


## Patient safety from the perspective of fetal alcohol syndrome: Scoping review

 <https://doi.org/10.56238/sevned2024.018-041>

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### ABSTRACT

**OBJECTIVE:** The aim of this study was to map the effect of Fetal Alcohol Syndrome with a view to patient safety. **METHODOLOGY:** scoping review, carried out in the Science Direct, Cochrane and CAPES Portal databases. The search resulted in 2,014 publications, of which 30 remained after the selection stages. **RESULTS:** The highest number of publications was in 2019, with 26.67% of the total, 40% of which were in the USA, 96% of which were in English. It can be mapped that the deficit in the diagnosis of Fetal Alcohol Syndrome and its similar, negatively affects patient safety and modifies social behavior. The complex and heterogeneous nature of the maternal profile and context, culture and historical-social legacy were identified, as they are related to the etiology and epidemiology of the spectrum. **CONCLUSIONS:** the effective implementation of the various screening and diagnostic tools was listed as urgent, as early childhood is a predictor of a better holistic development of the individual, which minimizes any losses related to the syndrome and patient safety.

**Keywords:** Fetal Alcohol Spectrum Disorders, Developmental Disabilities, High-Risk Pregnancy, Fetal Alcohol Syndrome, Patient Safety.

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## INTRODUCTION

Linked to gestational alcohol consumption, there are deleterious effects on the embryo and fetus associated with intrauterine exposure to alcohol. For Mesquita (2009), these effects are grouped into the spectrum of fetal alcohol disorders (FASD), which are represented by physical, mental, behavioral and learning impairment. These changes can be perpetuated throughout the individual's life, who may have a high chance of becoming addicted to alcohol and other drugs, cognitive, school and work difficulties, inappropriate sexual behavior and even legal complications.

In FASD, the most severe condition is configured by Fetal Alcohol Syndrome (FAS), which includes facial changes, pre- and/or postnatal growth restriction, and structural and/or functional abnormalities of the central nervous system (CNS). Even though the clinical presentation of intrauterine alcohol exposure is known, there are still obstacles in the diagnosis and previous identification in the children of alcoholic mothers. (MESQUITA, 2009).

Tangent to the implication of the teratogenous use of alcohol, putting life and its quality at risk, the concept of Patient Safety is necessary. This term has been present since Ancient Greece when the Father of Medicine, Hippocrates (460 to 370 BC), coined the postulate *primum non nocere*, which means "first do no harm", based on the awareness that care has the potential to cause damage if not done correctly.

In this sense, the quality of pregnancy is one of the factors directly proportional to prenatal alcohol consumption. In 2007, in Rio de Janeiro, it was identified that 40.6% of pregnant women had drunk alcohol at some point during pregnancy, and of these, 10.1% had consumed it by the end of the gestational period. In 2009, in a poor community in São Paulo, 21.4% of pregnant women consumed this substance throughout their pregnancy and 33.3% only at some point during it. (MESQUITA, 2009) In 2012, in turn, in Minas Gerais, 23.1% of the group in question consumed in some of the quarters and 6.1% in all of them.

The devastating consequences of irrational alcohol use are completely preventable if there is alcohol abstention immediately before and during pregnancy. According to the fact, it is necessary that screening for alcohol use during prenatal care be done routinely, since the visibility and importance of the theme are still neglected by health professionals and Brazilian government agencies. (MESQUITA, 2009).

Even though the clinical presentation of intrauterine alcohol exposure is known, there are still obstacles with regard to the diagnosis and prior identification of children of alcoholic mothers. In this context, the guiding question of this research arises: what are the effects of Fetal Alcohol Syndrome on patient safety?

Seeking to analyze the proposed theme, this study is a scoping review research, which was conducted by the principles of the *Joanna Briggs Institute (JBI)*.



According to the mnemonic PCC, the research question was defined, in which P (population) refers to patients with or without a diagnosis of APS, C (concept) to Fetal Alcohol Syndrome, and C (context) to patient safety.

The search was carried out in stages by three independent reviewers, as suggested by the JBI criteria, in the Science Direct, Cochrane and CAPES Portal databases. The inclusion criteria were: studies with high methodological rigor; of the last 10 years related to the theme and articles in Portuguese, English and Spanish.

The descriptors used were: Diagnosis; Fetal Alcohol Spectrum Disorders; Developmental Disabilities; Pregnancy, High-Risk; Fetal Alcohol Syndrome; Social Behavior; Child Neglect or Child Neglect; Patient Safety.

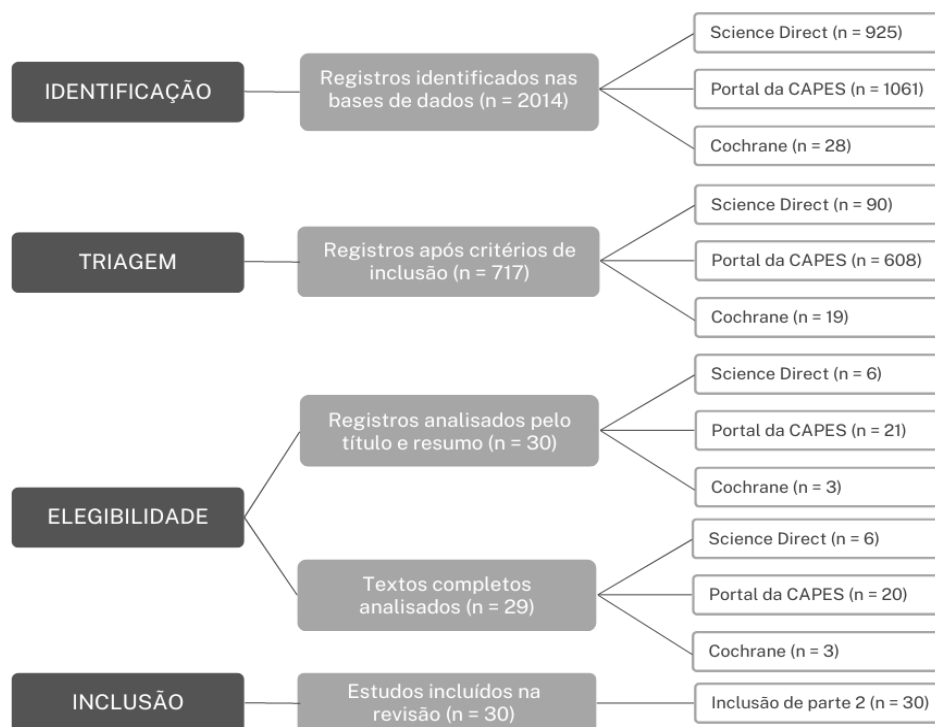
The article was filed in the *Open Science Framework* (OSF) under identification of: <https://doi.org/10.17605/OSF.IO/A39U8>.

## RESULTS

In total, 2014 studies were identified. After temporal filtering, there were 1164 articles available. After selecting by type of article and language, 717 publications remained. Also, with the screening of titles and abstracts, 30 were selected for reading in full and of these, 29 met the inclusion criteria. Finally, part 2 of one of the studies found was added to the group of selected articles, totaling 30 articles. The disagreements between the reviewers were resolved by consensus.

The article selection process can be found in the PRISMA-ScR flowchart (Figure 1), according to the recommendations of the JBI.

FIGURE 1. Selection Process Flowchart



Source: authors (2023)

The publications of the first and last 5 years of the time filter placed, from 2012 to 2022, were equal (46.67%), with emphasis on the year 2019, which had a production of 26.67% of the studies, followed by the year 2014 (16.67%).

According to geographic distribution, 12 studies were conducted in the United States of America (USA), followed by Australia (seven) and Canada (six). Two articles are Brazilian, two are European (Switzerland and Italy) and one is from South Africa. In general, the research covered different methods, such as: review, cohort, quantitative and qualitative approaches, exploratory, randomized and case study. In addition, 96% of the articles were found in English.

After an in-depth reading of each study that made up the final sample, it is possible to apprehend categories, that is, outcomes that were repeated or converged. Pedagogically, the results found were divided into categories, which will be discussed sequentially:

## DEFINITIONS AND CONCEPTS

Prenatal exposure to alcohol is the leading cause of preventable congenital abnormalities and neurodevelopmental disabilities worldwide, especially in countries where it is considered socially acceptable. (HOWLETT, 2019; NASH, 2017; PAINTNER, 2012a) It was only at the end of the 60s that the first publications reporting the teratogenic effects of alcohol appeared. In 1973, Jones and Smith documented the patterns of physical and cognitive abnormalities of fetuses exposed to alcohol during pregnancy. (DOAK, 2019) Thus, with the identification of this phenotype, it was possible to



establish diagnoses and recognize the harmful effects of prenatal exposure to alcohol (PAE). (PAINTNER, 2012b).

For Miller (2013), the current terminology for alcohol-related disorders in neurological development creates dilemmas in the causal inference of prenatal alcohol exposure. In this sense, there are ethical and legal issues in diagnosing a child based on maternal behavior when the cause is not conclusive. Thus, it would be preferable to separate the descriptive and etiological aspects in the diagnosis, using a more generic term, such as "complex neurodevelopmental disorder", which encompasses risk factors, including prenatal exposure to alcohol. (MILLER, 2013).

However, currently the literature brings several terms and definitions for the consequences of gestational alcohol use. Fetal alcohol spectrum disorders (FASD) is a generic term that encompasses categorical medical diagnoses, from the complete presentation of fetal alcohol syndrome (FAS), to the most diverse variants, which include fetal partial alcohol syndrome (pFAS), alcohol-related birth defects (ARBDs) and alcohol-related neurodevelopmental disorders (ARNDs). (PEI, 2016) Although they are pragmatic, for Miller (2013), ARND and FASD have their own semantic, thematic and epistemic meanings. (MILLER, 2013) Later, the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, fifth edition) brought the nomenclature neurobehavioral disorder associated with prenatal exposure to alcohol (ND-PAE), as well as was also cataloged by the American Association of Intellectual and Developmental Disabilities, now in its twelfth edition. (AAIDD-12). (HOWLETT, 2019; HASKEN, 2021; WAGNER, 2018; SENTURIAS, 2014a; ADEBIYI, 2019; GREENSPAN, 2022).

### **Fetal Alcohol Spectrum Disorders (FASD)**

The original nomenclature in English Fetal Alcohol Spectrum Disorder (FASD) supports the existence of a spectrum of diagnostic conditions, in the sense of being a non-diagnostic umbrella term. (KABLE, 2015) Thus, it can be used in the description of brain and body conditions that occur among individuals with PAE, including problems of cognitive, behavioral, adaptive, socio-emotional and physical functioning. Flannigan, et al. (2021) state that there will rarely be individuals with the same clinical presentation, but who, even without a formal diagnosis, may experience significant disability and adverse outcomes to PAE. (FLANNIGAN, 2021; NASH, 2017).

### **Alcohol-related neurodevelopmental disorders (ARND)**

Unlike APS or pFAS, which require growth and structural formation as a diagnostic criterion, the English term Alcohol-related Neurodevelopmental Disorder (ARND) refers to the diagnosis of children with normal growth and structural development, but who present cognitive or neurobehavioral anomalies characteristic of PAE. These problems include difficulties in performing



tasks, communication, emotional control, motor coordination, academic performance, social interactions, and atypical physiological responses, such as sleep disorders and exaggerated sensitivity to sensory stimuli. For Senturias, et al. (2014a), of all the conditions represented in the spectrum, ARND is estimated to be more prevalent than APS.

According to Miller (2013), when trying to diagnose ARND, it is necessary to distinguish between the possibility of causality and retroactive statements in medicine. It is necessary to question the association between EAP and neurological disability, requiring epidemiological evidence based on extensive research. In addition, it is necessary to determine whether prenatal exposure to alcohol caused neurological disability in a specific patient. Thus, to establish retroactive causality in cases of prenatally exposed children who have cognitive, adaptive, and behavioral impairment but without physical characteristics of FAS, a high level of specificity in the relationship between exposure and outcome would be required. However, the evidence for this specificity is still weak. The term alcohol-related birth defects (ARBD) was discouraged due to the difficulty of attributing the cause. (DÖRRIE, 2014).

### **Fetal Alcohol Syndrome (FAS)**

Fetal Alcohol Syndrome (FAS) includes the physical malformations of PAE. (NASH, 2017) The term contemplates the classic triad: abnormal facial features (such as flattening of the upper lip), growth retardation (lower height-to-weight ratio), and central nervous system (CNS) abnormalities (such as smaller head size). (PEI, 2016).

When the individual has some of the three characteristics of FASD, but not all, he can be diagnosed with pFAS, ARND or ARBD, for example. These diagnoses encompass physical abnormalities linked to EAP but do not imply severity. It is important to emphasize that, although patients with APS have the classic triad, their symptoms are not necessarily more severe than individuals with the other three diagnoses. (PEI, 2016).

### **Partial Fetal Alcohol Syndrome (pFAS)**

pFAS is diagnosed in the presence of facial dysmorphologies that meet the criteria for APS, together or without other abnormalities of the central nervous system. (DOYLE, 2015).

### **Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)**

Proposed by the DSM-5, in the section "Conditions for Further Study", the new terminology Neurobehavioral Disorder associated with PAE is enlightening, with the aim of representing the range of neurodevelopmental and mental health symptoms associated with PAE. (DÖRRIE, 2014) Diagnostic criteria include the confirmed presence of PAE, but do not emphasize the need for the

presence of facial or structural features. For example, individuals diagnosed with EAP may also be diagnosed with Fetal Alcohol Syndrome (FAS) or partial APS. (KABLE, 2015).

TABLE 1. Terms and Definitions

|  |   |
|--|---|
| Fetal Alcohol Spectrum Disorders (FASD)                                | Generic nomenclature that refers to the spectrum of categorical diagnostic medical conditions. Umbrella term. (KABLE, 2015; FLANNIGAN, 2021)  |
| Alcohol-related neurodevelopmental disorders (ARND)                    | Presence of cognitive or behavioral abnormalities with confirmed EAP. (HASKEN, 2021; SENTURIAS, 2014a; HASKEN, 2021)  |
| Fetal Alcohol Syndrome (FAS)   | Complete syndrome. Characteristic facial dysmorphologies, growth retardation, CNS anomalies. With or without confirmed PAE. (PEI, 2016)   |
| Partial Fetal Alcohol Syndrome (pFAS)                                  | All or some characteristic facial dysmorphologies in conjunction or not with CNS abnormalities. Some guidelines require confirmed PAE. (DOYLE, 2015)  |
| Prenatal Alcohol Exposure-Associated Neurobehavioral Disorder (ND-PAE) | Deficiencies in the functional, neurocognitive, and self-regulatory domains, without necessarily facial or structural changes, with confirmed SAP. (DÖRRIE, 2014; KABLE, 2015; DOYLE, 2015) |

Source: authors (2023)

## MATERNAL FACTORS

### Maternal profile and risk factors

Physical, neurobehavioral and social disorders resulting from exposure to alcohol in the prenatal period are a teratogenic consequence, as pointed out by the research carried out by Paintner, et al. (2012b), with children of women who had PAE in the United States. This fact is closely linked to the maternal role and lifestyle adopted during the gestational period. (PAINTNER, 2012b).

Tangent to the list, in the United Kingdom, according to Howlett, et al. (2019), women of reproductive age are in the group of highest alcohol consumers, with 41.3% of them consuming this substance during pregnancy. In addition, the results of the UK Infant Feeding Survey indicate that two out of five women confirm the use of alcoholic substances during pregnancy. These data support the aforementioned observed consumption in Western societies (20-30%), compared to the global average of 10%. (HOWLETT, 2019).

Even though alcohol consumption is as low as one drink per week, cases of violent behavior during childhood have been associated, which suggests that there is no safe amount of prenatal alcohol exposure. (DÖRRIE, 2014; KABLE, 2015) In addition, updated data suggest that a history of more than minimal alcohol exposure during pregnancy, prior to recognition of pregnancy, should be



sought. (KABLE, 2015) Therefore, maternal self-report of gestational alcohol use, spouse, relative, or friend who observed the biological mother drinking alcohol during pregnancy, even medical records, can confirm the use of more than the minimum exposure. It is recommended that the use of alcohol is not done when planning the pregnancy and throughout it, to avoid any type of teratogenicity. (KABLE, 2015; MUGGLI, 2014; ROCHA, 2020).

In a study carried out with 94 children living in orphanages in the Northeast of Brazil, described by Rocha, et al. (2020), it was found that half of the biological mothers had abused alcohol, resulting in the diagnosis of FASD in 17% of them. Several studies have been found that show alcohol consumption during pregnancy in Brazil reaching 57%. (ROCHA, 2020).

Finally, the prevalence of alcohol use by women can be linked to the lack of knowledge about the adverse effects of alcohol consumption at this stage of life. This fact corroborates the need for active intervention by health professionals on this topic during this period. (NASH, 2017) After all, the serious consequences of prenatal exposure to alcohol are the risk of fetal death and miscarriages, malformations with dysmorphic characteristics, growth deficiency, cognitive and behavioral deficits, which will be addressed in this article. (PAINTNER, 2012a; DÖRRIE, 2014).

### **Metabolic Factors**

It is not yet known precisely what dosimetry data are needed to exceed a threshold for the occurrence of adverse effects during pregnancy. According to Paintner, et. al. (2012a) and Dörrie, et. al. (2014), the consumption of 5 drinks in a period of 2 hours per week can be an important threshold for adverse outcomes in women weighing approximately 60 kilograms. (PAINTNER, 2012b; DÖRRIE, 2014).

The National Institute of Alcoholism and Alcohol Abuse (NIAAA) defines 1 standard drink as 14 g of ethanol. After ingestion, ethanol is easily absorbed by the stomach and enters the mother's bloodstream, crossing the placenta and quickly reaching the fetus and amniotic fluid, resulting in similar concentrations within minutes. Blood alcohol concentrations peak when absorption and metabolic enzymes match, and begin to decline when enzyme activity exceeds absorption. (PAINTNER, 2012b).

For Nash, et al. (2017), it is possible to feel the teratogenic effects of intrauterine alcohol 1 to 2 hours after maternal ingestion, which can vary depending on the dose, pattern, timing of exposure, and overall well-being of the fetus. The elimination of toxic by-products depends on maternal capacity, which may vary according to the pregnant woman. Most of the time, they end up accumulating, interfering with cellular functioning and leading to malformations in the cardiac, renal, neurological, skeletal, ophthalmic and auditory systems. (NASH, 2017).





## Preventive factors

The first step towards prevention, or even intervention depending on the case, is to screen for alcohol use during pregnancy. (CHIODO, 2019) This assessment should be routinely performed by health professionals, including nurse-midwives, in primary care services, or in any care provided to pregnant women. The emphasis of this screening is on the identification of alcohol use and health education, and it can also be applied in preconception. (HOWLETT, 2019) After all, there is no amount of alcohol use that is proven safe for the development of the embryo or fetus. (CHIODO, 2019; HAYES, 2022).

However, the evaluation of alcohol consumption habits by pregnant women and women after pregnancy often involves feelings of guilt and stigmatization. (FERRAGUTI, 2019) Such feelings may cause mothers to be hesitant to report consumption. In addition, there is difficulty in obtaining correct information in the case of foster or adoptive families. (SENTURIAS, 2014a).

In view of this, to overcome the obstacles, screening instruments were developed especially designed for pregnant women. (FERRAGUTI, 2019) Decades of evidence have elucidated that universal screening by validated questionnaires is effective in this identification, in addition to providing consistent and clear information regarding the risk of alcohol consumption by this population. (NASH, 2017) In fact, screening is one of the pillars for medical decision-making in situations like this, because from the compilation of information obtained, counseling and possible intervention can be applied - which is cheap, fast and easy to execute. (NASH, 2017).

## SOCIAL CONTEXT

### Maternal

It is understood that the risk of FASD is highly dependent on maternal decisions during the gestational period, with regard to the frequency and quantity of alcoholic beverages consumed and the period of pregnancy in which this consumption occurred. Based on this, importance should be given to the factors and antecedents that can influence such individual decisions: vulnerability to alcohol, maternal age, culture in which they are inserted, ethnicity, nationality, socioeconomic factor, education, housing, smoking habit, poor diet, use of other drugs, marital status, unemployment, lack of support. (FERRAGUTI, 2019; DÖRRIE, 2014; PEI, 2016).

Prenatal exposure to alcohol, according to Dörrie, et al. (2014), whether due to social context or lack of knowledge of pregnancy, is not uncommon in early pregnancy, especially in the first weeks, however, it is also necessary to identify potential confounders that can influence the development of the fetus and pregnancy, such as smoking, drug use, eating habits and genetic factors. (DÖRRIE, 2014) Thus, Banerji, et al. (2017) explain that it is necessary to individualize the cases in order to strengthen the process of prevention and identification of FASD, in addition to



seeking to reduce the impact on the life of the diagnosed child. This should be prioritized in populations where there is a low rate of investigation of this syndrome, such as indigenous people. (BANERJI, 2017).

### Children diagnosed

From the beginning of life, according to Dörrie, et al. (2014), children diagnosed with FASD suffer comparatively much higher adversities than those not diagnosed. Many of them are in environmental instability, as up to 90% of those with AFS are removed from home and are raised in multiple foster homes. (DÖRRIE, 2014) This vulnerability of care, according to Flannigan, et al. (2021), promotes several negative effects on the child's development, especially in the context of mental health. (FLANNIGAN, 2021).

Added to this is the fact that these individuals - found among the groups of lower socioeconomic status - experience disproportionately high situations of abuse, mistreatment, traumatic experiences and neglect - reaching the rate of 85% of them. These children then live in a constant state of "double jeopardy", due to the diagnosis itself and the associated complications. (FLANNIGAN, 2021; KABLE, 2015; PEI, 2016).

Based on this scenario, Flannigan, et al. (2021) state that it is possible to identify protective factors that can provide better results in the child's development, such as a safe, welcoming, and stable home environment (regardless of whether with biological parents, adoptive parents, or relatives), early diagnosis, and assertive intervention. Finally, it is worth mentioning that the factors related to environmental protection are modifiable, which provides an opportunity for intervention. (FLANNIGAN, 2021).

## REGIONAL FACTORS

### Worldwide

A highly rigorous scientific study, analyzed by Nash, et al. (2017), estimated that in the world population the prevalence of APS is around 1.5 cases per 1,000 births and FASD, about 15 per 1,000 births. For comparison, the authors presented this epidemiological factor with regard to autism and Down syndrome, which are 14 and 1.4 per 1,000 births, respectively. (NASH, 2017).

Alcohol consumption by women during pregnancy, according to Rocha, et al. (2020), is approximately 10%, which results in about 190 thousand children born with APS annually. Similarly, the consumption of this psychotropic drug by pregnant women has a different prevalence among countries, according to the authors, being 58.3% in South Africa, 36.5% in Russia, 27.0% in France, 4.8% in Canada and 10% in the USA. (ROCHA, 2020).



## Developing countries

It is estimated that alcohol consumption above "occasional" use, according to Andrade, et al. (2013), is practiced by about two-thirds of the Western population, with alcohol dependence being among the five major global health problems among the age group of 15 to 44 years. In Brazil, this dependence is 5.7% among women and around three times as high among men. (ANDRADE, 2013) A consequence of this, according to Rocha, et al. (2020), is the presence of APS in 0.5 to 2 cases per 1,000 born annually in the country, which represents 1,500 to 6,000 children with APS. (ROCHA, 2020).

In this context, it is known that the understanding of developmental disability is inserted in and totally dependent on the cultural variety existing in the world, and there are, therefore, different points of view on this theme. According to Faruk, et al. (2020), in addition to the individual perspective of each culture, factors such as economics, politics, and geolocation are influencing access to quality healthcare for individuals with disabilities. In Southeast Asia, several societies consider it shameful to have children who are not healthy, thus promoting social deprivation and lack of support for these families, whether socially or in terms of access to health, such as diagnosis and treatment. (FARUK, 2020) In addition, among developing countries, South Africa is the country with the highest rates of FASD, ranging from 68 to 89.2/1,000 births. (ANDRADE, 2013).

Still on Brazil, Andrade, et al. (2013) evaluated a study in which researchers detected that 40% of women consumed alcoholic beverages three months before pregnancy on a weekly basis, and during pregnancy this number dropped to 20% and so on during the trimesters, up to a rate of 17.1% at the end of pregnancy. These same researchers evaluated the prevalence of APS in the city of São Paulo in 1964, which was 38.7 per 1,000 births. In addition, they observed that in Porto Alegre, 49% of the mothers of male institutionalized adolescents admitted to consuming alcohol during pregnancy, compared to 40% of the mothers of male students, with the presence of symptoms being more common in the first group. (ANDRADE, 2013).

In view of this, it is also important to understand that, according to Rocha, et al. (2020), there is great difficulty in evaluating some of the developing countries, such as Russia, in which the discrepancy between the data in several studies is considerable. According to the authors, this is due to the difficulty in correctly diagnosing these individuals. (ROCHA, 2020) Therefore, it is worth noting that not only socioeconomic conditions influence these data, but also the diagnostic method and the provision of services offered to this group. (ANDRADE, 2013).

## Developed Countries

In developed countries, the early identification and diagnosis of developmental delay is one of the pillars of good health practices, and is even recommended by the American Academy of



Pediatrics. According to Faruk, et al. (2020), these countries prioritize the development of children, unlike those in which health practice is focused on identifying only acute diseases and growth itself. (FARUK, 2020) Such a perspective, according to Senturias, et al. (2014a) meets the needs of the United States, for example, since FASD has a prevalence of 0.2 to 1.5 per thousand births, and is therefore one of the most common causes of developmental and intellectual disabilities in the nation. (SENTURIAS, 2014a).

Still in the USA, in addition to FASD being common, the prevalence of APS has also been frequently found in minority groups, such as American Indians, and may be related to poverty and historical traumas, such as residential schools, according to Banerji, et al. (2017). In addition, there are economically significant costs associated with the necessary support that this group provides, which can reach at least 2 million US dollars per individual annually. (HAYES, 2022) In Canada, where FASD is one of the most common developmental disabilities and the estimated prevalence is 1% of the population, these costs are related to the judicial system (40%), health care (17%), education (17%), social services (13%) and others (9%). (PEI, 2016; BANERJI, 2017).

In New Zealand, according to Brookbanks, et al. (2021), although there are no studies that estimate the prevalence of FASD, it is estimated that alcohol has affected around 1 to 3 in every 100 live births. In Australia, in turn, according to Doak, et al. (2019), this prevalence is 10.82 per 1,000 births.

Finally, according to the studies by Banerji, et al. (2017), although FASD is found in all socioeconomic groups, some indigenous communities are highly affected, as seen in Inuit and Cree women living in Northern Québec, in which, even though fewer women consumed alcohol, those who consumed it did so in large quantities. Thus, even if there are indigenous communities in which alcohol is prohibited for women, those in developed countries are ten times more likely to practice this abuse than non-indigenous communities, resulting in higher rates of FASD in the country.

## NEUROLOGICAL CONDITION

The clinical fetal alcohol spectrum goes beyond the physical abnormalities that result from PAE. Thus, it is possible to find in these individuals a compromised neurodevelopment, behavioral problems and disturbances of cognitive function. (BROWN, 2019).

CNS criteria used for the diagnosis of APS can be satisfied through documented structural, neurological, or functional anomalies. Structural criteria are met by means of anomalies detected by imaging or decreased head circumference (head size in the 10th percentile or smaller). Neurological criteria, on the other hand, can be considered in the examination and can be composed of focal symptoms (such as tremors, decreased visual or auditory acuity) or generalized symptoms, such as unprovoked seizures. Finally, functional CNS abnormalities are recognized by the way the child



thinks, learns, and behaves, as well as in the results of neuropsychological and developmental tests. (PAINTNER, 2012a; SENTURIAS, 2014a).

It is tacit to mention that, according to the research of Ferraguti, et al. (2019), exposure to gestational ethanol can impair the development, growth, and migration of brain cells and structures. Neurotrophins, which are fundamental in regulating these processes, are one of the main resources known to be disrupted by prenatal alcohol exposure.

In a general overview, APS can be diagnosed in children with compromised or normal structural development, but who have cognitive or neurobehavioral anomalies, which are comprehensively presented. (SENTURIAS, 2014a)

### Neurocognitive functioning

In general, there is a consensus in the literature that non-specific cognitive impairment may be related to EAP. Long-term neurocognitive development is marked by failures in many domains, and often the level of independence does not match the age of the individual. In practice, cognition, executive functions, memory, and social perception are mostly impaired. (DÖRRIE, 2014).

In the study by Hasken, et al. (2021), it was noted that the physical growth of the child is directly related to predictions of neurobehavioral repercussions, with those who are born with low weight exhibiting the worst results. For Paintner, et al. (2012a), it is in adult life that the high rates of mental retardation and neurocognitive deficiencies are highlighted.

It is important to mention that children with fetal alcohol spectrum disorders may have withdrawal symptoms and present characteristics of nervousness, increased respiratory rate, hyperacusis, increased reflexes, and sleep problems. (PAINTNER, 2012a).

### Cognition

Cognitive impairments differ according to the child's stage of development. (NASH, 2017) Even if some manifestations are clear, for infants and preschoolers, it can be difficult to characterize elements of EAP. According to Kable, et al. (2015), about half of young children show a marked developmental deficit in the first three years of life. Cognitive manifestations, in turn, become more evident at school age with learning delays, decreased IQ, communication difficulties and limited memory.

Global intellectual deficits or evidence of significant global developmental delay in early childhood are indicators of neurological dysfunction due to PAE. (KABLE, 2015; SENTURIAS, 2014a) In this sense, the research by Dörrie, et al. (2014) shows that the average IQ of children with APS is close to the lower-middle line range. The spectrum, in turn, can extend from mild mental retardation to the upper middle range. Nash, et al. (2017), on the other hand, showed in their study



that the IQ of affected children ranges from very low to normal, unlike adolescents and adults who have lower academic performance than suggested by their IQ score. According to Doyle, et al. (2015), although the most severe disabilities are regularly observed according to greater physical dysmorphology, the deficit in global IQ is not limited to appearance, nor to the history of EAP, with 20-50% of those with APS achieving an IQ below 70.

As a negative result, there is a recurring scenario of low grades, failure and school dropout. (PAINTNER, 2012a; KABLE, 2015) This information relates to evidence showing higher rates of incarceration, drug addiction, and mortality in this population compared to the general public. (BROWN, 2019).

### Memory

Reduction in hippocampal volume was associated with impairments of working memory. Kable, et al. (2015), in their study, state that children with PAE have impaired memory, including auditory memory, for drawings, tales and spatial memory, that is, for both verbal and non-verbal materials. This failure in the storage of information serves both for free recall and for recognition in the forced/multiple choice test. According to the list, memorization difficulties are the result of the deficit in encoding new information and can be evidenced when the child demands frequent reminders, repeatedly makes the same mistakes, has difficulties remembering long verbal instructions or tends to lose their belongings. (DOYLE, 2015; KABLE, 2015) This high-risk behavior tends to be misinterpreted as oppositional. (DÖRRIE, 2014).

### Visuospatial perception

Evidence of specific deficits in the perception and visuospatial construction of individuals with APS was found in the literature, including obstacles to visual memory and visual-motor integration with spatial memory. In this sense, these symptoms can be expressed as disorganized or poorly planned construction designs, difficulties in differentiating right or left. This leads to a negative impact on adaptive functioning capabilities in daily life. (KABLE, 2015; DOYLE, 2015; SENTURIAS, 2014a).

### Executive functioning

According to the research of Wagner, et al. (2018), individuals whose mothers used alcohol during pregnancy were described as having deficiencies in executive function, mainly due to damage to the regions of the prefrontal cortex. Therefore, it is through these cognitive processes that one can plan, organize, attend, solve problems and inhibit answers. Also, it is through this mechanism that it is possible to self-regulate emotional responses and behavioral actions. (WAGNER, 2018).



Therefore, deficiencies in this functioning lead to changes in behavior and a drop in the level of learning, resulting in educational deficits in the child, such as when he tries to deal with complex school demands. (WAGNER, 2018) Other manifestations of this problem are poor planning and organization, cognitive inflexibility, and difficulty in solving problems. For these and other reasons, the diagnosis of APS at school age is more likely. (DOYLE, 2015; (KABLE, 2015).

### Self-regulation

According to Doyle, et al. (2015), in order for a deficiency in self-regulation to be truly considered, a child must have deficits in at least one of the following areas: mood or behavior regulation, attention, and/or impulse control. It is important to mention that, for the diagnosis of ND-PAE, at least one symptom that characterizes a deficit in self-regulation is required, together with deficiencies in two other additional domains. (KABLE, 2015).

### Mood regulation

Behavioral outcomes are largely affected by negative psychosocial agents, commonly experienced by individuals with FAS. For Kable, et al. (2015), parental substance abuse, mental health problems, child neglect and family violence are some of the adverse scenarios, reported in research, that surround children with PAE. Such influence contributes to problematic consequences, in particular in the area of behavioural regulation. In addition, the research by Dörrie, et al. (2014) states that there is an increase in prefrontal volume, the brain area responsible for logical reasoning and emotion control.

Individuals affected by alcoholic teratogenicity are at high risk of developing deficits in behavioral regulation, mood, and emotional functioning, as found in the studies by Dörrie, et al. (2014), including depressive disorders and negative humoral effects. In addition, externalization and internalization of problems have high rates of occurrence among these patients, as well as oppositional and conduct disorders. (DOYLE, 2015).

It is common to observe aggressive behaviors or depressive episodes in adults with FASD, however, such symptoms are rarely formally diagnosed and, in cases of internalizing disorders, often go unnoticed. According to population studies, up to 92% of young adults with FASD have some type of psychiatric disorder, with the most common diagnoses being ADHD (65%), followed by depression (47%) and panic disorder (21%). (DÖRRIE, 2014)

### Attention deficit

Doyle, et al. (2015) state that parents and teachers highlight, in their reports, attention difficulties in children with APS. In addition, they found, in several studies, the emphasis on the



presence of attention hyperactivity disorders (ADHD) in children exposed to intrauterine alcohol. This number reaches 95% of those affected. In fact, this characteristic is one of the first to be noticed regarding self-regulation. (PAINTNER, 2012a) These children have higher rates compared to the typical population. The difficulty of shifting attention and sustaining mental effort to fulfill tasks among those on the fetal alcoholic spectrum have been described and replicated in animal models. (KABLE, 2015).

Compared to children with ADHD not associated with prenatal alcohol exposure, those who were exposed to teratogen have greater difficulty in verbal comprehension and perceptual reasoning. (DÖRRIE, 2014) In addition, adaptive skills in these children showed significant delay and lack of improvement with age, both in socialization and communication. In healthy management, young children without prenatal alcohol exposure need lower levels of adaptive support from caregivers. For Kable, et al. (2015), defiant and oppositional disorders (ODD), conduct disorders (CD), and ADHD should be carefully evaluated in the presence of PAE.

Difficulty in impulse control Often, the behavioral regulation or temperament of the individual on the fetal alcohol spectrum can manifest in a negative way, with irritability, emotional outbursts, or emotional lability. Especially, children with ASD tend to have impulsive responses and greater externalization compared to children with only ADHD, suggesting that there is difficulty in following rules, maintaining behavioral control and solving problems. (DOYLE, 2015).

### **Adaptive operation**

To characterize the individual with loss of adaptive function, he/she must present at least two of the following items: communication deficit, social deficit, disability in daily life and disability in motor life (the first or second must be mandatorily present). (DOYLE, 2015; SENTURIAS, 2014a).

While the newborn and early childhood phase usually present growth deficits, congenital problems, feeding difficulties, irritability and sleep disorders, in childhood and early adolescence functional deficits of the CNS emerge and their consequences, as mentioned earlier. As postnatal environmental factors adjust, PAE has been associated with an increased risk of conduct disorders in older individuals. Over time, other inappropriate behaviors may also emerge. (DÖRRIE, 2014).

### **Communication deficit**

Although not completely understood, the language disorders of children with APS have been documented in most studies. (KABLE, 2015) These deficiencies involve the comprehension of words, the ability to name, and expressive and receptive capacities. (DOYLE, 2015) Not infrequently, there is a significant delay in language acquisition, in addition to deficiencies in





syntactic, grammatical and semantic skills. It is tacit to mention the greater risk associated with hearing loss. (ANDRADE, 2013; DÖRRIE, 2014).

The participants in the study by Andrade, et al. (2013) showed considerable changes in the development of oral and written language, including failures in tasks involving categorization, definition and immediate memory, consistent with the literature found. For Dörrie, et al. (2014), children suffer mainly from reduced language comprehension and from not being able to produce a contextually integrated discourse.

According to Kable, et al. (2015), affected individuals exhibit dissent with figurative and abstract language, which leads to decontextualized and increasingly complex messages. In the clinic, these impediments are characterized by excessive loquacity, a clearly passive communication style, a tendency to make numerous comments that seem off-topic or out of the context of communication and/or understanding.

### Disabilities of daily living

Deficits in daily living skills can include delays in using the bathroom, eating, or bathing. (KABLE, 2015) Other examples of insufficient daily living skills include difficulty managing daily schedules or problems arising from personal safety rules. (DOYLE, 2015; KABLE, 2015). Individuals with FASD, according to Kable, et al. (2015), often seem to trust strangers and tend to behave indiscriminately in society, potentially putting themselves in unsafe situations. (KABLE, 2015) Repeatedly, caregivers reported difficulties in the spatial orientation of children, who get lost even in known routes. (DÖRRIE, 2014).

Difficulties sleeping and handling of sensory stimuli can also be mentioned. The ability to calm down on their own seems to be one of the most common symptoms of neurological development associated with alcohol. Often, difficulties in understanding can result in prolonged tantrums. This problem becomes more evident in the preschool years when children are expected to have more self-control. In addition, since cause-and-effect reasoning is less efficient for children with APS, it becomes more difficult for them to learn from previous experiences. (SENTURIAS, 2014a).

### Motor disabilities

A wide range of studies have shown that infants and children with APS have delayed motor development. This becomes evident during growth milestones, with direct impact on coordination, overall balance, delayed motor response, peripheral nerve conduction abnormalities, abnormal gait, and tremors. (KABLE, 2015) These deficiencies include both gross and fine motor skills. In the gross motor domains, children have difficulties with postural control and, in the fine domains, hand-eye coordination, finger dexterity, strength and motor speed are impaired. (DOYLE, 2015; SENTURIAS,



2014a; KABLE, 2015) In early childhood, CNS dysfunction can lead to poor sucking and irritability. For Dörrie, et al. (2014), many of the children with FASD suffer from motor difficulties regardless of IQ.

## THE INDIVIDUAL WITH FASD IN SOCIETY

It is notorious that many of the individuals diagnosed with FASD present, in addition to physical, neurological and cognitive factors, several significant behavioral and social alterations. Such alterations are called secondary disabilities associated with FASD, and these are exacerbated especially when there is no support for the individual and his or her network. These social and psychological problems involve several areas and can manifest themselves as: educational interruption, employment difficulties, inappropriate sexual behavior, substance abuse, psychiatric conditions, psychopathologies, problems with the judicial system, among others. (BRINTNELLA, 2019; LARRANDABURU, 2019; NASH, 2017; KABLE, 2015; FLANNIGAN, 2021; HAYES, 2022; PEI, 2016).

Due to this, according to the article by Chiodo, et al. (2019), the fact that there are several costs throughout the life of the person with FASD is corroborated, which are very individualized and difficult to estimate accurately, but remarkably considerable, and can range from hundreds of millions to billions of dollars. Thus, it is essential to invest in prevention and health education, screening, diagnosis and possible treatments and rehabilitation that may be related to the syndrome. (CHIODO, 2019; FARUK, 2020; CHIODO, 2019; FARUK, 2020; PEI, 2016; FLANNIGAN, 2021).

### Behavior and socialization

Among the secondary disabilities observed in individuals with FASD, Doak, et al. (2019) emphasized the difficulties that these people have in relation to behaviors and relationships. According to the author, starting and maintaining friendships and regulating emotions are some of them. It was also observed that the presence of antisocial behaviors and the practice of intimidation in places where they live together, such as school, are frequent in this group, which also has a high rate of mental health comorbidities and suicide.

According to Dörrie, et al. (2014), this change in social-emotional behavior occurs from the beginning of the child's socialization in the early years of education, when social adaptation occurs. Even though the FASD influences the severity of this situation, according to Dörrie, et al. (2014), it is possible to observe that the child, between 6 and 7 years of age, presents behaviors such as aggressiveness, delinquency, impulsive temperament and reduced capacity to process emotions.

In relation to the socialization of the child, Doyle, et al. (2015) point out that the difficulties occur because during a social interaction, individuals are required to have several skills - such as



cognition, attention, memory, communication and linguistic organization and understanding the other person's point of view - which this group has difficulty in managing, which makes the task painful. Also in the same article, it was reported that children on this spectrum may have a propensity to use ambiguity and not correctly understand the meaning of words in a narrative, consequences of which are friendliness towards strangers, misunderstanding of social consequences, which leads them to the serious relationship they have with the justice system. (DOYLE, 2015; LARRANDABURU, 2019) In this way, it is possible to understand the large expenses associated with the course of the life of the individual with FASD, after all, the loss of productivity and difficulty in arranging and staying at work is a consequence of difficult socialization. (BANERJI, 2017).

### The judicial system

Individuals with FASD have substantial involvement with the justice system, according to Brintnella, et al. (2019), given the social, neurocognitive difficulties and other secondary disabilities. In American studies analyzed by Dörrie, et al. (2014), about 60% of this group came into conflict with the law, with half the number of arrests; in the Europeans, this number was lower. Banerji, et al. (2017), reported that in a sample of 473 individuals with FASD, 12% of them, at the age of 9, were already involved in criminal activities. Therefore, as most of these individuals are related to the correctional system, it is essential that these places have the capacity to serve them. According to Brintnella, et al. (2019), the Canadian adult penitentiary system exhibits flaws in the screening and evaluation of these incarcerated people.

To understand the relationship between people with FASD and the prison system, it is essential to understand that exposure to alcohol in the womb can affect, from mild to significantly, the entire brain area of the developing fetus, especially the limbic system, responsible for impulse and emotional control, social judgment, and decision-making. In addition, this group has difficulty in reasoning abstractly, such as seeing the big picture, understanding the relationship between action and consequence, and learning from experience, which results in the fact that they are more easily placed in risky situations, as they do not skillfully predict when their actions and behaviors will cause conflicts with the law. Therefore, a Canadian analysis identified that this group is 19 times more susceptible to contact with the justice system compared to those not diagnosed with FASD. (LARRANDABURU, 2019).

Tangent to this line of reasoning, Brintnella, et al. (2019) presented in their study the Corrections and Community Connections (3C) program, which aims to monitor adult men who have frequent contact with the Canadian corrections system. Identified by the authors as an 18-month model project, the program addressed screening, diagnosis and other assessments, with the objective of optimizing the identification of this group, providing the return to the community based on the



development of life skills, in addition to promoting a support system for these men after returning to society. According to the authors, this sample of the 3C program made it possible to identify that violations of conditions are the main infraction committed, in addition to most self-declared gang members, facts that converge with empirical evidence presented by health and law professionals, who state that offenders with FASD follow legal supervision orders with difficulty, in addition to having a low response to treatment and higher rates of recidivism.

Analogous to the difficulty of individuals with FASD to effectively participate in the criminal justice system, due to the aforementioned limitations, this group is also disadvantaged in the trial procedures, given their inability to be tried. (BROOKBANKS, 2021) This is due to two aspects: the first is due to the insensitivity of the authorities and legal professionals, whether lawyers, judges, among others; the second, due to the limitations of the person with FASD due to the associated brain impairments, such as memory difficulties about the facts and their behavior, in offering instructions and evidence to lawyers, in being active in the defense process (becoming a spectator). Added to this, it has high suggestibility and an apparent coldness (a reflection of the low ability to understand the perspective of others), among others. Thus, it is concluded that there is a substantial risk of judicial error in these cases. (LARRANDABURU, 2019; BROOKBANKS, 2021).

From the identification of this social gap, the Canadian Justice, according to Pei, et al. (2016), recognized the vulnerability of this group and the possible obstacles in the judicial process, therefore, it joined the Juvenile Justice Policy Section in favor of preventing the involvement of children and adolescents with FASD with crime, by the National Center for Crime Prevention. It also provided FASD training to police officers and a network of assistance as it relates to care and intervention. Finally, these positions are of great value, given the need to guarantee the rights of the population with FASD.

In addition, Brintnella, et al. (2019) point out that in fact, the postnatal risks of individuals with FASD influence their immersion in crime, whether due to negligence, abuse, witnessed violence, home and family instability, vulnerability, among others. Among the sample of the 3C project, 57% of them presented at least one of the risks mentioned, since they are social determinants. Thus, early exposure to these risks has the potential to influence exposure to situations of high risk to oneself and others, as demonstrated by the crimes for which the sample was convicted: robberies, break-ins, crimes with weapons and drugs, driving motor vehicles. (BRINTNELLA, 2019; PEI, 2016).

Finally, it is worth mentioning the results of the 3C project presented by Brintnella, et al. (2019). The researchers analyzed that a positive result of the program and its objective of reinserting the individuals in the sample into society could be evaluated by the recidivism rate. The study followed the group for 6 months in the community and observed that, according to the participants,



the program helped to contain anger, manage stress and self-awareness, perceive behavior patterns, and improve self-esteem. They also reported the importance of physical exercise, initiated in the program, and, consequently, improvement in relationships and employment.

## PHYSICAL CHARACTERISTICS

Prenatal exposure to alcohol, in addition to neurological and behavioral characteristics, may result in prematurity (below 37 weeks of gestation), being small for gestational age (<10th percentile for gestational age) and/or low birth weight (less than 2,500g regardless of gestational age), factors that promote greater risk to the child's normal development. In addition, growth restriction, characteristic of children diagnosed with FASD, may also present as a smaller head circumference. (NASH, 2017; HASKEN, 2021; ROCHA, 2020; FERRAGUTI, 2019) Based on this information, it is understandable, if there is knowledge of alcohol consumption during pregnancy, that these characteristics are early indicators of a risk of postnatal deficiency such as FASD, according to Hasken, et al. (2021), thus requiring referral for appropriate investigation.

In addition, in addition to what is observed at birth, diagnosed children may have several other physical characteristics such as short palpebral fissures, a thin vermilion border or upper lip, a smooth or flattened philtrum (vertical groove between the nose and upper lip), flattened nasal bridge, small nose turned upwards, maxillary hypoplasia, strabismus, ptosis, retinal malformations, epicanthal folds, narrow or high palate, heart defects, abnormal palmar folds, clinodactyly, camptodactyly, dental malocclusions, joint contractures, "railroad track" ears, hearing loss, hydronephrosis, microcephaly, among others. The first three characteristics mentioned are considered central to the diagnosis of APS, and the others are associated, but not exclusive, with prenatal exposure to alcohol. (FERRAGUTI, 2019; SENTURIAS, 2014a; NASH, 2017).

However, not all affected children have the physical characteristics, which promotes underdiagnosis in this group, resulting in less access to support and necessary interventions. (NASH, 2017) An example of this are pFAS and ARND, which have no involvement with physical parameters. Due to this, according to Hasken, et al. (2021), further studies are needed to better assess the relationship between prematurity and low birth weight and diagnosis within the FASD spectrum. In addition, it should be noted that many of the characteristics mentioned can be confused with other genetic and teratogenic syndromes, including the three main facial dysmorphia of APS: smooth philtrum (grade 4 or 5), the thin vermilion border (grade 4 or 5), and short palpebral fissures. (SENTURIAS, 2014a).



## DIAGNOSIS

Given the prevalence rate of FASD in the USA, 9.1 per 1000 live births, it is likely that many children and adolescents will go undiagnosed. (PAINTNER, 2012a) As previously listed, the individual with PAE is susceptible to permanent damage and various functional problems. The study by Hasken, et al. (2021) showed that, in South Africa and the United States, the more trimesters of alcohol consumption, the higher the risk of FASD diagnosis. Brintnella, et al. (2019) point out that since disabilities are permanent, the identification, diagnosis, and provision of appropriate services are crucial to support and enhance an individual's ability to function in society.

According to Nash, et al. (2017), some factors that contribute to missed or inaccurate diagnoses are: (a) lack of familiarity with FASD, (b) absence of distinct physical signs, (c) lack of knowledge of the history of prenatal exposure to alcohol, and (d) high incidence of mental health disorders related to FASD. In addition, Doak, et al. (2019) highlighted the lack of knowledge and training of health professionals, linked to the lack of funding to support comprehensive and multidisciplinary diagnostic evaluations.

### Prenatal diagnosis

Ferraguti, et al. (2019) estimate that FASD affects 2% to 5% of people in the United States and Western Europe, while in Italy, infant prevalence ranges from 2.3% to 6.3%. In this sense, the author makes it clear that there are several approaches to identify possible cases of FASD, such as analyzing the mother's alcohol consumption habits during pregnancy, examining alcohol metabolites in the biological fluids of pregnant women, and evaluating the morphoneural characteristics of the fetus. Furthermore, for Kable, et al. (2015), prematurity cannot be a critical factor for exclusion from EAP, since the fetus exposed to alcohol may be born with extreme prematurity.

Howlett, et al. (2019) address screening for alcohol use during pregnancy through maternal blood and urine testing, umbilical blood, and meconium, thus having the potential to detect EAP. In addition, the study by Ferraguti, et al. (2019) investigated in pregnant women the association between the biomarker of alcohol consumption, Ethylflucuronide (EtG), urine and indicators of the physical characteristics of FASD by prenatal ultrasound in the second trimester of pregnancy. The research also correlated the data with questionnaires administered to the mothers, such as AUDIT-C, T-ACE/TACER-3, TWEAK, and food diaries – in order to track alcohol consumption during pregnancy.

According to Brown (2019), the meconium test is the only screening tool available among the diagnostic resources for newborn babies when it is not feasible to obtain direct confirmation of alcohol exposure from caregivers. According to Brown (2019), this test analyzes the fecal matter that



accumulates during the second and third trimesters for chemical signatures of ethanol, indicative of PAE, and has an average cost of 175.00 US dollars.

At present, there are no diagnostic criteria available for the prenatal detection of fetal alcohol spectrum disorders. Even so, Paintner, et al. (2012a) emphasize the importance of confirming the initial diagnosis as soon as possible, since in this way, interventions will lead to better results. He says that "early recognition has the potential to decrease the need for later developmental interventions and reduce residential placement and entry rates to substance abuse treatment programs and correction systems."

### Postnatal diagnosis

Due to the discrete and challenging nature of identification, individual FASD abnormalities are usually subtle, non-specific, and difficult to detect. (PAINTNER, 2012a) Thus, obtaining an accurate diagnosis can be challenging and require intensive resources, as addressed by Brown (2019). For him, diagnosis usually requires an extensive series of tests performed by several specialized health professionals, with a cost of up to 5,000 Canadian dollars in 2017. Thus, the author proposed screening for children suspected of having FASD before diagnostic tests, as a way to avoid testing in children with a low probability of receiving a diagnosis.

Early diagnosis of FASD, before the age of six, provides early intervention and care, reducing rates of secondary disabilities such as mental health problems, inappropriate sexual behavior, drug abuse, incarceration, and school exclusion. (BANERJI, 2017; ANDRADE, 2013) In addition, it helps to reduce the risk of future pregnancies with prenatal exposure to alcohol. (HOWLETT, 2019) It therefore helps the child to be inserted more quickly into special assistance services, especially by preparing him for the school years and improving life skills by minimising the sequelae resulting from mental deficits. (BANERJI, 2017; ANDRADE, 2013). Faruk, et al. (2020) complement this, saying that one of the ways to identify the characteristics of FASD is the monitoring of developmental progress, monitoring and observation of children's advances by parents or guardians, who play a primary role in this scenario.

As the child grows, the diagnosis of developmental disorders becomes more identifiable (PAINTNER, 2012a). The authors also state that most cases of FASD are identified when the child is in the ideal window of 2 to 16 years of age – a period in which it is possible to perform an assessment of cognitive development, speech and language, attention, fine and gross motor skills, and other aspects of delayed or aberrant neuropsychological functioning. It is tacit to mention that, according to Paintner, et al. (2012a), information on the diagnosis of FASD in adults is limited and in the elderly it is practically non-existent.



Therefore, the diagnosis of this condition depends on the presence of a set of diagnostic criteria related to four distinct categories: facial features, growth retardation, structural or functional problems in the central nervous system, and history of prenatal alcohol exposure. (DÖRRIE, 2014)

For the diagnosis of Fetal Alcohol Syndrome, defined by the American criteria of the National Center on Birth Defects and Developmental Disabilities (NCBDD), Centers for Disease Control and Prevention (CDC), and the National Task Force on Fetal Alcohol Syndrome, it is necessary that the individual has the triad (A) growth deficiency; (B) damage and/or impairment of the central nervous system; (C) at least two facial features. (SENTURIAS, 2014a).

### Screening tools

In the research developed by Brown (2019), the author addresses the most diverse promising technologies in the identification of individuals with FASD. In the study, he evaluated the cost-effectiveness of the tools used to screen children suspected of having FASD before diagnostic tests. They are: i) Neurobehavioral Screening Tool (NST); ii) ethyl esters of meconium fatty acid (MEAE) (meconium test); iii) Maternal Drinking Guide Tool; iv) Medicine Wheel Student Index/Medicine Wheel Developmental History (Medicine Wheel); and v) FASD Screening & Referral Form for Youth Probation Officers (Asante Screening Tool).

When compared by Brown (2019), the meconium test and NST, both tools resulted in reduced costs and shorter diagnostic time compared to a diagnostic strategy without screening. Thus, screening newborns with meconium tests resulted in a reduced cost of almost 90,000 Canadian dollars for every 100 individuals screened, resulting in 38 fewer years of life diagnosed by age 18, with an incremental cost-effectiveness ratio (ICER) of \$2,359.00. On the other hand, the screening of children with NST resulted in a reduced cost of \$183,895.00 for every 100 individuals screened, with less than 77 years of life diagnosed by the age of 18 years, corresponding to an ICER of \$2390.

Currently under study, the biomarkers of fatty acid ethyl esters (products of ethanol metabolism) and microRNAs (small RNAs that repress protein translation) may correlate with moderate to heavy alcohol consumption during pregnancy. Although promising, Nash, et al. (2017) point to the failure in clinical support of biomarkers at the moment, which do not have evidence in the high-level literature to accurately indicate EAP in screening. Other types of methyl ester screening can be performed, such as searching the hair and nails of mothers and newborns at the end of pregnancy, to then identify mothers whose children may be at risk. (DÖRRIE, 2014).

Thus, the study by Brown (2019) concluded that screening is related to a reduction in the use of health resources, but also results in fewer years of life with a diagnosis of FASD compared to a diagnostic strategy without screening. The author reinforces that in the event that diagnostic tests are





not available, screening should not be a sub-test for diagnosing, as it can lead to inappropriate conclusions and care.

## Prevention

According to the research by Nash, et al. (2017), based on the results of more than 40 years of evidence, universal screening using validated tools would be effective in order to identify individuals vulnerable to PAE and convey clear warning messages about the risks and consequences of alcohol exposure during pregnancy. For Nash, et al. (2017), waiting until a woman or adolescent is aware of her pregnancy to advise her to stop drinking alcohol may be too late, preventing the opportunity for intervention. Also, the entire screening and counseling process is quick, easy, inexpensive, and refundable in many cases. In addition, when done frequently, it reinforces knowledge about FASD and thus its prevention.

## ROLE OF THE HEALTH PROFESSIONAL

### Before diagnosis

The health professional has a crucial role in providing the necessary information for the prevention and identification of FASD, which, if done early, significantly helps in maternal and fetal follow-up. Therefore, adequate screening of alcohol use during pregnancy should be one of the priorities of clinical practice, in addition to a thorough investigation of the home environment and the use of other substances. (HOWLETT, 2019; PAINTNER, 2012a).

According to Howlett, et al. (2019), screening and other early interventions have documented efficacy, and, if added to guidance on the consequences and severity of alcohol consumption during pregnancy, they have the potential to reduce adverse outcomes and improve developmental outcomes and possible treatments. In view of this, it is understood that health professionals need scientific knowledge on the subject in order to optimize all the steps involved in the recognition and care of the FASD.

Primary care providers, such as nurses, physicians, and even midwives, should educate non-pregnant women of childbearing age and pregnant women about the harmful effect of alcohol during pregnancy. (DÖRRIE, 2014) According to Chiodo, et al. (2019), the objective, in addition to instructing and identifying these women, is to reduce the amount and frequency of prenatal consumption in a practical way, thus reducing the risks of developing FASD.

Screening, as stated by Chiodo, et al. (2019), is considered an intervention in itself, since questioning about alcohol consumption, even if decontextualized, has the potential to raise awareness and change the consumer's profile. However, according to a survey conducted by Howlett, et al. (2019), in which 600 obstetrician-gynecologists in the USA were asked about the application of



screening, only 20% of respondents advised abstinence as safe at this stage of life, among the 97% who said they talked to pregnant women about the topic. In addition, around 13% did not know how harmful the use would be, and 4% of them believed that the consumption of 8 or more drinks consumed weekly by these women would not bring adverse effects. In addition, the authors observed that most of these physicians advised patients vaguely or only recommending reduction rather than alcohol cessation.

In light of the above, it is understood that there are barriers in the application of maternal alcohol consumption screening, which involve the professional's knowledge about the topic and its consequences, and the communication between the health professional and the patient in search of the evaluation of their habits (CHIODO, 2019; FERRAGUTI, 2019; HOWLETT, 2019) According to Chiodo, et al. (2019), many professionals report discomfort in questioning the use of alcohol by pregnant women, for example, since they suppose it is a delicate and very personal subject and that it will promote the feeling of guilt in the patient, which, according to the authors, does not occur for most of them. (CHIODO, 2019) Due to this, the application of the questionnaires addressed in the previous topic makes this consumption survey more objective. (KABLE, 2015) Therefore, overcoming such barriers can have a positive impact on maternal-fetal health and child development. (CHIODO, 2019).

Therefore, it is necessary to expand the population's knowledge, and thus raise awareness about the risks related to maternal alcohol consumption, beyond women, thus including their partners and family members in a routine way. (DÖRRIE, 2014) Rocha, et al. (2020) observed that initiatives against alcohol abuse circulate in Brazil, such as the National Policy on Alcohol promoted by the Ministry of Health in 2007, however, it is difficult to find specific information or implemented strategies that relate to FASD.

### During diagnosis

It is a fact that FASD is a permanent condition, however, much can be done for diagnosed patients. (FERRAGUTI, 2019) For this, it is up to health professionals to be, in addition to what has already been discussed, prepared to establish an accurate diagnosis according to the standardized criteria established by the DSM-5. (KABLE, 2015) This diagnosis, in turn, requires a team of mental health professionals, such as psychologists and psychiatrists, however, it is necessary that primary care physicians are prepared to identify and refer such patients for diagnostic evaluation and to specialists, preferably before the age of 6, aiming at a better prognosis. (KABLE, 2015; NASH, 2017).

In addition, other professionals can, and should be, involved in this diagnostic process (and future management), such as primary care physicians, pediatricians, psychiatrists, neurologists,



geneticists, psychologists, occupational therapists, physiotherapists, speech therapists (especially audiologists), as well as social workers, educators and justice personnel who work with this group of people. (HAYES, 2022; ADEBIYI, 2019; BANERJI, 2017; PAINTNER, 2012a; KABLE, 2015) It is up to this multidisciplinary team, as far as they are concerned, to carefully evaluate and understand the needs of each patient individually, so that interventions offered by each specialty are effective based on the difficulties encountered, minimizing sequelae. (PAINTNER, 2012a; ANDRADE, 2013).

On the other hand, as discussed by Adebisi, et al. (2019), professionals state that there is a lack of guidelines to be followed for an easier diagnosis and also for a better follow-up of the diagnosed child. This fact converges with the current underreporting of FASD or misdiagnosis (such as ADHD), which, in turn, are also associated with the lack of knowledge on the part of professionals about the syndrome. (HOWLETT, 2019).

### After diagnosis

Early diagnosis is essential for a good prognosis, however, this will only become a reality if accompanied by efficient intervention. According to the study by Wagner, et al. (2018), the Fitz Roy Valley community pointed out that the lack of support in this process has affected the holistic development of their children diagnosed with FASD, which may be analogous to other communities. Based on this local reality, the author reported the application with positive results of "The Alert Program", developed by occupational therapists, which helps in the emotional, behavioral and relational skills of individuals with FASD, together with their support network, which can be the family and the school, depending on the group to which it was applied, since it is a program with applicability to multiple age groups.

### Drug interventions

Currently, there are no treatments that promote cure in patients with FASD, but as for symptomatic patients, more studies are needed, as Dörrie, et al. (2014) address selective serotonin reuptake inhibitors, antipsychotics, mood stabilizers, tricyclic antidepressants, psychostimulants, among others. However, some are used off-label, such as stimulants to control ADHD symptoms, but this result is not observed in some children within the spectrum of the syndrome, as pointed out by Kable, et al. (2015). It is therefore up to the specialized professional to address each case individually.

### Supporting interventions

Primary care physicians, according to Nash, et al. (2017), play a fundamental role in monitoring and supporting the support network of children diagnosed with FASD. Parents (or



guardians), when they receive the diagnosis, need to deal with the emotions involved in the new reality, accept the child's disabilities, relearn to understand it and receive active support, especially from people with experience. After all, as stated by Nash, et al. (2017), the diagnosis is both parental and child's, given the emotional weight and guilt often involved at this moment, with regard to the mother's alcohol intake during pregnancy.

In addition, professionals should offer therapeutic interventions related to education, executive and cognitive functioning, and social skills in order to prepare the individual for society. With these skills, the potential for delinquency, gang membership, indebtedness, substance abuse, and incarceration decrease, and the chances of independence and quality of life increase. (DÖRRIE, 2014; PAINTNER, 2012a; KABLE, 2015; ANDRADE, 2013) However, it is important to emphasize the need for clear and objective language for caregivers, in order not to overload them with an excessive amount of information, which, consequently, may result in the non-application and non-adherence of the recommendations provided. (HAYES, 2022).

It is also important that, together with the support network, professionals research and point out the vulnerabilities and strengths of each diagnosed individual, in order to then outline the plan of goals and future follow-up, as explained by Hayes, et al. (2022). Therefore, it is essential for the multiprofessional team to take a close look at the personal (emotional, social, psychological, educational) and environmental (inspirational and family context) aspects of the person with FASD.

Finally, it is imperative that the professional community and the population in general have access, understanding and awareness on the subject, in order to better support these individuals. In addition, to promote professional training opportunities, together with the work of elaborate and close monitoring with health professionals and support network, so that, finally, they are fully inserted in society. (HAYES, 2022; SENTURIAS, 2014b).

## CONCLUSION

In this study, an in-depth reading and reflection on the outcomes of the different studies that made up the final sample studied was carried out. In this way, it was possible to map that the deficit in the diagnosis of Fetal Alcohol Syndrome and its similar, negatively affects the patient's safety and modifies their social behavior.

In view of the scenario presented with 30 articles researched, it was possible to identify the complex and heterogeneous nature of the impact of the maternal profile and context, culture and historical-social legacy on individuals with FASD, since they are related to the etiology and epidemiology of the spectrum. In addition, it was observed the broad manifestation of the spectrum in the individual, with regard to physical and neurocognitive issues, adaptive functioning, secondary comorbidities, as well as difficulties in their social and interpersonal relationships.



In addition, issues inherent to the importance of health professionals in this context were explored, showing their role in raising awareness and active intervention in alcohol consumption during pregnancy. In addition, the reason for the urgency in the effective implementation of the various screening and diagnosis tools in the health system was listed. After all, early diagnosis is a predictor of a better holistic development of the individual, which minimizes any losses related to FASD.

Finally, although there are studies on this theme, it is believed that there is a need for research with a greater depth on this diagnosis and the consequences of not doing so, to the detriment of its direct effects on the individual's safety and social behavior.



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