

# Design and Cultural Treatment of Trisomy 21 in R.D.Congo

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**Abstract:** *We are getting interested in the ethno psychiatry of the Down syndrome. Each society has his way to conceive and comprehends reality of the running life. In general Africa and D.R.Congo particularly, the cultural design of trisomy 21 differs from others. Several explanation and opinions are given on this abnormality. Families have tendency to disguise victims of the Down syndrome so that everybody should not see them. So, what is the design and the treatment of this syndrome in Congolese cultures? The goal is to reveal then describe the design and the treatment of the Down syndrome in different cultures of Congo. The Down syndrome would be apperceived as curse, witchcraft, or jinx and the treatment reserved to the victim would be death, mockeries, insults and other sorts of maltreatment. In the following lines, we are going to show the cultural design of trisomy 21 according to different cultures of the D.R.Congo especially in the following cultures: Pende from Bandundu, Bangu-Bangu from Maniema, Songue and Luba from the high Lomamie, Lulua from western Kasai, and Bufuliri from south Kivu, Hema and Tabwa from Tanganyika, Tchokwe and Sanga from Lualaba, finally, Bemba from high Katanga.*

**Keywords:** trisomy 21, design, cultural;

**Methods:** investigation of psychosocial, descriptive;

**Technics:** Maintenance, questionnaire

## 1. Pende Culture

### Cultural design

In the Pende tribe, the trisomy 21 is named "Giyulu"; this term translate the chromosomal disease without precision from which the patient affected shows several clinical signs such as mental retardation, psychomotor retardation, etc. Pende people perceive the victim as a carry woe of the family cause of not respecting the nature and cultural rules, shortly. This abnormality is considered as God's punishment.

### Cultural treatment of trisomy 21

In this culture, trisomy 21 or any other chromosomal abnormalities are cured in two ways:

Traditionally, our forefathers had a place called "bingi" which was reserved only to those victims, for they had a belief according to which **Giyulus** have ancestors of food, that is why they should not be mixed up with others. To say this, **Giyulus** were distant from their families and they were fed at distance.

For the treatment of these victims, forefathers were using trees such as "lusambi, lusuki and muheta"; they were taking peels of trees those which they were burning together to get a drink, and roots of the tree called "lusemu" to chew up in other to make them grow in a good way. It is only after these ceremonies, they will be brought back in the village. Of our days, in the case of failure, pende people resort to prayer in other to draw up victims

## 2. Songue Culture

### Cultural design

For "Basongue" people trisomics are called "TSHILENGALENGA" which means: without value, bully.

He is the result of several mystic problems among which we tell of: witchcraft and jinx.

### a) Witchcraft

How is it possible that trisomy 21 would be witchcraft? Here the example of the selfish hunter of games who doesn't share with the people of the village especially with those of the surrounding. For this hunter, it is probable that the child descending from his union might have congenital malformations similar to trisomy 21; mostly if his surrounding is made up of wizards and that his wife is pregnant. In this case it is not only neighbours who are responsible of this disease, but also members of his family if they do not profit of anything.

### b) Jinx

They can cast a bad spell on the family sometimes cause of her misdeed, most of the time if the wife is not respect full towards people, she can even disrespect a notable or a chief customary, who are capable of casting a bad spell on them "wife and husband" wich is going to resound with their offspring. In the case of a thief women and she breaks in to houses or fields of others in other to take things without any permission, this can cause this family to have a trisomic 21.

### Treatment

In our culture there is two sorts of treatment of trisomy 21:

- **In the family** : when there is the birth of a "TSHILENGALENGA", the family stays near him no matter what is his disease, the family shows affection to him. Even if the family can charge people of this. In this culture, they do not hurt the trisomic child in other to kill him as is the case of other cultures. On the other hand, he has his place in this family. He (the trisomic) can have privilege on hardware plan concerning dressing, feeding and other things which other children would have so that

he will not worry or to feel mistreated cause of his disease.

- **In the surrounding** : the treatment reserved to trisomic by neighbours, “ autochthonous of the village” who are not from his family, is different from that of his own family, instead of being respected and honored by his surrounding, they push him away, avoid him and forbid their children to play with him. For them, this disease is transferable, the must not approach him. Let’s say that, besides the good treatment given to him by family, the outside people (neighbours) reserve him a bad treatment.

**Therapeutic strategies:** to avoid repetition of such disease in the family, the custom get involved in this matter, it means that the chief of the clan and notables of the village gather together and call members of the concerned family them:

- If they have transgressed standards in other to be purified
- If the wife has the habit of eating forbidden food “snakes, lizards etc...”?
- If one of spouses does not respect notables, the chief customary, chief of the clan etc.?

After this evaluation, the will make ceremonies not with purpose to heal the “Tshilengalenga”, him, he will be sick but ceremonies will be made with his parents to avoid the repetition of the disease in the family. Let’s note that they will make this ceremonies only in the case of relapse to mean; if only had at least two (2) or (3) “Tshilengalenga” and not only one.

### 3. Tchokwe culture

#### Cultural design

In Tchokwe language, trisomic people are called “Tshiepuke” which means “remembrances of the fruits of unhappiness”. A T 21 was considered as a curse for the family, the tribe, which result from not respecting customs or disobedience to family law.

He’s also considered as punishment of the god of the tribe in the case of a man committed adultery with the wife of someone else or again the of parents who have misbehaved, he is considered as the result of a jink, or if the wife reversed to the family reconciliation, there is a big likelihood that she give birth to a “Tshiepuke”. The victim had no consideration in clan, he was considered as incapable, a villain without intelligence.

#### Treatment

To cure a “Tshiepuke” is something difficult. In Tchokwe culture, the “Tshepuke” was hidden in the house or separated from other children so that he would not be seen. If it is the chiefs of clan who were taking control of him.

### 4. Bangu-Bangu Culture

#### Cultural design

Bangu-Bangu » culture has a particular way to conceive things, her particular way of living, of expressing herself and other things. In this culture, the trisomic child is called “Kizezi” or “Kiluba Luanyi” in the case where he was born

sick but “Chingi” is given to the person who was born normal, but further to some circumstances of life (jinx, curse, fetish etc.) shows the same symptoms of a trisomic born.

Indeed Bangu-Bangu people consider that the child is born trisomic by the will of the Supreme Being, here, the disease is considered as any other handicap as for example a blind or a deaf and dumb in other to show the will of the all mighty or for maleficent source, this conception is scattered in many different ways and it is the most frequent and prevalent, we are going to explain some figure without taking all the list, or transmission of the offspring.

Trisomy considered from a maleficent source

- Trisomy considered from a maleficent source: this first figure is explained by hatred in case of a person who does not good relationship with others, as consequence, they cast a bad spell on the family and there is a pregnant women for example, it is probable that she gives birth to a trisomic 21 child, if it is a man, he is the one who is going to be the victim.
- The second figure is due to transgression, the fact of not respecting customs, or the opposition at a cultural order, or again the fact of not respecting cultural interdicts is a predisposition at that curse.
- The third figure is due to sacrifice, for example someone who consults a witchcraft in other to be rich by sacrificing his offspring, the person can make a vow to witchcraft in other have only “Kizezi” children.

The treatment of these victims concern acquired trisomics “chingi” and not “Kizezi”, ceremonies or rituals are made in other to cure them: they dig a hole which looks like a tomb, they lengthen him the “Chingi” inside, on the top they put woods, sands they build the fire, after this ritual, the person is healthy. Many ceremonies like this are performed.

### 5. Luba Culture

#### Cultural design

Concerning his appellation, this disease does not have a specific term cause of the lack of strict diagnostic and indefinites symptoms which should make difference between T21 and other mental or chromosomal diseases.

Indeed, our researches have shown us different names of trisomy 21 at Luba people: “Kivila”, “Kapone” and “Kilubi”. This allow us to discover different confusions on trisomy 21. From explanation that we had, we find out that the term which design very well trisomy 21 is “Kivila” for “Kilubi” means in Luba language “crazy” or mental sick and “Kapone” someone who has a big head.

Luba people from Malemba-Nkulu consider that trisomy 21 has diabolic origin from which we can name witchcraft, taboo (the fact of not respecting traditional conventions or traditional engagement), magic, and curse due to crime against the tradition, human sacrifice..., some people talk about the anger of God punishment for a sin etc.

Almost in the same idea, the wisdom of Malemba-Nkulu shows and enters that trisomy 21 is a difficult to name but

easy to interpret by uncertain and less important illusions and hallucinations.

They are sometimes considered as villains and are a burden for the population. The population has to work to make the community developed but their presence blocks up the work of some. The pathology, cause of its diabolic origin (witchcraft, fetishism etc.) cause families of the victims to have difficulties to make relationship with her direct environment.

Our researches show that trisomics are not welcomed in the territory of Malemba-Nkulu and that our society has a bad social consideration of this disease, for every child showing signs and symptoms of this disease ought to be killed.

Somehow, the luba community of Malemba-Nkulu does not have a retrain center nor a formation to social life for these victims, for them, it is impossible to educate or retrain them, they are the most searching the origin of this disease. For our community, the application of modern treatment is difficult for this can work only if all parents of the victim are dead because the origin is hidden "Bibitshampe" all is about witchcraft and others.

### **Treatment**

In our Luba tribe, the efficient contribution to the trisomy 21 is the religious or traditional treatment. Le treatment is religious if they turn back to the servants of God such as priests, prophets etc..., the treatment is traditional when they turn back to "bavidje" or witchcrafts. And they believe on their effectiveness on the disease.

These days, a T21 is considered as a villain, someone who does not warrant anything to the society and who is not useful in the communal life. Some sectors of this place want to kill every new born affected by this disease by injection of toxic products or to bury him alive, this technic is possible only at two conditions which are: if the pathology is not known and the impossibility of healing the disease or/and if that is approved by the parents the victim. Victims who have the good luck to survive and to grow up with this disease in territory, have no considerations in the community even if authorities of this place are fighting for the respect of the duty of their citizens.

## **6. Hemba Culture**

### **Cultural design**

Trisomy 21 in Hemba is called Ilegelege (Kilegelege) it means the one who has incurable malformations. It caused by: witchcraft and curse.

It's a curse or a jinx due to the fact of not respecting interdicts or taboos such as: "the pregnant wife or her husband should not steal, beat, insult parents", the fact of not respecting this interdicts generates often physic or psychic malformations. The presence of this disease in the family, it is way punishing, interpellate, to correct or to make suffer for the bad things committed by the parents genitor of this child.

### **Consideration and treatment of the victim**

The presence of trisomy 21 in the family, is a suffering, a useless and unbearable burden for the family. That is why, in order to abolish and delete traces of this abnormality, wise men the village had ceremonies they were doing : to kill the victim, to chop and burn him in the bush pronouncing words to the victim so that he will not come back in family.

When these ceremonies are performed, nobody (parents, members of the family) should not cry nor regret or worry in order to avoid the relapse (the return of this pathology in the family).

## **7. Lulua culture**

### **Cultural design**

For Lulua people, trisomy 21 is called "TSHILENGULENGU or TSHILUA or again TSHITATAKENE": who has dreadful physical look. According to the custom, it forbidden to look at the victim, to have prejudices, to mock or to spit saliva on the ground when we are before him so that you should be yourself a victim in his procreation.

According to our researches, these victims are a curse or a result of disobedience to given standards or the transgression of customs by one of the parents of the victims. This human being was considered as jinx thrown against the family.

Besides these causes, we they recognise that at the conception, one the parents was drunk, others thin that the child is sacrificed by one of the parents in order to get richness, to mean that one of the parents made fetishes and has sacrificed the intelligence or the spirit of the child, then the rest (body) is fucked, this is the "Tshilengulengu".

Some else, it is the mother (the wife) who is the origin of this monstrous birth, in this sense that she did not like children during her youth or she was bearing babies or the children of her neighbours with a lot of disdain or with insults, disregard, mockeries or again when was pregnant, she did not love and have consideration of children of others. Or she was mocking pregnant women and was thinking that pregnancy was disgusting and could spit seeing a pregnant woman and there will many questions about this subject. They are considered as keepers of fetishes capable of keeping secrets of the master, they were also considered as bad spirits who lived long ago on earth and who by their wickedness have been expelled by the Supreme Being in order to up with the punishment of God. Brief, they are considered as the result of the bad things done by their parents.

### **Cultural treatment of the victim**

A trisomic baby, should not be presented to the public (members of the family, neighbours, acquaintances etc.) for fear that the news should not be diffused, if necessary, the victim was killed or forsaken just after the birth.

Survivors did not have place in the society, their place was behind the house and they would never be presented as sons and daughters of the family.

They could not be registered at school because that seemed to be a waste of money.

## 8. Bifuliru culture

### Cultural design of trisomy 21

In the bifuliru culture, there are two kind of Bifuliru people: bifuliru people from the mountain and bifuliru people from the plain, given that we are from the plain, our research had concerned only bululiru from the plain.

Bifuliru people from the plain call trisomy 21 "Kizeze", which means a living being without importance, nor intelligence and one who cannot bring anything to family. They conceive trisomy 21 as a result from following actions or facts:

- When a young man get married to wife older than him;
- When a man misbehave (or commit adultery) when his wife is pregnant;
- Witchcraft in the family (members of the family who put a spell on other people in family who have the family tie)
- The fact of not respecting cultural standards for example, a wife who eats testicles of the bull or the male goat.

### Treatment

The treatment was not made in other to find a solution but rather to adapt them to some situations. They were doing it two ways according to whether the family is rich or not economically. Rich families were going to see a healer and poor ones were using leaves of the trees called Mubirizi and Katundulo:

- a) For rich people: the was digging a hole, then they were extending the victim in that hole then they putting pigtails on the top of hole invoking sinister spirits. After that, they were taking the victim in other to tattoo him and put on theses tattoos the powder of the root of tree called Kilondolondo.
- b) For poor people, they were going to take leaves of the tree Mubirizi near the source of the river. Those which they are warming up to give a drink to the victim, and the leaves Katundulo tree, which was used to purge the victim, after, the were putting the victim in the loincloth build in shanty shape with a cooking pot containing hot water made of katundulo leaves. This treatment came to nothing but it allowed members of the family and the surrounding to accept to be in touch with the victim without having any bad thoughts about him.

## 9. Tabwa Culture

### Cultural design

In Tabwa culture, trisomy 21 is called "Kalubi Katalala" who they consider as a meek crazy.

Causes: Tabwa people considered trisomy 21 as a curse for the family and this could happen only when a pregnant woman was robbing, or is she has accredited the pregnancy to the person who was not responsible of the pregnancy, or again if during the pregnancy period the wife disrespected her mother in low, etc.

### Treatment

The victim Kilubi Katalala considered as a curse, this was laying down not only on the family, but upon all the community which was touched, so the only option to be taken was to kill the victim by suffocation in other to end this malediction, that is reason that Batabwa people would not see Kalubi Katalala.

Actually with the coming of Christianity and globalization, the authority of the state, and charters of men right not only tisomics but also other mental or physic handicapped are lightly accepted even if they still being mocked and often misunderstood, few are those who the chance to find education in specialised centers, but until now (2015), our territory of Moba no specialised center is accounted for mental handicapped at least that of physic handicapped in occurrence SHALOOM center.

## 10. Sanga culture

### Cultural design

In Sanga cultural design, a normal person cannot have a trisomic child, to have him would be a curse. For Musanga people, they should not get married no matter how or to no matter who, doing so, would a risk of having a birth of a trisomy 21. This was a punishment to those who were not respecting customs or cultural standards. It is for example the case of married woman who commit adultery and is finally pregnant, if she cheats her husband saying that the pregnancy is his, she can give birth to a trisomic who will not live longer.

In the Sanga culture, the trisomy 21 is called "Kilemafwe, Nganse". Kilemafwe means a mental or physic handicapped to whom we find the characteristics of a T21 which makes him different from albino and crazy.

The Nganser: is someone who was normal at birth but while growing up he started to manifest the same symptoms shown by the Kilemafwe. Basanga people say that Nganser is the result of witchcraft, of this fact, he is considered as a living dead called "MUFUWENDA".

The taboo or interdict lead according to Sanga culture to trisomy 21, it the case of:

- The wife or the husband cannot dispute with the brother in low, the sister in low the mother in low or the father in low (brief; the wife must have good relationship with his family in low):(concerns relational aspect);
- They should not have conflicts or quarrels with the community.

For the wife:

- A pregnant woman cannot eat dog, swine, caiman, crocodile, tortoise (food hygiene)
- A pregnant woman cannot walk in the sunshine for example on 12 o'clock (body hygiene)

For the man:

- If he steals things of others
- If they find him committing adultery with the why of someone else



### **Treatment**

Having a Kilemafwe in the family is a curse that is why, when in the family there is a birth of a Kilemafwe, he is thrown the river called “Dijibadyakaelwa” in other to avoid relapse and the transmission this pathology. After, they have to keep him out of the village calling the chief customary for rites and ceremonies which result to nothing. At present, the Kilemafwe is considered as every child, no matter what his pathology, his insufficiencies and characteristics, was they understood that he is a handicapped like any other handicapped.

## **11. Culture Bemba**

### **Cultural Design**

In our culture, every handicap is considered as a curse, a jinx, or a sacrifice. Moreover, psychiatrics pathologies were not scientifically well diagnosed or categorised, all were assimilated to cursed or sacrificed persons. In our culture, trisomy is called “IKINGULYALY”.

### **Treatment**

The treatment was made at birth by the grandfather who was calling all the family for reconciliation, after that, they were calling the witchcraft in other to take control of the victim with hope to recuperate him which would be a success. With the coming of Christianity, many run back to the men of God in other to be exorcized, others run back to nuns so that they would place them into a boarding school in other to get rid of them (IKUNGULYALY).

## **12. Conclusion**

The trisomy 21 which is scientifically a chromosomal abnormality, defined by the presence of an extra chromosome at the twenty first pair, our researches show that it is the result of the curse, of sacrifice, of witchcraft, of jinx, of God’s punishment, etc. cause of many reasons such as the fact of not respecting de nature or customs, for this fact, different treatment are reserved in our culture and it depends of the conception of each tribe or ethnic group about this pathology. So, the most frequent treatment was to stave off the victim from his family or to kill the victim in other to avoid relapse.

In what precedes, we think that psychoeducaton of the Down syndrome to the Congolese population has to be accounted for in other rectify their conception of the pathology and their consideration of the victim.

### **List of students having participated to the research**

Kinaka Gisupa, Mitutu Sekele, Kabangu Mukonkole, Twite Kamalondo Albert, Rachidi Tshisedi, Ngoie Kalomba Fifi, Kibamba Sehenu, Tshishipela Tshamala jean Mariel, Mwanza Jean-Marie Miradji, Mambwe Mbolyo, Kaifndo Kanyata, Kilumba Tondo and Capimba Cabala all of them student in the first graduate of clinical psychology of the year 2014-2015 under the direction of Mrs.KALENGA NONGOLOLA Noëlla chief of works at the faculty of psychology and educational sciences of the university of Lubumbashi in D.R.Congo.

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