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# SUSCEPTIBILITY FACTORS AND FAMILY RESILIENCE IN INTELLECTUAL DISABILITY OF CHILDREN WITH DOWN SYNDROME: PERSPECTIVES OF SOME MARRIED INDIVIDUALS

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## ABSTRACT

This paper examined the various factors in Intellectual Disability, and family residence with special focus on Down's syndrome type. A descriptive survey research design was employed in the study. Simple random sampling technique was adopted to select 291 participants from Ibadan, Oyo state (150 males and 141 females). Two research questions were raised and multiple regression analysis was used to anelyse the data collected from the administered validated Down Syndrome Type Questionnaire (DSTQ; $\alpha$ = 87). The results obtained, revealed that independent variables (chromosomal abnormalities, mother's age, heredity, ignorance in marriage incompatibility and environmental agents) when put together, yielded a co-efficient of multiple regression 0.37 and multiple correlation square of 0.247, this indicated that 25% of the total variance in participants disposition to Intellectual Disability of Down's Syndrome type is accounted for by the combination of the five variables that is significant at 0.05 level (f 95.502; P, 0.05). Also, each of the independent variable except environmental agents made significant individual contribution to the prediction of Intellectual Disability of Down's syndrome type. The researcher reported a correlation between mother's age and Down syndrome incidence, hence, it was recommended that prospective mothers should get pregnant before the age of 35 years. Equally emphasized is the importance of medical tests and other preventive measures towards curbing the incidence of Down's syndrome in the family.

**Keywords:** Chromosomal abnormalities, Down syndrome type, environmental factors, family resilience, intellectual disability

## INTRODUCTION

Intellectual disability refers to a sub-average general intellectual functioning and adaptive behaviour. Major causes of intellectual disability include genetic condition, environmental agents at prenatal, peri-natal, and post natal stages of development, mother's age, chromosomal abnormalities, and ignorance on marriage incompatibility. Children with Down syndrome are at risk of considerable deficits in intellectual functioning (i.e., low intelligent quotient, delay learning and impaired language development), and by implication these children face various health challenges including learning and memory deficits, congenital heart disease, Alzheimer's disease, leukaemia and cancer (Adediran, 2011).

Down syndrome is named after John Langdon Down, who first described the condition in 1866. He wrongly attributed the condition to some ancient Mongolian ancestors, and as such, people used the term Down syndrome and mongolism interchangeably to describe children suffering from mental retardation due to chromosomal anomalies.

Research findings and laboratory records had shown that chromosomal anomalies majorly contribute to the problems of Intellectual Disability in children with Down syndrome, Adima (1981) reported the discovery of the first human chromosomal aberration which was

made public by Lejuna and his colleagues in 1959. Ever since, the discovery of chromosome analysis was employed extensively in the diagnosis of Intellectual Disability. Accordingly, any aberration of chromosome whether numerical, structured or multiple is included under chromosomal anomalies.

The incidence of Down syndrome, according to Plomin, Defries and McClean (2015) is evident clinically among aged mother and they are of three types namely; non-adjunction type, traslocation type and mosiacism type. According to them, the implication of chromosomal anomalies to Intellectual Disability is somewhat complex. Human beings normally have 46 chromosomes in all; that is 23 chromosomes from each parent, but when the number exceeds 46, the result is abnormalities in individual. Any child born with 47 chromosomes will be intellectually disabled; this is no-disjunction type.

During sexual intercourse, if a man releases three, rather than the conventional two chromosomes, (i.e. X47), the extra chromosomes released will result into intellectual disability. It is unusually occurs in 21st chromosomes. When this happens, the man is deemed to be a victim of Trisomy. On the other hand, if a woman releases three chromosomes instead of the conventional two, that is, XXX chromosomes, it means the woman is a victim of translocation type which usually occurs on the 15th chromosomes.

The mosaicism type however, occurs when the extra chromosomes is found in some cells of the body and not in the others. Children of this type usually have fewer physical signs of the condition. There is abundant evidence to indicate that heredity plays a part in the causation of Down's syndrome. Human genetic abnormalities are common, involving as many as half of all human fertilization. This is confirmed with the findings of Francis Galton in the latter part of $19^{th}$ century, as he solidly supported the fact that birth defects were hereditary. According to Galton, while exceptional intellect was "hereditary, so too were feeble minds and criminal tendencies (Rao, 2017).

The effects of these aetiologies in Down's syndrome are the manifestation of different pathological features of mongoloids, that is, physical observable signs and clinical symptoms which are sufficiently pronounced to enable easy identification of children with intellectual disability. Thus, Cleland (2018) gave vivid description of the feature of a mongoloid; They have almond-shaped slanting eyes, flat face and nose, large and deeply issued tongue, irregular and misshapen teeth, snail skull, protruding belly, undeveloped genitalia and disproportionately small legs and arms. The height of an adult Down's syndrome does not exceed four feet about two third of Down's syndrome are imbecile and the remaining one third are idiots.

When a child with Down's syndrome is born into a family, couples think of all sorts of errors of omission or commission they may have committed. For example, the mother may think she was a little flirtatious, or that she ate a forbidden food during pregnancy or probably she contravened a natural law. More often than not, these thoughts are mere-imaginary than real (Obani, 2014). Obviously, the presence of children with Down's syndrome in the family may bring about chronic sorrow and possible family disintegration if the burden becomes intolerant to the parents and even relations. To this effect, Obani (2014) observed that suspicion, quarrels, guilt feelings and apportioning of blame often dominate the lives of the affected couple. The parents may conjecture all sorts of reasons for being robbed of their perfect child. Their social life may breakdown, due to fear of interacting with other members of the community. Neighbours are suspected for malicious actions and witchcraft; Doctors, nurses/midwives are blamed for carelessness during delivery. All these are psychological reactions which are quite usual and normal as long as they are temporary, and it would however, give way sooner or later.

Kar (2016) pointed out that parents of children with Down syndronme may develop guilt complex and exhibit glaringly over advanced age. Also observed, is that as a result of over protection, the child would be eliciting a type of behaviour characterized by dependent style of interaction. However, over protection, and denial may cause adjustment difficulties for such type of children.

In a typical African country, Ufford (2017) pointed out that families with a child with Down's syndrome face problems caused by superstitious beliefs that surround the birth of this handicapped child into the family, thus, parents are regarded as being wicked and being punished with the birth of the handicapped child because of the sins they might have committed against the gods. Accordingly, societal ostracization may arise when neighbours at times stop visiting such a family, thus, culminating into their social withdrawal from the society to avoid embarrassing comments and negative societal reactions to them.

Apart from these psychological effects in the family, there are other basic problems that go with the birth of the child with Down's syndrome. Ajobiewe (2010) explained basic problems that are associated with that physical care of the child which may be more demanding, and that may require energy and patience, especially of the mother. For instance, a child with Down's syndrome may not achieve bowel or bladder control as quickly as non-retarded child. This means more patience would have to be bought to bear and more time would be required in personal hygiene. Also obvious is financial implications, a child with Down's syndrome may need medical attention that may be expensive. He or she may require specialized equipment which has to be paid for. Other expenditure includes the cost of placement in a special school with boarding facilities. Further added in the management of a Down's syndrome is the suggestion of Obani (2014) when he mentioned the use of some child guidance or assessment centres, Special Schools and Rehabilitation centres that are springing up in different parts of Nigeria. These include Federal College of Education (Special), Oyo; Department of Special Education's Child Clinic, University of Ibadan, Child Guidance Centre, Yaba, Lagos; Rehabilitation Center, Moniya; among others.

Kar (2016) asserted that aged mothers are prone to having children with Down's syndrome, as such, medical examination through testing whether the foetus in the uterus is a mongoloid or not is now possible. Amniocentesis can be carried out, as the child in the womb would be injected and the fluid taken to the laboratory for testing. The result would show whether the child will be a mongoloid or not, thus, the couples have the choice of therapeutic abortion of the pregnancy or preserve it for nurturing.

In his suggestion in the prevention of Down's syndrome incidence in the family, Shield (2018) recommended genetic counselling as a method for the prospective couples by seeking medical counselling of blood group identification and union suitability. Thus, if one of them is detected to have extra chromosome that can produce Down's syndrome, it is left for them whether to call off the marriage or to go ahead.

**Statement of Problem**

The effects of having children with Down's syndrome in the family is not something pleasant, obviously, it is an experience every parent would want to run away from. But once this situation occurs in the family, parents should come to grip with the situation and accept the child as a family member just like other children.

The incidence of Down's syndrome is increasing and has devastating consequences on the families. This study was concerned with factors in Intellectual Disability of Down's Syndrome type and also examined family resilience pattern of some selected married Individuals in Oyo state, Nigeria. Although, genetic counselling is relatively new in Nigeria, it

may be said that ignorance has greatly affected families that they do not consider genetic counselling important. With this in mind, the research problem can be safely focus on the factors that predisposes that having Down's syndrome babies in the family and that when it happens, how would the family adjust with living with such a child.

**Research Questions**

Two research questions were raised in this study. These include;

1) What is the joint contribution of the independent variables (chromosomal aberration, ignorance, age of the mother, heredity and environmental agents) on the outcome measure (Down's syndrome)?
2) What is the relative contribution of each of the independent variables on the dependent variable (Down's syndrome)?

## METHODS

**Research Design**

The study adopted a descriptive survey research design. It seeks for knowledge of the aetiologies and prevention of incidence of Intellectual Disability of Down's syndrome type with implications on the family adjustment.

**Sample/Sampling Technique**

The participants used for this study consisted of 291 men and women selected through simple random sampling technique from Ibadan, Oyo state, Nigeria. They comprised of men, 150 (51.55%) and women, 141 (48.45%) females. Their ages ranged between 17 and 45 years with a mean age of 31 years.

**Instrumentation**

The instrument used for this study was a validated questionnaire tagged "Down's Syndrome Type Questionnaire, tagged (DSTQ)". The participants responded to the extent that they understand and perceive some itemized aetiological factors in Down's syndrome, and family disposition. This was placed on 4 point Likert type scale ranging from 1 – not at all informed, 2 – fairly informed, 3 – well informed, to 4 – adequately informed.

**Psychometric Property**

To test for validity and reliability of the instrument, it was validated by the experts in Special and Rehabilitation Education Department, University of Ibadan and medical practitioners from Paediatric Department, College of Medicine, University of Ibadan to establish its content and face validity. The consistency of the instrument was determined using co-efficient alpha and reliability estimate of 0.76.

**Data Analysis**

In analysing the data collected, multiple regression analysis was adopted to determine the susceptibility of independent variables on dependent variable.

**RESULTS**

**RQ 1: What is the joint contribution of the independent variables (chromosomal aberration, ignorance, age of the mother, heredity and environmental agents) on the outcome measure (Down's syndrome)?**

**Table 1: Summary of Multiple Regression Analysis between the Predictor Variables (chromosomal aberration, ignorance, age of mother, heredity and environmental agents) on the outcome measure (Down's syndrome)**

| Multiple R (Adjusted = .371<br>Multiple R2 (Adjusted) = .247<br>Standard error of estimate = 7.1264 | | | | | |
|---|---|---|---|---|---|
| Source of Variation | Df | Sum of Square | Mean Square | F Ratio | P |
| Regression | 2 | 465.100 | 4850.136 | 95.502 | .000 |
| Residual | 289 | 19173.400 | 50.785 | | |
| **Total** | **291** | **24377.188** | | | |

Going by the result presented in table 1, the five independent variables (chromosomal aberration, ignorance, age of the mother, heredity and environmental agents) when put together yielded a co-efficient of multiple regression of .371 and multiple correlation square of 0.247. This showed that about 25% of the total variance in participants' disposition to Intellectual Disability of Down's syndrome type is accounted for by the combination of the five variables. The table also indicated that the analysis of variance of the multiple regression data produced an f-ratio value significant at 0.05 level ($F_{(2, 291)} = 95.79$).

**RQ 2**: **What is the relative contribution of each of the independent variables on the dependent variable (Down's syndrome type)?**

**Table 2**

| **Predictor** | **Unstandardized Co-efficient** | **Standard Co-efficient** | | | |
|---|---|---|---|---|---|
| | B | SEB | Beta | **t** | **P** |
| Hereditary factor | .199 | .091 | .036 | 2.167 | <0.05 |
| Ignorance factor | .122 | .078 | .021 | 3.183 | <0.05 |
| Environmental factor | .99 | .056 | .107 | 1.742 | >0.05 |
| Chromosomal aberration factor | .259 | .189 | .149 | 4.248 | <0.05 |
| Age of the mother | .693 | .161 | .147 | 4.234 | <0.05 |

From the result displayed in the Table 2 above, each of the independent variables, except environmental agents made significant individual contribution to the of Down's syndrome which represented the relative contribution of the independent variable to the prediction were observed. Chromosome aberration factor (β = .149; 4.248; P < 0.05), age of the mother (β = .147; 4.234; P = < 0.05); Environmental factor (β = .107; 1.742; P = > 0.05); Ignorance factor (β = .021; 3.183; P = <0.05) and Hereditary factor (β = .036; 2.167; P < 0.05).

Although, four variables made significant relative contributions to susceptibility factors in of Intellectual Disability of Down's syndrome type, chromosomal aberration factor made the greatest contribution followed by age of the mother factor, environmental factor, then ignorance factor and lastly hereditary factors of Down's Syndrome type.

## DISCUSSION

From the result displayed in Table 2 above, each of the independent variables except environment factors makes significant individual contribution to the prediction of Intellectual Disability of Down's syndrome type, and family resilience, chromosomal aberration makes highest contribution followed by age of the mother, then ignorance factors and hereditary factors. Chromosomal aberration factors (Adima, 1981; Shied, 2018), age of the mother factor (Kar, 2016: Plomin, Defries, & McClearn, 2015), Ignorance factor (Obani, 2004; Ufford, 2017), and hereditary factors (Plomin, Deefreis, & McClearn, 2015; Rao, 2017) all makes significant relative contribution to susceptibility to Intellectual Disability of Down's syndrome type. These findings are however in line with previous but recent research findings.

### Recommendations

It is suggested in this study that prevention is preferred to treatment and rehabilitation of Down's syndrome children. With evidence of statistical analysis that revealed that there is a correlation between the mother's age, genetic aberration, hereditary, ignorance and Down's syndrome incidence, public enlightenment programmes should be introduced, as a matter of urgency to inform parents or prospective couples to have children before the age of thirty-five years and the expectant mothers to visit antenatal clinic.

If parents suspected that their child is mongoloid, they should subject him or her to a medical check-up first. If possible, they should seek the guidance of psychological centre to ascertain the degree of mental retardation. If it is confirmed that the child is a mongoloid, they should face the problem courageously and with determination, they should provide the child with basic security needs with love, affection and avoid apportioning blame to anybody or exhibit anxiety and confusion, which may persist long after the child has been diagnostically confirmed. They should think and take step on how their child can be enrolled in an educational environment where he would be placed and received educational benefits placements in a special school.

## CONCLUSION

Intellectual Disability of Down's syndrome type is not an illness or disease to be treated but an unexplained error in replicating DNA, genes and chromosomes at the earliest stages of embryo development. This study was able to establish that there is a relationship between age of the mother and risk of having a child with Down's syndrome, the older the mother, the higher the frequency. Though, children with Intellectual Disability of Down's syndrome are at an increased risk for certain medical conditions such as congenital heart defects, respiratory and heart problems and thyroid conditions.

However, antenatal screening, avoidance of reproduction at advanced maternal age, pre-implantation genetic diagnosis for couples and genetic counselling are essential towards reduction or elimination of having children with Intellectual Disability of Down's syndrome type.

Although, the law of probability method in counselling was advocated, that is, minus times minus is equal to plus (- x - = +) in Mathematics. This law is transferable to counselling

before marriage. In this case, a lady with extra chromosome would be advised to look for man who is also a carrier of extra chromosomes to marry. Hence, both of them are negative and their product would be Down's syndrome free (Adima, 1981).

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