

ORIGINAL ARTICLE

Negotiating political power and stigma around fragile X Syndrome in a rural village in Cameroon: A tale of a royal family and a community

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Abstract

Background: Fragile X Syndrome (FXS) is a neurogenetic condition that significantly impacts the lives of affected individuals and their families due to its association with intellectual disability (ID) and stigma.

Method: In this paper, we present the findings of an ethnographic study in the community of a patient who received a genetic diagnosis for FXS in Cameroon. This study builds on data from 28 participants of a royal family and 58 from the community who participated in 20 in-depth interviews and nine focus group discussions.

Results: We identified two types of stigma in this community: public stigma directed towards the royal family and associative stigma experienced by royal family members. We outline the stereotyping labels used for the family and its children with Fragile X Syndrome and describe the stigma-power dynamic between the community members and the royal family. First, most villagers use less stigmatizing terms to addressing FXS children from the chieftaincy because of their position in society. Secondly, due to their social position, the royal family uses their status to negotiate marriages with community members. From these observations, we can suggest that the primary role of stigma in this community is to keep people away from FXS and keep them down through domination and exploitation.

Conclusion: We advocate that other researchers examine if the same pattern exists in other inheritable forms of ID and conduct more qualitative research on FXS in Africa.

KEYWORDS

Cameroon, Fragile x syndrome, qualitative study, stigma-power

1 | INTRODUCTION

Fragile X syndrome (FXS) is a neurodevelopmental condition that is genetically known as the leading cause of

Intellectual Disability (ID) and Autism Spectrum Disorder (ASD) (Crawford et al., 2001). Individuals with intellectual and developmental disabilities face stigma, prejudice, and significant obstacles that restrict their human rights

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(Mitter et al., 2018). People suffering from FXS and other forms of ID are also susceptible to developing significant mental health problems due to other factors like social deprivation (Dykens, 1999; Pattison, 2005). While social and other adaptive issues might be why people are marginalized, a distinction must be made between people's actual disabilities and the social barriers arising from stigma and discrimination. Stigma occurs when a person differs from dominant social norms and is negatively evaluated by others. Hence, the person's whole identity is defined by that dimension, and the person is dehumanized, to a degree, by those who hold such views (Goffman, 1963; Link & Phelan, 2001).

Stigma has a significant impact on the lives of individuals living with ID. In many communities, people with disabilities are stigmatized. Their disability has been associated with curses, disease, dependence, and helplessness, resulting in social avoidance, stereotyping, and discrimination (Edey & Robey, 2005; Goffman, 1963). Cooley in 1992 described "the looking glass self-theory," which elaborates on the processes wherein individuals base their sense of self on how they believe others view them. Using social interaction as a type of "mirror," people use the judgments they receive from others to measure their worth, values, and behavior (Cooley, 1992). In this light, people with disabilities may manage their condition in ways that protect them from being stigmatized by people in their surroundings (Morris et al., 2014). If this is not managed correctly, it can result in emotional problems such as anxiety and depression (Gilbert, 2007; Jahoda & Markova, 2004).

Tajfel et al. in their book "human groups and social categories," describe challenges associated with dealing with people who have a mental disorder. In this narrative, taking care of disabled individuals, especially those with severe mental illness, is thought to be a contribution to bring some social normalization, which is achieved through belonging to groups and establishing a policy for the society (Tajfel, 1981). Many people with mental illnesses are in a situation where they experience a conflict between the positive value of belonging to a group of other patients and the danger of stigmatization resulting from being identified with them (Hall & Cheston, 2002). The impasse between the need to belong and the danger of stigmatization is accentuated in small communities (Ekeland & Bergem, 2006). However, people who live in groups can easily cope with their situation through social and political actions, which can change social norms such as complaining to the authorities that they are being bullied (Jahoda et al., 2010). Other scholars have shown that people with intellectual disabilities can focus on nonstigmatizing personal characteristics to cope (Dagnan & Sandhu, 1999; Finlay & Lyons, 2000).

In 2001, Link and Phelan conceptualized a process by which stigma develops (Link & Phelan, 2001). Diverting from considering stigma as merely a mark (Goffman, 1963),

they imagined stigma as a process through which society navigates. They defined stigma as the association or co-occurrence of labeling, stereotyping, loss of status, and discrimination. Link and Phelan also pointed out that the social representations of groups can be stigmatizing, and that these social representations are often well understood by members of stigmatized groups themselves. People with ID and those with other forms of stigmatizing disabilities can cultivate positive social interactions like having employment, being a member of a church group, or self-advocating for their condition, which will help buffer the emotional damages of stigma (Dagnan & Sandhu, 1999).

Intellectual Disability and inheritance patterns have long been described in African cultures, but very few works have associated genetic concepts with current understanding in the African population (Raghavan & Small, 2004). In most African cultures, inherited forms of ID like FXS are usually attributed to interesting ancestral stories that follow an inheritance pattern. They may be related to stigma, gendered blame, or a curse (Meilleur et al., 2011; de Vries et al., 2020). The return of an FXS genetic diagnosis to a Cameroonian family in the rural part of the country unveiled several explanatory beliefs concerning the understanding of FXS and other forms of inherited intellectual disability in this community. To understand the stigma-power dynamic around FXS in Cameroon, we think it is necessary to examine the beliefs of people living with FXS and their social position. In this light, this exploratory study attempts to provide an insight into the dynamic relationship of stigma between families with FXS and the community in which they live. In this paper, we present findings from a rural community in Cameroon's western region formally described as having a high ID incidence and where an FXS genetic cluster was identified in the royal family (Kengne et al., 2020). We then elaborate on the different forms of stigma identified in this community and evaluate the strategies that community members and family members use to cope with stigma.

2 | METHODOLOGY

2.1 | Ethical compliance

Before starting this study, we obtained ethics approval from the Institutional Committee for Health Research (no. 698/CIERSH/DM/2018) in Yaoundé, Cameroon, and the University of Cape Town's Faculty of Health Sciences' Human Research Ethics Committee (HREC: 782/2017). Written informed consent was also obtained from all participants who were legal adults, including permission to publish photographs. Then, administrative authorizations were obtained from the local traditional and medical authorities. Our study builds on a more extensive study, which aims at

exploring the impact of giving back a genetic result in a rural community. In this paper, we shall be focusing on the stigma component.

2.2 | Site and population

In this paper, we report on the stigma experiences of 86 participants who were either relatives of P0 or her community members. P0 was our initial patient, a mother of three children who received a diagnosis of FXS for her two kids in 2011 at the child neurology unit of the Yaoundé Gynaeco-Obstetric and Pediatric hospital, Cameroon. Information shared during her first consultation revealed that in the village P0 originates from, her children's condition was associated with a curse directed at the founder of her family, a royal chief. The community of P0 is found in a rural region of western Cameroon. This rural community is characterized by poor access to health services and severe economic limitations. With a population of approximately 2000 inhabitants, this rural area is historically known to be a locality with a high ID incidence. In 2020, 46 subjects from the royal family were clinically evaluated and screened for FXS, and 18 of them had a mutation on *FMRI* (OMIM 309550) (Kengne et al., 2020). Intrigued by the coexistence of traditional narratives to explain the inheritance of this severe condition and a modern genetic diagnosis, we sought P0's permission to conduct a qualitative study with her family and member of the community, to better understand how people in a rural African setting make sense of genetics and inheritance, and how this condition had affected the family and the community.

Of the 86 participants, 58 were community members, while 28 were members of P0's extended family – which is the royal family in this village. Two selection criteria were used to include participants in the study. Firstly, individuals 18 years and above who were either resident of the community of P0 or members of her extended family were included in the study. Secondly, individuals who were knowledgeable about either FXS or the issues surrounding ID in the village were recruited. The demographic characteristics of the family and community groups are shown in the table below (Table 1).

2.3 | Procedure

We used a semistructured questionnaire to guide the conversations with all the different participants through 20 in-depth interviews and nine Focus Group Discussions (FGDs). Before scheduling an in-depth interview, the first author spent several hours with the participants, either in their homes or workplaces, to gain confidence and let the

TABLE 1 Socio-demographic characteristics of participants

	Family	Community	Summary
Number	28	58	86
Sex			
Male	11	16	27
Female	17	42	59
Mean age	47.8 years	38.4 years	41.5 years
Age range	28–69 years	18–81 years	18–81 years
In-depth interviews	16	4	20
Focus group discussion	3	6	9

interviewee know that private information will be treated in strict confidentiality. In addition to building a trust relationship, the first author thus also obtained insight into the participants' way of seeing life, which provided a better understanding of the data context and how to facilitate dialogue flow. On the other hand, participants for focus group discussions were recruited after participating in a family reunion organized by the family of P0. Moreover, announcements were passed in churches and marketplaces to sensitize and inform community members that a research team was in the community to discuss issues relating to inheritable diseases like FXS/ID in their community. Snowball sampling was used to recruit all the participants in the FGDs and IDIs. Most of the FGDs organized with the community (5/6) were organized in the church premises of the community of P0, where we could secure a room for the purpose. On the other hand, FGDs with family members were conducted either in their residences (1/3) or in a conference room (2/3) in the city where they resided.

The first author, who conducted all the interviews, had a list of topics to cover while promoting dialogue and allowing the participants to raise issues that they saw as necessary. The interviews were conducted either in French or English, depending on the interviewee's first language. However, in certain circumstances, some participants could not express themselves in any of the official languages preferring instead to speak Ngombale, the local language. Where this was the case, one of the research assistants who is a member of the community translated to English. With regard to the data presented here, the interviews covered participants' views on FXS, experiences of stigma, and coping strategies. We did not approach sensitive issues directly; instead, we used terms primarily accepted by the community and family members as less stigmatizing. "Alienate" was the term used to represent people with ID and FXS during our interviews. The IDI and FGDs lasted between 27 and 90 minutes. All the interviews were audio-recorded and transcribed verbatim.

2.4 | Analysis

All the transcribed interviews were imported in NVivo 12 (QSR International, 2020). The first step of the data analysis was a content analysis of the interviews to identify what the participants reported regarding their experiences of stigma and discrimination. Then these transcripts were analyzed qualitatively through the identification of themes (Braun & Clarke, 2012). This involved producing a summary of the views each participant expressed about stigma. The transcripts were then examined to establish the main themes that emerged regarding how the community and the royal family manage to cohabit in the face of stigma directed towards FXS.

3 | RESULTS

In our study, we encountered public and associative stigma relating to FXS. These stigmatizing beliefs and behaviors could be articulated either between P0's family and her community or remained solely within the family. In this light, stigma manifested partly in descriptions of the labels given to the parents of children with FXS or even to the royal family as a whole. We also observed stigmatizing behaviors through the interactions which members of the royal family had with their peers or the community. In the following, we shall illustrate the stigmatizing events in this community before describing the complex stigma-power dynamic that exists between the community and the royal family.

3.1 | Associative Stigma as experienced by members of the royal family

Few participants in our study described courtesy stigma. An associative stigma is a form of prejudice that people with FXS or families with FXS direct to themselves. Some participants described instances where they were discriminated against, or one of their children who has FXS had discriminatory treatment from others. A family member reports a discriminatory treatment that her sister lived with her children. She quoted:

I went to Yaoundé a year ago, the alienated child [child with FXS] took a rubber band and tied it on the cat's neck. The father of this child whipped him properly. What caught my attention was that my sister was in tears because her husband had beaten the son. She confides to me with great sadness that she did not choose to have insane children and went on to say that despite their condition, she still loved them. Her

husband had more preference for the cat than for his child.

(IDI family female 8)

Other healthy family members could associate with children who were suffering from FXS. Several royal family members described situations where they were marginalized in society just because they come from the royal family. More interestingly, during an IDI with a male informant from the family, he sorrowfully elaborated on the fact that FXS is affecting several generations of the royal family. He followed by saying he could have been happy if the condition was limited only to earlier generations and not passed onto the grandchildren. He reported:

There are several insults coming from others in the community. When you hear these insults, you can be demoralized, and it makes you uncomfortable to hear and see these situations. What have we not done up to date in our family to put an end to this evil? Unfortunately, it could still be limited in our circle, but it is not good when it crosses to go to the grandchildren. It hurts.

(IDI, family male 6)

3.2 | Public stigma directed at the royal family by the villagers

3.2.1 | Labels given to the royal family and people with FXS in the community

In the community where P0 lives, community members use specific labels to address people with FXS. These labels are collectively agreed upon and can quickly generate impressions and expectations of individuals who belong to families affected by FXS. Most of these labels describe the characters of people who have to be isolated due to their behavior or physical appearance. For instance, one mother who has two children with FXS reported that people in the community refer to her as "mother of fools." The common understanding of being a fool is that of a person who cannot think properly and cannot obey simple commands. This mother recounted her experience:

I would start with the negative effects of FXS. I have gone through a lot because of the stigma with which the society gives to such a situation, I have gone through it. Like people who call me "mother of fools," "mamy foul-foul," [mother of fools] meaning that I have given birth to fools. The stigma has been too much

(IDI family female 1)

Another name that is used to describe the royal family colloquially is “la'an Kuate”, translated as “the descendants of Kuate”. Kuate was the royal families’ founding father, who is believed to have cursed his daughters because they did not assist him in mourning one of his intellectually disabled servants. Hence “la'an Kuate” equates to “being cursed” – a powerful epithet in African communities that often signals stigma. Several community members recognize this label, and members of the royal family are conscious of this fact. One of P0’s relatives describes how people use this label:

You know that is kind of thing that the whole village, my village people, and then my husband's people know that we have those kinds of children from my mother's family. So, there is a way to refer to my mother's family as far as those kinds of children are concerned. In the dialect, we say “La'an kuaté” [the descendants of Kuate]

(IDI family female 3)

Some participants also described that others may use the term “Joujou” to describe individuals with FXS and ID. To them, “Joujou” is a representation of a frightful totem which is generally used during traditional ceremonies to scare children. This label is mostly related to the physical appearance of people with FXS and ID in the community. A community member during a FGD enlightened us on this character. He recounted:

It all starts with the mentality because when some children see this type of person, they can call him “Joujou,” and they run away. I think that often when we see people with FXS for the most part, they are always dirty, and when we see them, we always say that they are crazy.

(FGD 5, community, male)

3.2.2 | Stigma dynamics between the community and members of the royal family

Although villagers used stereotyped labels for people with ID and FXS, most villagers believe that FXS children from the chieftaincy should be addressed differently than nonroyal children with ID because of the former's position in society. During one of our focus group discussions with the community, we noticed a dynamic for how people named children from the royal family. The intellectually disabled children of the royal family were termed “rheureuh” while the term used to describe other children with ID was “Peuh.” “Rheureuh” and “Peuh” are used in the vernacular language to address individuals with intellectual disabilities, with Rheureuh being

used to describe a milder form of ID. We were subsequently obliged to adopt this appellation because the members of the FGD categorically dissociated themselves from calling children of the royal family “Peuh” or fools. We followed up on this discussion with other community members and recorded our observations in our field notes.

In the local language, “rheureuh” means a child who is an Alienate [child who is different from others], while “Peuh” means madness or fools. Informants reported that their children are not mad but somewhat alienated. They preferred that we used “rheureuh” in subsequent interviews. This is because “rheureuh” is “better” than “peuh” since you can take care and support a “rheureuh” until he/she even gets married while you cannot do anything for a mad man. This community respects traditional customs and will not like the royal family's name to be tarnished. Before adopting the name “rheureuh” for ID in the royal family, we had a harsh discussion with the informants up to a point where they threatened to withdraw their consent if we continue to use labels that can undermine the moral status of members of the chieftaincy. “Rheureuh” [alienate] was finally adopted as the term which will be used in subsequent interviews

(Field notes 15 October 2018)

Many people in the community would love to be part of the royal family. This could explain the fact that nearly all the women in this family are married. During an early conversation with a member of the royal family, he argued that “*they are not marginalized at all, and if that was the case, then there could have been several single princesses who are 30 years and above, and this is not the case*” (IDI, family male 5).

This royal family also uses its position in society to arrange marriages for their male children with community members, even when they know that the match is disadvantageous for the marital partner. Several family members are conscious of this situation. One of them described a circumstance that led to the marriage of one of their relative who is known to have FXS. She recounts:

The week we were in the village for the meeting, he [brother with FXS] saw a girl and the girl interested him; he told his mother that he liked this pretty girl. This is how we went to negotiate with her parents. With us in the chieftaincy, so many parents who are not of this line would like to be in the royal family. When anyone from the royal family asks for their

daughter's hand, they are immensely proud to join the royal family. So that is what this is about.

(IDI Family Female 8)

Furthermore, parents of children with FXS will tend to actively seek a wife for their male children because they do not want their in-laws to notice that their child has a disability. In most marriages with this royal family, the disability is mostly discovered only after marriage. According to local custom, it is difficult to untie a bond that has been made traditionally because of the shame that could occur. A family member recounted a situation that is known by several community members:

It seems that the marriage of the one [relative with FXS] who is here in Douala was arranged between the parents from the village. The girl did not know exactly how the guy was. He got married, and his wife left shortly after. It seems that it was the parents who arranged the marriage. The girl did not know how the guy was. When she got to him, she saw that he did not have all his senses, and they did not get along. So, she started threatening members of the royal family that she was going to leave. She could not leave because we had spent a lot to make her the wife of the insane guy. We endowed her; we did everything. She was ashamed to get up suddenly and leave after all the expenses that his family had made. And the girl's parents could not accept her coming back.

(IDI family Female 7)

Despite the advantages that one can obtain by getting into the royal family, another stigma-power dynamic was noticed between the royal family and the community members where the community members were seeking to have the upper hand over the royal family. Some interviewees from the royal family described instances in which a suitor in order to save-face sought to tarnish her and her family by describing them as a family where many children are developmentally delayed. Two females in the family quoted:

There is a gentleman who walked behind her [the elder sister of the informant] for a wedding... you often know when your heart does not accept a thing, you also have to make manners to go away. Later, to explain why it had not worked with my sister, the gentleman said that he had even been told that we give birth only to the insane in our family, which is why he left

(IDI, Family Female 7)

When I was still a student, I was engaged to a guy; in the meantime, I realized that I do not want to be with him, and I stopped the relationship. Later in the informal conversations, he said he broke up because he noticed that there are so many mentally ill people in our family.

(IDI, family female 8)

One way of understanding these quotes is that stigma is used as a means to gain some form of domination over (some members of) the royal family by people who are excluded from its power. For instance, in the case of the snubbed suitor, his inability to be part of the royal family could have led him to use stigma in an attempt to maintain domination over the girl. In other cases, family members described a perception that people seem to be of the impression that the girls from the royal family are easy to get as wives because they do not think. In our focus groups, we observed that when community members cannot be part of the royal family, they downplay family members.

3.2.3 | Stigma-power dynamic in the family

Importantly, we found evidence not only of stigma directed to the royal family by community members but also within the family. There were a few instances where family members emphasized their superiority to other family members with a lower IQ. A family male describes a situation that happened in their family.

Often when we pass, people say that the chief's sons are only insane. There was a time, one of the sons of the founder of the royal family insulted his brother by saying: "there are many alienates here in the chiefdom, but there are other alienated who think they are normal and who are well dressed."

(IDI, family, male 5)

This shows how stigma-power dynamics can occur in this family. This behavioral modification is to show their kin that they are superior to them. On another note, in families with many FXS children, parents discriminate among them by treating them better than those with ID, as previously reported.

4 | DISCUSSION

In this African community, people suffering from FXS have a double challenge. On the one hand, they struggle with symptoms and disabilities that result from FXS. On the other, they are challenged by the stereotypes and stigma resulting from the explanatory beliefs of FXS. Our findings

summarize some characteristics of stigma relating to FXS in a rural community of western Cameroon, which appears to be an FXS genetic cluster similar to what has been reported in Colombia by Saldarriaga et al., 2018. We outlined the stereotyping labels used in this locality before describing the stigma-power dynamic between the community members and the royal family.

In this community, the royal family is seen as politically powerful, and many people from the community may want to be part of this family. This creates a stigma-power dynamic between the royal family and her community. According to Link and Phelan (2014) and Phelan et al. (2008), power is a key feature of how stigma occurs and is maintained. Arguably the main aim is to push people down and out of society, thereby maintaining the current social order and preserving power. Phelan et al. (2008) argue that stigma keeps people in a socially subordinate position where they are compelled to accept low pay, substandard housing, or inefficient health services, and is more effective when it is covert or implicit (Phelan et al., 2008). Link et al. in 2014 suggested that when there is no rapport of power; it merely means there is no stigma (Link & Phelan, 2014). We described that given the royal family's position, several community members seek to challenge or erode the royal family's power when they cannot be part of the royal family. Others articulated that this royal family should be given the respect they deserve by providing less derogative labels to affected princes and princesses from the chieftdom. One way this strategic function of stigma in the community is evidenced is through the different terms community members applied to ID occurring in the royal family – which they named 'RheuRheu' – and ID occurring outside of the royal family – which was called "Peuh." Some participants described that the first condition was less stigmatized than the latter, which could suggest that, in this case, the community tried to affirm the political power vested in the royal family.

On another note, the royal family, to maintain their social position, use their status to negotiate marriages with community members. Several observations reveal that the family needs to resort to "tricks" to get spouses for its affected males, actively bringing to bear the strong incentive for people to marry into the royal family because of the access to power and privilege that it brings.

4.1 | Clinical implication

Phelan et al. (2008) suggested that to reduce stigma, we must have a thorough understanding of stigma's function, which in our case was to either keep people away from FXS or keep them down through domination and exploitation. Concerning disease-related stigma, this can be nurtured by automatic emotional reactions. However, familiarizing with

the condition can reduce this stigma. This may be associated with desensitization, which can be seen after being exposed to evolutionary phobias as reported by Kolodziej and Johnson (1996) who support this argument by suggesting that personal contact with people with the disease is a decisive factor in the reduction of stigma (Kolodziej & Johnson, 1996). Papadopoulos in 2016 argued that experiencing stigma could be minimized by focusing on reducing associative and internalized stigma (Papadopoulos, 2016). Thus, the identification of stigma is essential because the stigmatized individuals develop coping strategies to become resilient. The coping strategies can be improved by the education of the people surrounding them. We can argue that knowing the cause of a condition may bring relief from stigma, especially when the disease in question is not contagious, like in the case of FXS. Also, offering early genetic counseling for FXS and psychotherapy services through peer support groups to families at risk of experiencing stigma can provide emotional support. In these groups, caregivers will share their experiences, which can be regarded as an early form of intervention.

4.2 | Conclusion

In our concluding note, we can say that our work has made progress in understanding FXS-associated stigmas and its interaction in an African rural community. This was through the description of the public stereotypes translated through discriminatory behaviors in this rural African community with a high incidence of ID. At the same time, we have described a complex stigma-power dynamic between the community members and the royal family. Given that this is the first qualitative study exploring stigma related to FXS in Cameroon, we advocate that other researchers examine whether the same pattern exists in other inheritable forms of ID and conduct more qualitative research on FXS in Africa.

4.3 | Study limitation

In our study, we focused on the views of participants about stigma in the community. We rarely interrogated participants' perceptions of the social structure that makes up their society. Besides, understanding society's social customs and the meaning participants give to these norms are essential components when exploring stigma in a complex society like in our study. In this light, researchers should think of introducing this component in their interview guides.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests. The funders had no role in study design, data collection, and analysis, decision to publish, or preparation of the manuscript.

AUTHOR CONTRIBUTIONS

KKK: Design, data collection, interpretation, and writing; NSM: Interpretation and writing; SN, JDV, AW: design, interpretation and writing.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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