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THE SOCIAL REPRESENTATIONS OF RARE DISEASES IN CAMEROON: A DESCRIPTIVE PHENOMENOLOGICAL STUDY OF TEN MOTHERS OF CHILDREN SUFFERING FROM A RARE DISEASE IN YAOUNDE

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ABSTRACT: *Rare diseases (RD) are challenging complex and sometimes novel health events that give rise to numerous interpretations in society. RDs have very low prevalence and the majority do not have treatments. They are chronic, debilitating and may lead to premature death. Moreover, most of these diseases do not have specific names in many cultural lexicology, making them to be viewed as an abnormal phenomenon. In many cultural areas, a normal disease is one that is known, mastered and especially treatable; when a disease is resistant and persists despite actions engaged to manage it, like RDs, it becomes mysterious and suspicious. The aim of this paper is to describe the social representations of RDs in Cameroon. In this light, data presented here were obtained by applying a qualitative inquiry method which allowed us to explore in-depth descriptions, explanations and narrations of the experience of mothers who have children suffering from a RD. Ten (10) mothers were met in Yaounde through a patients' organization and they were selected using a non-probability (purposive) sampling from November to December 2021. The theory of social representations by Jodelet was utilized to determine the genesis of knowledge constructed on RDs in Cameroonian context.*

KEYWORDS: Social representation, rare disease, Cameroon.

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INTRODUCTION

RDs are complex health events that cause numerous challenges to families and healthcare systems. They are defined as conditions that affect fewer than 1 person in 2,000. According to the Rare Disease Act (Public Law 107–280 November 6th 2000: 350): *“Rare diseases and disorders are those which affect small patient populations, typically populations smaller than 200,000 individuals in the United States. Such diseases and conditions include Huntington’s disease, amyotrophic lateral sclerosis (Lou Gehrig disease), Tourette syndrome, Crohn’s disease, and cystic fibrosis, cystinosis and Duchenne muscular dystrophy.”* There are approximately 7,000 known RDs worldwide, with new diseases being identified each year. These diseases are challenging and very little is known about them and: *“although they do seem rare, it is estimated that 6–8% of the world’s population, i.e., approximately 300–350 million people, are affected by RDs”* (Domaradzki, 2022: 1). However, the definition of a RD varies from one country to another, thus *“Unlike the EU that established a single prevalence for all its member states, in Latin America, there is no consensus in the definition of RDs, and each country uses a definition through its own national regulations or public policies.”* (Encina et al., 2019: 1). In Cameroon *“there is no visibility of these diseases”* (Ngoumou et al., 2023: 479) due to the fact that *“there exists no official definition of what a RD is, making the issue ambiguous and difficult to master”* (Ngoumou et al., 2023: 479). Beyond the uncertainty associated with the definition of rarity, the availability of high-quality epidemiological data on RDs remains very limited in Cameroon. In the absence of this information, coupled with the limited understanding of many specific RDs, the population level burden of these conditions is difficult to estimate. Drawing on these facts, it is important to recognize that while each RD affects only a small number of individuals in the population, collectively, these diseases present an important public health challenge and causes many social hardships to families. In fact, they cause a lot of social disorders and conflicts in family dynamics so much so that the participation in social life for PLWRD remains very challenging and difficult.

RD patients are isolated, rejected and stigmatized because most of these diseases are associated with changes in physical appearance that are uncommon or unfamiliar to the public. PLWRDs also face numerous challenges due to gaps in knowledge about their disease and how to manage it. This poses a huge threat to the equitable future for PLWRD because in this case they are not directed to places where they can be taken care of appropriately. Ngoumou and Djouda Feudjio (2024: 2) talking about the impact of RDs on patients and families shared that: *“The challenges they face are numerous and they impose severe impacts on the family and society structure and hamper social development and individual fulfillment.”* These hardships faced by patients and families are linked in particular to the way society interprets these health conditions. In general, they are viewed as supernatural events and persons affected by these diseases are managed following what the disease is believed to originate from. In effect, according to Jodelet, our representation of an event determines our actions and decisions towards that event. In general, the way individuals give sense to these health conditions is by attributing names to them. In effect, as Moscovici puts it, by naming a thing: *“We extricate it from a disturbing anonymity to endow it with a genealogy and to include it in a complex of specific words, to locate it, in fact, in the identity matrix of our culture”* (Moscovici, 2000: 46). The process of naming these diseases gives rise to different interpretations that constitute the backbone of the social representations of these diseases. The logic behind the naming system of these diseases gives us an ideal vantage point to penetrate in the social and imaginary universe of individuals to better understand how they view these events and also how they

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“treat” them. Therefore, the aim of this paper is to describe how Cameroonians perceive these diseases and what they attribute as causes of these diseases.

MATERIALS AND METHODS

The study used a qualitative inquiry method. This approach allowed us to explore in-depth descriptions, explanations, and narrations of the experiences of mothers caring for a child with an RD. Ten mothers were enrolled and informed consent to take part in the study was obtained from each of them. Participation was based on voluntary and informed consent. Participants were also reserved the right to withdraw from the study at any time they desired. Data were collected through semi directive interviews with key informants. These interviews were conducted using a voice recorder where permission was secured. Notes were also taken during interviews. Ethical principles were respected throughout the study. Anonymity of respondents was ensured and they were given codes in place of their real names. The theory of social representations was utilized to understand how causative factors attributed to rare diseases contribute in giving a certain status in the Cameroonian society.

RESULTS

Sociodemographic Profile of Mothers

Ten mothers were included in the study. They all lived in Yaounde and belonged to a patients’ organization where they tried to create coping strategies to alleviate their daily hardships. Also, all of them were single mothers and were the sole caregivers to their children in many cases where family did not assist them. Nine of the ten mothers became single immediately their child was born and presented abnormal physical features. In most cases, the mothers told us that the fathers of the children refused to identify themselves with such ‘abnormal children’ and accused the mothers of witchcraft. All interviewed mothers talked about financial hardships related to the daily care of their child. In fact, they were unable to ascertain a fixed monthly revenue. Concerning their level of education, very few had a university degree, while most of them had at least secondary school level education. All interviewed mothers were of christian faith and their age range was between 24 years and 45 years.

Cultural and Social Diseases

Certain forms of disease like RDS are viewed as cultural and social diseases because it is believed that the majority of them occur due to the violation of established social and cultural norms by either one or both parents. These norms include feeding habits during pregnancy, the respect of social roles and functions, marriage systems, etc. In effect, women who give birth to children with RDs are believed to have committed a fault especially as the children may present physical traits that are uncommon in ‘normal’ children. The presence of such a child in a family is very often accompanied by unending conflicts and even their physical appearance is enough proof that a norm, be it cultural, social or religious, has been violated. In our explorations with some mothers, it appeared that many RDs are viewed as a violation by women of cultural norms defining gender roles and functions. It is accepted in many cultural areas that at a certain age, women should be preoccupied by marriage and child bearing instead of social and professional aggrandizement. Therefore, women who are not concerned about these at a certain age are viewed as abnormal and might expose themselves to sanctions. Such women are those who had their first child at an advanced age. One informant, talking of a relative who has a child suffering from a RD, says: *"She was a woman who did very long studies and never thought of marriage. They kept on telling her to get married but she never considered that option. She instead went to Europe to continue studying and when she returned from there, she came back with mental illness; she was mad."*

According to this informant who also had a child suffering from Down syndrome, her relative had a child with Down syndrome because she did not think of settling down for marriage or bearing children but was only concerned about her studies and personal aggrandizement instead of building a family in time. She adds that, she ended up having folic crisis which can be considered here as a sanction for not respecting gender roles and functions. She further elaborates talking about her relative by saying: *"She spent a greater part of her time looking for money and comparing herself to men instead of settling down as it is expected of every woman."* In the view of her relatives, the health condition of her child is a consequence of violation of socio-cultural values. Her ignorance of the sexual division of social functions, as defined by cultural and social norms, caused her to have an abnormal child. Thus, there is a strong belief that diseases that are strange and that happen especially to children are closely linked to faults, that they are a sign that a rule has been violated. If no reparation is done, it is believed that the family will go through repeated misfortunes that extend to any person directly associated to the woman. The results showed that RDs generate multiple conflicts in families and society as most of them have very strange symptoms.

Mystical Diseases

In the absence of clear guidance of what an RD is, many families conclude that these conditions are supernatural. When they occur, they are usually cases of the family justifying why at times they are regarded as mystical. Indeed, most mothers we interviewed testify that they had never come across such diseases until they had to experience them with their own child. The effect of the novelty, strangeness and confusion it brings in a family gives rise to their association with witchcraft. Any child born with a strange condition is seen as a violation of traditional belief systems by the mother and causes her close relatives and family to suffer from ambivalent reactions. This view is further consolidated by the fact that they are chronic and usually cause early deaths in children. When a young child dies in many Cameroonian cultures, it is viewed as an ill omen for the family's prosperity. Furthermore, the majority of RDs are without treatment; they cause long-life disability to affected persons and in many cases even health practitioners do not know how to address these diseases. Also, the fact that in many cultural areas there are no local names for many of these conditions makes them to be viewed as exterior attacks, events oriented and created to cause harm. This is made easy to believe because these diseases are chronic and most especially significantly modify the life pattern of others in the life of the concerned person. A mother whose child suffers from Down syndrome recounts: *"Before I was transferred here (Yaounde), I was in Nkongsamba. I had an accident; it was only later I remembered that I fell from a bike when I was eight months pregnant. When I came back to Yaounde, I was told there are a lot of witchcraft practices in Nkongsamba. There was an old man there who used to sit at a junction; they said he threw something evil on my unborn child that made him to be deformed at birth. So, these things, when people tell me, I consider them."*

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From the statement of this mother, it is obvious that she does not believe her child's health condition is a natural disease. She readily believes what her social environment tells her about the probable mystical origin of her child's disease which is a rare and strange thing to happen to a child. This shows that Africans in general and Cameroonians in particular are not prepared to have a sick child. The child is viewed as a blessing and fragile who is exposed to numerous evil practices if not well protected. In fact, they are the gateway to a family, a medium through which evil forces penetrate to destroy a family's dynamic. This is a very common belief in many African societies that view diseases as events that are not natural.

Diseases Stemming from Occultic Practices

Certain strata of the population believe that RDs only attack persons of sophisticated social class and/or persons who get involved in ritualistic practices to get wealthy. The social opinion is dominated by the idea that not all riches a man or woman accumulates in society is obtained through the right way. The consequence of such practices leads to a succession of tragic events in a family line among which can be the birth of sick children often leading to early death. Children who present signs and symptoms of a RD are therefore seen as children who have been sacrificed either by their own very parents or relatives to acquire wealth. This was highlighted by a mother who informed us that: *"In general, it said that they are children to whom the disease has been thrown, 'spoilt children.' It is someone in the family who wanted to be rich and then he sacrificed someone in the family."* This shows that, in general, when an RD affects a child, it is always correlated to the social status of their parent(s) or relatives. The unexpected social ascension of a parent or relative for the popular opinion is regarded as suspicious especially if they have children who present some abnormal physical features.

This has further implications on the well-being of the child who might suffer maltreatments. In this case, the child is viewed as a potential offence to the normal family cohesion and might go through various forms of violence as this parent narrates: *"That type of child is a wizard. Is that type of child even normal? If I see such a child here, now I will push it away from me. That type of child is the totem of a home, while everyone else in the house sleeps at night, he keeps the house. And you will notice it is very common among rich couples, and they will buy a whole car to drive it wherever it wants, in school. I am telling you, that type of child is a sign of witchcraft. The theories of chromosomal malfunctioning are not even valid here; it is witchcraft."*

This is enough evidence that children with RDs are viewed negatively in Cameroonian society. They are believed to be evil or simply a negative totem that binds their parents to a certain lifestyle. These children therefore become unwanted and rejected implying that RDs are viewed as malpractices. Therefore, the social status of a family is always correlated with a child's condition. When the family of the child is wealthy, it is believed their wealth is not 'simple.'

Consequences of Incestuous Relations

RDs are also viewed as diseases that originate from incestuous relations between persons of the same bloodline or same clan. In this sense, having sexual relations with a family member or with someone of the same clan usually causes children to be born with severe physical malformations and complex health conditions. In this study, we came across a mother to three children all suffering from RDs and congenital malformations. They had Down syndrome, hydrocephaly and a congenital malformation of the leg. In her quest to figure out ways to help her children, her social environment began to suspect that the union with her husband could be incestuous. She recounts that: *"People started saying that my husband and I have the same blood that is why we have sick children. I could not believe that, because before marriage my husband and I ran a series of premarital tests. The results were good; they told us we could have children without any problem, so I don't know."* In many cultural areas in Cameroon, the marriage system is exogamous, meaning marriage ties cannot exist between persons belonging to the same ethnic group.

DISCUSSION

The long-lasting disability they cause and the disruptions they cause in the lives of the carers of affected persons can cause negative social representations of these diseases. This assertion corroborates the view of Gruenais who says that every disease that is persistent and difficult to treat will lead to the interpretation of this one as evil or an attack by evil spirits (Gruenais, 1990). This points out the fact that religious and cultural beliefs have a significant part in the social construction of RDs as a social phenomenon. Blanc (1999), distinguishing internal and external diseases, says that external diseases are those that are linked to immoral social practices or the violation of a prohibition that can be punished by evil. The author further adds that to effectively get rid of such a disease, the intervention of a shaman (witch doctor) is required. This was highlighted by Pritchard who, after observing the Azande people, concluded that any event that occurs out of the 'normal' is usually viewed as witchcraft. The author explicitly says that: *"If blight seizes the groundnut crop, it is witchcraft; if the bush is vainly scoured for game, it is witchcraft (...) if, in fact, any failure or misfortune falls upon anyone at any time and in relation to any of the manifold activities of his life, it may be due to witchcraft"* (Pritchard, 1976: 63). RDs are uncommon and hard to treat, making them quite strange and confusing. Many families who come through a RD usually do not have any experience with them. This can cause them to speculate on their origin and meaning. In fact, this is common with many RDs in families as stated by many studies.

In many families, as the ones met during this study, they were unaware of most RDs before their relative or child came down with the condition. A similar view was mentioned by Marsh et al. (2011, p. 348), talking about sickle cell disorder in children. They highlighted that, in most cases, prior to their child's condition, many parents had not heard about the disease. This is very common with many chronic RDs and only contributes to complexifying them. The effect of novelty greatly contributes in constructing the negative social representations that surrounds them. In effect, RDs can cause patients and their families to be stigmatized and discriminated because of the physical alteration these diseases cause to their victims. Their parents can also go through many accusations that hinder their fulfillment in society. The existence of (sexual) relations within the same ethnic groups can lead to several misfortunes in the lives of individuals such as the birth of severely ill children. Thus, RDs in some cases is also believed to be the consequence of incestuous relations. In effect, according to Tolra (2010), incestuous relations are the root cause of many misfortunes in the family line. They are often manifested through miscarriages, stillbirths, congenital malformations or premature death of children.

CONCLUSION

The social representations of RDs in Cameroon are negative and contribute to the labelling and construction of long-lasting stigma of PLWRDs and their families. The constructed knowledge that surrounds these diseases indicate that society, communities and families do not have substantial knowledge on these diseases. There is a need to raise more awareness on causes, risk factors, care and treatment options of RDs in society to build knowledge on these diseases that do not cause society to reject and marginalize PLWRDs and their families. This suggestion therefore engages partnering strategies to establish multi-stakeholder work between RDs patients' organizations and across healthcare systems and authorities to effectively address the issue of RDs in society.

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