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Stigma, caregivers and the child with Down syndrome: a bioethical analysis

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Abstract

The aim of this study was to analyze the perception of parents of children with Down syndrome about social stigma and reflect on the theme in the light of bioethics. This study consists of the elaboration and validation of a measurement instrument whose pilot test had 106 participants. Results showed the stigma creates feelings of inferiority on those affected, causing social disadvantage, unemployment, decreased financial resources, non-acceptance, intolerance, social invisibility, less access to health services and worse quality of life. This generates negative effects on the parents' health. It was concluded that stigma is present in society, so public policies that raise awareness among parents and guarantee their right to health are required. Despite being another element of illness, stigma should not be underestimated.

Keywords: Social stigma. Caregivers. Down syndrome. Bioethics. Human rights. Right to health.

Resumo

Estigma, cuidador e criança com síndrome de Down: análise bioética

Objetivou-se analisar a percepção de pais de crianças com síndrome de Down acerca de estigma social e refletir sobre o tema à luz da bioética. Trata-se de estudo de elaboração e validação de instrumento de medida cujo teste-piloto contou com 106 participantes. Os resultados apontaram que o estigma inferioriza os afetados, acarretando desvantagem social, desemprego, diminuição de recursos financeiros, não aceitação, intolerância, invisibilidade social, menor acesso a serviços de saúde e piora da qualidade de vida. Isso gera efeitos negativos na saúde dos genitores. Concluiu-se que o estigma está presente na sociedade, e por isso faz-se necessário formular políticas públicas que conscientizem os pais e garantam seu direito à saúde. Reconhece-se que apesar de ser mais um elemento de adoecimento, o estigma não deve ser subestimado.

Palavras-chave: Estigma social. Cuidadores. Síndrome de Down. Bioética. Direitos humanos. Direito à saúde.

Resumen

Estigma, cuidador y niño con síndrome de Down: análisis bioético

El objetivo era analizar la percepción de los padres de niños con síndrome de Down sobre el estigma social y reflexionar sobre el tema a la luz de la bioética. Se trata de un estudio de elaboración y validación de un instrumento de medición en cuya prueba piloto contó con 106 participantes. Los resultados señalaron que el estigma inferioriza a los afectados, lo que conlleva desventajas sociales, desempleo, disminución de recursos financieros, no aceptación, intolerancia, invisibilidad social, menor acceso a servicios de la salud y el empeoramiento de la calidad de vida. Esto genera efectos negativos en la salud de los padres. En conclusión el estigma está presente en la sociedad, por lo que es necesario formular políticas públicas que concienticen a los padres y garanticen su derecho a la salud. Hay que reconocer que a pesar de ser un elemento más de enfermedad, el estigma no debe subestimarse.

Palabras clave: Estigma social. Cuidadores. Síndrome de Down. Bioética. Derechos humanos. Derecho a la salud.

Research

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In pediatrics, Down syndrome or trisomy 21 (T21) is the most common chromosomal alteration and the main cause of intellectual disability. This genetic condition confers specific physical characteristics and leads to delay in neuropsychomotor development. However, if stimulated in specific ways, people with T21 have potential and are prolific [1].

Although no official statistics exist, it is estimated that about 300,000 people with Down syndrome live in Brazil, where a child with T21 is born every 600 to 800 births, regardless of ethnicity, gender or social class [1]. Scientific advances and improved care have led to greater survival of these children, whose life expectancy has gradually increased – a trend that should continue as medical science develops [2].

Care is essential for children with Down syndrome, and this role has generally been exercised by parents, whose anguish begins at diagnosis. The health team does not always inform parents correctly, and it is not easy to receive this news, being commonly associated with negative feelings. This occurs due to the social meanings and beliefs of parents in relation to disability, especially intellectual disability [3].

Studies show that ultrasound plays an important role in the screening of fetal chromosomal abnormalities, and the measurement of nuchal translucency is a well-accepted method for this purpose. Despite not providing an undoubted diagnosis, this test has been widely used in clinical applications due to its low cost, safety and non-invasiveness [4]. However, since the discovery of cell-free fetal DNA in maternal plasma in 1997, new approaches to noninvasive prenatal testing have been used to screen T21. These tests can be done early and are accurate and safe [5].

It is noteworthy that in some countries with access to noninvasive prenatal diagnosis and elective termination of pregnancy due to fetal chromosomal changes allowed by law, the prevalence of Down syndrome in live births is considerably lower [6], demonstrating the strength of stigma in societies in which children with T21 do not even have the right to be born. Discussion on the theme of stigma was inaugurated by Erving Goffman's pioneering essay [7], *Stigma: notes on the manipulation of deteriorated identity*. From this work, contemporary researchers have defined the term in several ways, usually referring to the literal meaning of Goffman [7] and, for this reason, have been criticized over time.

In response to this conceptual variety, a modern conception was proposed from a sociological perspective, and is now widely used in the literature. This contemporary concept relates stigma to the convergence of five components: initially, the population distinguishes and "labels" human differences; then, cultural beliefs associate labeled people with a set of undesirable characteristics that form negative stereotypes; these individuals are then placed in different categories and social labels separate "us" and "them"; labeled people lose prestige and suffer discrimination, leading to unequal results; finally, the exercise of power concretizes stigmatization [8]. Stigma, thus, may pose a risk to the health of the individual beyond any possible deficiency or deficit. Although it is only one factor among many that influence the health of those affected, the stigma cannot be disregarded [8].

In this context, parents of people with T21 – in general, their primary caregivers – are at risk of becoming ill, as raising a child with disabilities can be challenging, although many parents report this experience as positive. They consider informal care a rewarding but demanding task, consuming time and resources [9]. In Brazil and in most cultures, care services charge considerable fees, and the role of "informal caregiver" is in general exercised by the mother – until recently, the father tended to be the family provider [10]. Historically, family roles were linked to conceptions of gender, with fixed and stereotyped activities for fathers and mothers [11].

However, social changes have brought new organization schemes to families and a new look at the performance of men in this context. Literature today recognizes greater paternal participation in the life and care of children. This change has been beneficial for the family context, because it recognizes the importance of the father in child development, and its presence is currently understood as a protective factor [11].

When the woman becomes pregnant, the family expects the child to be born according to socially accepted standards. The diagnosis of T21 requires adaptation, emphasizing daily care and specific therapeutic and school routines.

Soon after the birth of the child, parents are confronted by the fear of prejudice and discrimination that the child will face throughout life [12]. Society's lack of knowledge on the subject makes disability still be considered pathology, constantly subjecting these families to traumatic and stressful situations. One should note the first manifestations of prejudice occur, albeit covertly, in the family environment itself, extending later to society [12].

Parents have also been socially excluded due to stigma, at risk of both having to quit their jobs and not being accepted in new jobs due to the great demand for care of their child with T21 [13]. The consequences for stigmatized individuals include decreased self-esteem, discredit, shame, guilt, anguish, self-reproach, social restrictions, and illness or worsening health conditions. These factors can lead to isolation, unemployment and low income, in addition to being able to influence the demand for treatment [14]. Based on the above, it is clear that these families need multidisciplinary support starting from diagnosis, with a biopsychosocial focus, to guarantee their quality of life.

In this context, there is room for bioethical discussion. In 2005, the United Nations Educational, Scientific and Cultural Organization [15] approved the *Universal Declaration on Bioethics and Human Rights* (UDBHR). This document redefined the field by incorporating social, environmental and health issues of equal importance [16].

Thus, the sphere of study and action of bioethics, previously restricted to biomedicine, was expanded [16]. The field is considered to acquire a multidisciplinary character by extending its debates to areas as diverse as law, social sciences, anthropology, psychology, among others. In the health sciences, bioethics dealt with issues related to public policies, economics and social exclusion [17]. In Latin America, discussions have expanded due to the role of some bioethicists who incorporated other references or theoretical and practical categories, such as human rights, vulnerability, non-discrimination and non-stigmatization [16].

The inclusion of social themes in the bioethical agenda showed persistent situations that are still found in contemporary society [18], arising from the scenario of exclusion, poverty, injustice and violation of human rights present in Latin America. This incorporation demands respect for essential rights and the inclusion of vulnerable individuals in society [19]. Thus, there is concern and social, health and environmental commitment of bioethics in the region, whose socio-political and economic context undoubtedly assigns more relevance to the matter [20].

Given the above, the main objective of the study is to analyze the perception of parents of children with T21 about the stigma in the reality of Brasília/DF, to understand its effects on this population – a relevant issue at this time when social exclusion, discrimination and inequality are still experienced. We propose to reflect on the subject from the bioethical perspective, having as theoretical reference Article 11 of the UDBHR, which determines that *no individual or group should, under any circumstances, be subjected, in violation of human dignity, human rights and fundamental freedoms, to discrimination or stigmatization* [15]. Although much has been discussed about the care of people with T21, there are few references about their caregivers, who have remained invisible and forgotten not only by the State, but also by society.

Method

This is a study for which the *Escala de Percepção de Estigma de Pais de Crianças com Síndrome de Down* (Epesd – Scale of Stigma Perception for Parents of Children with Down Syndrome) was elaborated and validated, since no instrument was found in the literature that could be used for this purpose. The conception of Epesd followed Pasquali's stages of elaboration of psychological scales [21]. For the purposes of this study, the term "parents" was used to refer to the legal guardians of children with T21, whether biological, adoptive or grandparents.

Epesd items were elaborated based on the literature, on the experiences of ten professionals in the area and on interviews with ten parents. Subsequently, the items were submitted to the theoretical analysis of six judges, all experts in the area, resulting in the Epesd instrument with 15 statements classified on a five-point Likert scale – 1 (strongly disagree), 2 (disagree), 3 (neither disagree nor agree), 4 (agree), and 5 (strongly agree). Six questions on sociodemographic data of the sample related to age, marital status, education, number of children, profession and religion were also included in the questionnaire.

Then, a pilot test was carried out, with a sample of 106 participants. The pilot test included parents with mid-level education, even if incomplete, of any socioeconomic level and whose children – who should be aged between 2 and 10 years old – were being followed-up at the outpatient clinic of the Interdisciplinary Reference Center in Down Syndrome of the Regional Hospital of Asa Norte (HRAN), subordinated to the Department of Health of the Federal District.

Both the interviews for the elaboration of the scale and the pilot test were performed individually at the specialized HRAN outpatient clinic. Each participant received an informed consent form, which was returned with the completed questionnaire. The study was approved by the Research Ethics Committee of the Faculdade de Saúde da Universidade de Brasília and the Education and Research Foundation on Health Sciences. Resolution 466/2012 of the National Health Council[22] was respected. Given the objective of this article, the scale construction and factorial validation will not be evaluated here.

Results

This article is part of master's research and will analyze only the results of the pilot test. Data will be presented as absolute frequency and percentages. The sociodemographic profile showed that most of the 106 participants were women (n=85; 80.2%), married (n=66; 62.3%), Catholic (n=55; 51.9%), with complete or incomplete elementary schooling (n=40; 37.7%), with "housewife" as the main work activity (n=51; 48.1%) and a single child (n=27; 25.5%), predominantly aged between 31 and 50 years (n=78; 73.6%). The full answers are available in Table 1.

Regarding the questions about isolation and loss of sociability, 94 (88.7%) participants declared that they did not isolate themselves; 91 (85.8%) were not avoided by friends; and 81 (76.4%) did not recognize that they had at some point thought that social life had ended. When the subject referred to a psychosocial factor related to shame, 81 (76.4%) respondents disagreed with the statement "I do not feel comfortable when I am with my child in a social environment"; 98 (92.5%) disagreed with "I would prefer that people did not know that my child has T21"; and 102 (96.2%) disagreed that they would like to modify their child's facial features. Regarding the psychosocial factor associated with inferiority, 74 (69.8%) reported not having heard someone say that the genetic condition of the child was God's punishment; and 64 (60.4%) parents answered that people did not start to feel sorry after the birth of the child. Regarding the association of T21 with drugs, 81 (76.4%) respondents denied this statement.

Regarding life perspective and acceptance, 77 (72.6%) participants agree that children with T21 are not accepted by society; 97 (91.5%) denied that the child's father would have abandoned the family. Regarding the perspective of life and employment, most parents deny having left work (n=74; 69.8%) or having stopped being hired due to the child's condition (n=90; 84.9%). Finally, in the items that concern the future, 83 (78.3%) parents agreed that they do not trust anyone to take care of their child if they die soon, but the same number of respondents said they were not afraid of the future (n=83; 78.3%).

Table 1. Perception of parents of children with T21 about stigma

Items	Strongly agree		Agree		Neither agree nor disagree		Disagree		Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
1. "I have been secluded after my child was born."	7	6.6	3	2.8	2	1.9	3	2.8	91	85.8
2. "I feel that my friends have been avoiding me because of my child."	7	6.6	6	5.7	2	1.9	3	2.8	88	83.0

continues...

Table 1. Continuation

Items	Strongly agree		Agree		Neither agree nor disagree		Disagree		Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
3. "I do not feel comfortable when I am with my child in the social environment".	11	10.4	12	11.3	2	1.9	2	1.9	79	74.5
4. "I do not see acceptance of my child by society".	44	41.5	33	31.1	7	6.6	13	12.3	9	8.5
5. "I thought my social life was over after my child was born."	14	13.2	8	7.5	3	2.8	4	3.8	77	72.6
6. "I was told that the T21 of my son was a punishment from God."	17	16.0	15	14.2	0	0.0	3	2.8	71	67.0
7. "The father of my child left the family after his or her birth."	2	1.9	5	4.7	2	1.9	3	2.8	94	88.7
8. "I would rather people did not know that my child has T21".	1	0.9	4	3.8	3	2.8	7	6.6	91	85.8
9. "I would like to modify my child's facial features."	2	1.9	1	0.9	1	0.9	2	1.9	100	94.3
10. "I cannot die soon because I do not trust anyone to take care of my child, even if they are adults."	69	65.1	14	13.2	3	2.8	5	4.7	15	14.2
11. "People began to feel sorry for me after the birth of my child."	22	20.8	16	15.1	4	3.8	7	6.6	57	53.8
12. "I quit my job after my child was born."	26	24.5	4	3.8	2	1.9	2	1.9	72	67.9
13. "I was not hired to work on behalf of my child".	8	7.5	1	0.9	7	6.6	2	1.9	88	83.0
14. "I became afraid of my future after the birth of my child."	12	11.3	9	8.5	2	1.9	7	6.6	76	71.7
15. "I have already been told that my child was born with T21 because I used drugs, but I never used them".	17	16.0	8	7.5	0	0.0	3	2.8	78	73.6

Discussion

This study allowed us to understand the profile of parents of children with T21 in the reality of Brasília/DF. Mother were predominantly the primary caregiver, most of the respondents had complete or incomplete elementary education, and even though most respondents were of productive age, they did not have a professional activity. These results corroborate the findings in the literature on the subject [12].

In this article, to discuss the data, the five factors covered by Epesd were taken into account: isolation and social distancing; psychosocial aspects – feeling of shame and inferiority; low life perspective and acceptance; loss of employment; and fear of the future. Conclusions are limited due to the impossibility of standardizing the scale and applying it to the target population. The standardization will be the object of future research activities, but the items built here served as data to reflect on the theme from a bioethical perspective.

The results of this research regarding isolation and loss of sociability point to little use of this strategy in the studied reality, which seems to confirm the findings of other Brazilian studies, in which the most frequently used method of coping was the positive reassessment, whereas the least used was evasion [23]. Bioethics must study social phenomena so that the processes of stigma production and its implications for people's health are better understood [24]. Its consequences are always the same: isolation, social exclusion, less access to health services, worsening of quality of life, violation of human dignity and increased risk of death. Despite the findings of this study, many of those who suffer from stigmatization prefer social invisibility to avoid suffering, which can negatively impact their self-esteem. Those who feel stigmatized prefer to organize themselves in groups as a way to face the social isolation resulting from the fear of prejudice and discrimination [24].

Data on psychosocial aspects revealed that feelings of inferiority and shame have been experienced by parents due to stigma. Analyzing and reflecting on these results from a bioethical approach seems to indicate that society continues to attribute moralistic meanings to pathological or genetic conditions, whatever it may be, especially if its cause is unknown or there is no treatment. The genetic condition itself or body alteration is associated with evil and thus projected in the world [24], as can be seen in the items related to the attribution of T21 to divine punishment or drugs. Intolerance and unilateralism are frequent phenomena in behaviors related to situations that, despite social and scientific advances, persist in society. Discrimination is an example of this scenario and confuses the concept of difference with that of inferiority [25].

The results also seem to indicate that, from the perspective of most participants, society has not accepted people with T21. This data is worrying and has been a source of suffering and stress for the parents. Nevertheless, in the sample studied, most fathers did not abandon the family. Men started to have a more effective participation at home, not limited to representing authority or financial support. This change has been beneficial for the family context because it recognizes the paternal importance in the lives of children, whose presence safeguards their development in the current conception [11].

Regarding the analysis of the low life perspective, the stigma seems to promote inequalities, leading caregivers to unemployment and informality, and consequently impairing their ways of obtaining financial resources [12]. However, this data was not confirmed by most of the participants of this study, given that a significant part of the population studied did not work at the time of birth of the child with T21.

The results of this study seem to demonstrate that stigmatized individuals often do not even realize that they have been the victim of discrimination. Stigma has been so present in the lives of these people that they are slow to believe they are being subjected to unacceptable behavior. Many parents leave the job due to overload, but there are reports of dismissal from work due to various causes after reporting the T21 diagnosis. This confirms the power of stigma and, at the same time, constitutes a violation of human rights.

Society has a positive discourse of social inclusion, but people with disabilities are still seen for what they do not have or what they are not. The feeling of denial brings serious consequences to these individuals and their parents: social exclusion, discrimination and prejudice. In this perspective, looking at disability from the bias of denial results, therefore, in the refusal of the right of individuals with disabilities to live in society under equal conditions [26].

Moreover, the notion that a child with a disability is necessarily a "burden" for other people or that it decreases the quality of life of the family has not been confirmed by the international literature, which shows that having children with a disability positively affects the perspective of parents and siblings on life. Although children with T21 bring challenges, the quality of life of family members does not necessarily decrease. On the contrary, some studies show the concern of parents is more due to the lack of social support to meet the needs of their children than to the genetic condition itself [27].

In this study, issues related to fear of the future have been presented in a similar way to the results of other national studies, in which the longevity of people with T21 became both reality and fear. For parents, thinking about the early death of their children, especially when it comes to children with Down syndrome, is very painful. However, people with T21 have aged along with their parents, a fact simultaneously celebrated and a source of concern. This is because, although Brazilian legislation establishes that the care of dependent members should be the responsibility of the family, it is possible that no family member capable of protecting the person with disability exist when parents are absent.

Therefore, society must reflect on this new reality and even find alternatives for unfamiliar care for these people [28].

Fear of the future has often been related to the emotional overload of parents. This is because primary caregivers – in general, mothers – need to give up studies, work, personal life projects and even physical activities. Most continue to live with their children even when they are adults, because these individuals need company and supervision; parents do not feel safe leaving them alone or with other caregivers [12]. These data have been presented in the reality studied here, but in smaller numbers.

Finally, the "power of stigma" can exclude and exploit people, and its efficiency is greater if it is masked or little recognized by stigmatized people. Stigma is, therefore, a form of symbolic power, and people affected by its exercise are often influenced, sometimes without realizing it, to accept cultural evaluations of their "inferior" value in society [29]. The violation of human rights based on discrimination and prejudice should be the subject of debate and intervention of an interested and socially compromised bioethics. As the dignity of the person is a central principle of human rights, its defense requires the confrontation of processes of discrimination and stigmatization, which contribute to increase the vulnerability of certain groups [24].

Fundamentally, it was the UDBHR [15] that brought issues related to discrimination and stigmatization to the discussion agenda of bioethics, becoming a global achievement, especially for developing countries. This document describes bioethical themes related to human beings as moral, social, cultural and political agents [30]. Thus, the UDBHR [15] represents not only a political but also a theoretical advance to create a more socially just world. The lack of knowledge of this document, together with factors such as those observed in this study, contributes to the perpetuation of inequality, making people with T21 socially vulnerable [30].

Thus, low education, low income, informality at work, discrimination, stigmatization and social exclusion, as observed here, are factors that prevent the studied population from improving their quality of life, impairing their ability to demand viable solutions from the State to transform their reality, hindering the achievement of the much desired social justice. For the UDBHR [15] to be more authentic and effective, social control is necessary, especially in matters related to work, education and health [30]. In this sense, when analyzing article 11 of the UDBHR [15], there is no doubt that the theme addressed in this study holds relevance to the reality studied. As can be seen, stigmatization remains present in society, but it has been little debated.

Children with T21 and their parents are almost always inseparable. As the results of this study indicate, not only children but also their guardians are victims of stigma. The condition of stigmatized can be associated only with the issue of being a caregiver of children with intellectual disabilities, such as those with T21, reinforcing prejudices, inequities and social injustices [31].

In general, the research data reveal that part of the caregivers studied is more vulnerable, and it seems stigma is a part of this process, which can compromise income, negatively affect relationships, and lead to social exclusion. All this impairs self-esteem, worsens quality of life and, as a consequence, increases the chance of becoming ill. Therefore, informal caregivers must be aware that their condition makes them more vulnerable to the stress to which they are subjected daily, meaning they also need to be cared for [32].

As can be seen, stigmatization, even if veiled, is a violation of human rights and has affected the group studied. This shows that society is not prepared to accept differences, since it does not respect pluralism. It is urgent to plan actions whose purpose is to regain respect and improve the self-esteem of these parents. These interventions positively impact the quality of life of parents, children with T21 and the family as a whole, in addition to recovering their citizenship.

Therefore, the UDBHR [15] holds great value in addressing issues related to discrimination and stigmatization, being relevant to the analysis of the responses of the participants of this study. In view of the above, it is concluded that bioethics assumes the responsibility to bring to its discourse the social aspects contained in the principles of the UDBHR [15], which consolidate and recognize that health, according to the precept of the World Health Organization, can only be achieved via the suppression of harmful elements that are also part of the health-disease process. Vulnerable individuals must be protected since many of them still lack speech power, and bioethical discussions have this social function[33].

Final considerations

The analysis on the perception of parents of children with T21 on stigma revealed the role of women in the care of people with Down syndrome. The risk of the mothers becoming ill is higher, probably due to the overload combined with the need to abandon the job and submit to informality and, as a consequence, the decrease in income.

From the bioethical analysis of the problem and the results, it can be inferred that the consequences of stigma for individuals range from decreased self-esteem, discredit and shame to social restrictions. Stigma is an additional source of stress and social disadvantage, since it compromises the family budget by abandoning or dispensing with formal work, as obtained in the data produced in this research.

Stigma is also a source of isolation and social exclusion. It also decreases access to health services, worsens the quality of life of those involved and violates human dignity, thus making stigmatized people vulnerable. Stigma can be expected to have negative effects on the health of parents, similarly to other social determinants of health.

Given the above, proposing measures to raise awareness about the health care of parents will benefit them and the family as a whole, in addition to the effectiveness of the constitutional right to health of caregivers as a way to harmonize bioethics and human rights. Another relevant point refers to the urgent need to formulate robust and feasible public policies that support these families from pregnancy planning, when possible, to birth. From there, the entire health team must be trained in humanized care, changing the current care model focused on disability to the one centered on the person and with a biopsychosocial focus.

Although the effort to effect social inclusion is recognized and its results have improved the quality of life of people who live with T21, it is observed that it was not enough to reduce stigma. Stigma seems to have a deeper and broader impact on people's health than current research suggests. This article does not intend to exhaust the subject, but we expected to awaken a new look towards parents and intellectual disability, in addition to contributing to future research that favors the health of the stigmatized, not out of benevolence, but because they are subjects with rights.

Admittedly, most individuals suffer from stigma at some point in life. However, it is agreed that studies underestimate their impact on people's lives. It should also be noted that the adverse effects of stigma on health and well-being can vary significantly between stigmatized groups. Finally, despite being one of many elements that contribute to the illness of parents of children with T21, stigma should not be underestimated.

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Participation of the authors

Both authors conceived and designed the study, analyzed data and wrote the article. Beatriz Yara Farias de Amorim was responsible for the literature review and fieldwork, and Helena Eri Shimizu performed the critical review.

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