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ORIGINAL ARTICLE

Experience of Mothers of Children with Down syndrome at the Cocody University Hospital (Côte d'Ivoire)

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Abstract

Introduction: Down syndrome or trisomy 21 is the most common chromosomal aberration and the leading cause of intellectual disability in the world. It has complex repercussions on the lives of children and their families.

Objective: To describe the experiences of mothers of children with Down syndrome.

Methods: This was a prospective descriptive study from April 1, 2019, to January 31, 2021 (22 months) in the medical genetics unit of the Cocody University Hospital on children with trisomy 21 and their mothers. The descriptive qualitative approach was used. Data were collected using clinical interviews with mothers.

Results: Thirty-nine mother-child pairs were included. The average age of the mothers was 37 years and that of the children was 12 months. The sex ratio was 0.7. The diagnosis of Down syndrome was announced by a health worker in 87% of cases. In 77% of cases, the mothers knew that the disease would lead to mental retardation. Several psychological reactions were noted when the diagnosis was announced, namely the desire for protection (92.3%), refusal of the diagnosis (51%), feelings of guilt (25.6%) and depression (30.8%).

Conclusion: The announcement of the diagnosis of Down syndrome is followed by a difficult psychological process for mothers that require multidisciplinary care including psychosocial support.

Keywords

Down syndrome, Family care, Children disabilities

Introduction

Trisomy 21 (T21) or Down syndrome is a chromosomal disease defined by the presence, in part or in total, of an extra chromosome on the 21st pair leading to intellectual deficit and various malformations and morphological anomalies [1]. T21 is the most common chromosomal aberration with a global incidence of 1 case/700 births and the leading cause of intellectual disability in the world [2]. Antenatal screening is possible today with the realization of the fetal karyotype. The indications are based on ultrasound measurements (nuchal translucency, craniocaudal length), the dosage of serum markers, maternal age. The fetal karyotype is performed from maternal blood in which circulating free fetal DNA for trisomy 21 is detected [2]. Overall, in Europe, over the period 2011-2015, 54% of mothers resorted to medical termination of pregnancy after antenatal diagnosis of T21 [3]. However, a large disparity has been noted between countries with abortion rates estimated at 20% in Portugal, 50% in Germany, 68% in France and 83% in Spain [3]. In Côte d'Ivoire, antenatal screening is not systematic, and the high cost of fetal karyotyping is a barrier to its implementation. However, when the diagnosis is made antenatally, medical termination of pregnancy remains a taboo subject due to its socio-cultural impact. At birth, the announcement of the diagnosis

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of T21 plunges the family into shock and dismay at the prospect of uncertain neurological development [4,5]. However, the child with Down syndrome develops like any other ordinary child but in a slower way. For this, he needs to be stimulated, encouraged and supported by his parents who will be the fundamental pillar in his development [4]. The aim of this study was to describe the emotional, psychological and social experiences of mothers of children with Down syndrome.

Methods

The study took place in the clinical genetics unit of the Cocody University Hospital (CHU). It was a prospective descriptive study that spanned the period from April 1, 2019, to January 31, 2021 (22 months). A qualitative approach was used to describe the parents' experience. The study population consisted of mothers of children with Down syndrome whose age was between 0 and 10 years. Included were mothers with a child diagnosed with T21, living with the child daily. The non-inclusion criteria were mothers who did not have regular interactions with their child or mothers with adult children. The sampling was exhaustive. Data were collected during individual clinical interviews with mothers to gather testimonies about their experiences. The data were collected using a survey form. In each case, the social status, the circumstances of discovery of the disease, the announcement of the diagnosis and the social and psychological repercussions were studied. The psychological repercussions (anxiety and depression) of the parents were assessed respectively by the Hamilton scale and the Beck scale. The first has 14 items rated from 0 to 4 which cover all the sectors of psychic, somatic muscular and visceral anxiety, cognitive and sleep disorders [6]. The anxiety score was obtained by adding the scores for the 14 items. The second consists of 13 items that are presented in the form of four propositions rated from 0 to 3 [7]. The depression score was obtained by adding the scores for the 13 items as follows: 0 to 3: no depression; 4 to 7: mild depression; 8 to 15: moderate to moderate depression; 16 and above: severe depression. To assess coping strategies, the Brief-COPE was used. It measures 14 dimensions of psychological adaptation, each dimension comprising 2 items. These 14 dimensions assess all the distinct scales of adaptation: active coping, planning, and instrumental support, and emotional support, expression of feelings, positive reinterpretation, acceptance, denial, blame, humor, religion, distraction, substance use, and behavioral disengagement [8]. Participant data were anonymized, and no identifiable data were collected or entered the database. Data entry and analysis were done using SPSS version 23 software. Quantitative data were described by means, while qualitative variables were described by proportions. Confidentiality and privacy of participants was preserved. Informed consent was obtained from participating mothers before starting the interviews. They were informed of their rights (anonymity, right to withdraw from the study at any time, etc).

Results

This study aimed to describe the experience of mothers of children with Down syndrome. Thirty-nine mother-child pairs were received. The average age of the mothers was 37 ± 4 years (range: 18 to 45 years). Those who were over 35 years old represented 77%. Among them, 4% had a primary education level, 80% had a secondary education level and 16% had a higher education level. The socio-economic level was low (63%), medium (26%) or high (11%). The average age of the children at the time of diagnosis was 12 months (range: 1 month to 3 years). The sex ratio was 0.7. Regarding clinical signs, delayed psychomotor development was observed in 80% of cases. Cardiac ultrasound showed complex heart disease (25.6%) or an atrioventricular canal (26%). During follow-up, death occurred in 20.5%, secondary to complications of heart disease. The diagnosis of trisomy was announced at an average age of 12 months by a pediatrician (87%). The content of the announcement included several concepts such as trisomic facies (77%), malformation (2.6%), suspicion T21 (15.4%) and finally abnormal child (5.1%). Mothers' knowledge about T21 was dominated by mental retardation (76.9%). Figure 1 presents mothers' knowledge about the disease.

No psychological support was provided after the announcement.

The information received had a marked psychological impact with 31% of mothers presenting depression. This was mild (4 cases), moderate (5 cases) or severe (3 cases). Anxiety was also found in 60% of cases. It was either mild (8 cases), moderate (2 cases) or severe (2 cases). The different reactions of the mothers are shown in Figure 2.

The mothers' coping strategy was overprotection (92%), sadness (66.7%) and denial (51.3%) (Figure 2).

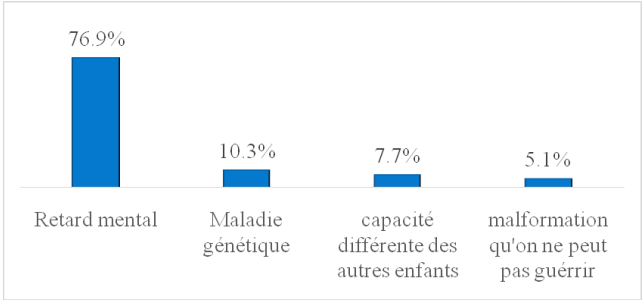

Figure 1: Distribution of mothers according to their knowledge of T21.

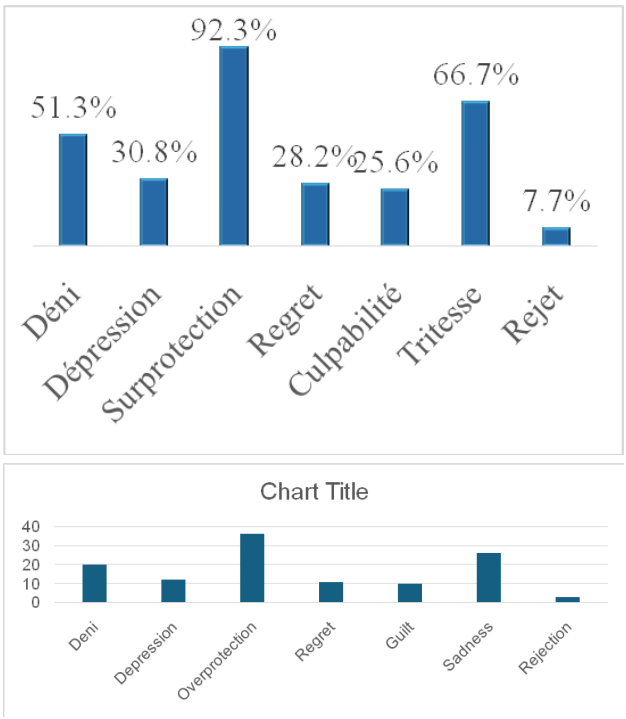

Figure 2: Distribution of mothers according to their psychological reactions after the announcement.

Discussion

This study describes the experiences of mothers caring for their children with Down syndrome. In Côte d'Ivoire, the arrival of a child with Down syndrome leads to relational disruptions sometimes due to the social representation of the child with Down syndrome. These children nicknamed "snake children" or "bad luck children" are considered a curse, devaluing both the patient and the parents. This consideration is a source of stigmatization and discrimination making it difficult to inform those around them [9]. This withholding of information by mothers is due to the fear of rejection and mockery [10]. This result in different psychological pathways including 31% depression and 60% anxiety reported in this series. Such an observation had been reported by authors [9,11]. The announcement of T21 can be traumatic for parents when it is not well conducted. According to some authors, the announcement should be made by a pediatrician in the presence of both parents to avoid abandonment [12]. There would be a behavioral difference between the way the diagnosis is announced and the way it will be experienced by the parents. The doctor will have to gather all the information on the disease to respond to the parents' concerns [13]. The announcement in this series was made late at around 12 months of age. This could be explained by the absence of prenatal diagnosis on the one hand and on the other hand by the fear of doctors to announce the diagnosis to the parents and to respond to their concerns. The role of the psychologist within the system of announcing to the parents takes on its full meaning, because it allows accompanying the parental couple in the work of psychological development, in addition to the information provided by the health personnel. Its participation favors the establishment of an initial contact and the establishment of a bond of trust [14]. It helps parents accept the illness, which is more necessary for the quality of follow-up as some parents initially go into denial. In this study, 51.3% of mothers had refused the diagnosis because they did not expect to have a child with Down syndrome. Normand had made the same observation [15]. Denial is a normal defensive attitude that parents present to avoid admitting the diagnosis. It comes from the fact that the child with Down syndrome does not correspond to the imaginary child expected by the parents. It is considered, by some authors, as pathological if it lasts. It is important for the doctor to help the parents to come out of their denial, to have their collaboration for better care of the child [15]. The role of the psychologist is also to work with the parents on the relationship they build with their child, a relationship weakened by the announcement, particularly about the protective function of the mother. The announcement can have an impact on the mother's confidence in her ability to be "a good mother" [14]. It is then useful to bring out the major anxieties which can accentuate feelings of guilt felt by certain mothers and to support them in building a secure and invested parent-child bond [14]. Self-blame and regret is coping strategies. They were found in 25.6% and 28.2% respectively. For many of them, it was a punishment from God for their behavior (anger at the husband during pregnancy, family tension, poor diet during pregnancy). Some authors had reported this feeling of guilt felt by many parents of children with disabilities [16-18]. However, it is important to weigh the frequency of depressive and anxiety disorders reported in this study. Indeed, mild depression and anxiety were present in 33% and 34% of mothers respectively, constituting warning signs or transient reaction symptoms rather than a major depressive or anxiety disorder. The scales used as a diagnostic tool in this study only provide snapshots at a given moment. Their results are less precise than those of an assessment conducted during a clinical interview. In any case, it is important to draw attention to these signs and to promote psychological care for mothers through early support. This type of adaptation would be encouraged by the uncontrollable nature of the disease.A disabled child causes parental stress, especially for the mother. Social support is effective in reducing parental stress. Data show that the physical and mental needs of these children as well as the time and energy required to care for them constitute challenges for mothers [19].

Conclusion

The announcement of the diagnosis of Down syndrome to mothers is followed by a difficult psychological process. It is a period of turmoil and

doubt for parents, which requires multidisciplinary care including psychosocial support. Genetic counseling could lead, while waiting for the adoption of a national policy for screening for aneuploidies, to an antenatal diagnosis based on ultrasound, serum, cytogenetic or even molecular arguments with the prospect of a medical termination of pregnancy.

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