feel that part of their private life is exposed to others, as if intruded upon. Confronted with others' gazes—perceived as rejection, aggression, mockery, or even disgust—they may feel disqualified and experience a deterioration in their self-image (Gardou, 1997). In line with these authors, the findings of this study also reveal the presence of such feelings among siblings.

Although the literature suggests that confusion between how one is perceived by others and how one perceives oneself (de Gaulejac, 1996) may lead siblings to feel shame for their brother, for themselves, or by a "contagion effect" (Scelles, 1997), potentially disrupting social relationships, it is important to distinguish between guilt and shame. While guilt is an integrative and structuring emotional signal, shame is a disintegrating one that may lead individuals to withdraw from social life (Tisseron, 2006).

In an attempt to escape others' gaze, siblings may isolate themselves and retreat into the family unit. However, in the sibling groups participating in this study, adaptive resources were developed to inhibit these feelings and allow them to function like any other sibling group. Rather than shame, a sense of pride toward their brother or sister with ID was observed. This highlights a nuanced difference between the findings of this study and those of previous research.

Most often, the expression of aggressiveness is difficult within sibling groups that include a member with a disability. Poujol and Scelles (2014) note the predominance of positive affects such as happiness and emphasize sibling complicity. This displayed complicity may serve as a reparative function for parents, who feel reassured seeing their children get along well. It may also reflect an intrafamilial injunction that prohibits the expression of aggression toward the child with a disability, or even an awareness among children with disabilities of latent death wishes directed toward them (Korff-Sausse, 2006). Thus, aggressiveness appears to be inhibited at multiple levels.

4. CONCLUSION

The objective of this study was to understand the subjective experience of Cameroonian siblings confronted with the intellectual disability of one of their members. To achieve this, a clinical method was used. Data were collected through semi-structured interviews with three sibling groups, each including one member with an intellectual disability. These data were analyzed using thematic content analysis.

The findings reveal that, over time, siblings' subjective experience of intellectual disability is marked by a range of emotional responses. For the child with an intellectual disability, the situation is a source of incomprehension and questioning. They do not understand why they are in this situation and express a desire for improvement so they can be like their siblings.

Members of the sibling group tend to perceive their brother or sister as a normal person with many abilities and competencies that are highlighted in everyday life. This leads them to state that their sibling is not "sick," which is consistent with the understanding that disability is not an illness but rather the combination of impairment, limitation, and disadvantage in relation to others or certain tasks.

It is important to note that, for these siblings, the discovery of the disability often occurred under unexpected circumstances, outside of everyday family routines.

These sibling groups are subject to discrimination and stigmatization, as is often the case in societies where disability is perceived as something supernatural, as a consequence of parental actions, or as the result of persecution by a third party.

Regarding relational dynamics, sibling relationships in families with a member with an intellectual disability are similar to those in families without disability. This allows siblings to project themselves into the future. A strong sense of unity and complicity exists among them, reflecting a shared sense of belonging.

These findings highlight the importance of considering siblings and their lived experiences in the care and support of children with intellectual disabilities. Concretely, professionals should implement interventions aimed at strengthening siblings' capacities so that they can develop the resources needed to cope with their brother's or sister's disability.

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