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Women's knowledge of the development and communication of children with Fetal Alcohol Syndrome (FAS)

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The aim of the article is to analyze the results of surveys on women's knowledge about FAS and its consequences for the development of a child's speech and communication. 130 women between 18 and 50 years old took part in the survey. A significant proportion of the surveyed women are aware of the problems and consequences of Fetal Alcohol Syndrome caused by the mother's alcohol consumption during pregnancy.

KEY WORDS: FAS, communication, communication disorders, maternal awareness

Introduction

"Fetal Alcohol Syndrome (...) is the name of a disease that includes a syndrome of congenital abnormalities that can be found in some children of mothers consuming alcohol during pregnancy"¹.

¹ M. Banach, *Dzieci wymagające specjalnej opieki zdrowotnej*, Fundacja Oświecenia Publicznego, Kraków 2004, p. 5.

FAS is a group of physical and mental developmental disorders². "Children with FASD can have many and varied developmental problems and dysfunctions of many organ systems. The manifestations of the consequences of CNS damage include:

- reduced intellectual abilities about half of the children have diagnosed intellectual development deficits of various degrees,
- disturbed functions of direct memory, it is inefficient,
- reduced generalization and planning skills,
- difficulties in abstract thinking,
- the occurrence of visual and hearing disorders and many other functional limitations"³

as well as: delayed speech development, processing and memory disorders, impaired articulation, melody and speech prosody, impaired fluency in word production, speech impediments, talking to oneself, impaired phoneme differentiation, problems with understanding social behavior, problems with understanding information not given directly: metaphors, allusions, hearing disorders, including auditory self-monitoring.

Research aim and methodology

The aim of the article is to analyze the results of surveys on women's knowledge about FAS and its consequences for the development of a child's speech and communication.

² M. Klecka, M. Janas-Kozik, *Dziecko z FASD. Rozpoznania różnicowe i podstawy terapii*, Wydawnictwo Edukacyjne PARPAMEDIA, Warszawa 2009, p. 8; M. Komorowska, *Potrzeby edukacyjne dzieci z FASD*, "Remedium" 9, 2007, pp. 24-25; D. Hryniewicz, *Specyfikacja pomocy psychologiczno-pedagogicznej dzieciom z FAS*, Wydawnictwo Edukacyjne PARPAMEDIA, Warszawa 2007, p. 8.

³ T. Jadczak-Szumiło. *Problemy diagnostyczne dzieci z Płodowym Zespołem Alkoholowym (FAS) – możliwości wykorzystania testu WISC-R w diagnozie różnicowej*, Unpublished doctoral dissertation written under the supervision of prof. E. Hornowska, UAM Poznań 2014, p. 21.

A questionnaire completed by 130 women between 18 and 50 years of age was used for the survey. The questions in the survey concerned general information about FAS, the characteristic features of children with this syndrome, and the influence of Fetal Alcohol Syndrome on speech and communication.

Characteristics of the research group

Some of the 130 surveyed women (62) are between 18 and 24 years of age, while the number of women in the remaining age groups is even, as shown in Chart 1.

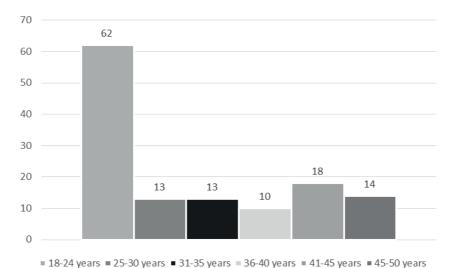


Chart 1. A numerical list of the surveyed women in individual age groups.

Source: own study.

Women participating in the survey live in villages, towns and cities. From among the respondents, only 1 woman has vocational education, while 63 has secondary and 66 higher education. Out of 130 respondents, 71 women did not have children, and the remain-

ing 57 declared having children. 32 women have one child, 24 women have two children, and 3 surveyed women have three or more children.

A question about alcohol consumption during pregnancy was addressed to all women who have children. The answers given are as follows:

- during pregnancy, <u>I consumed</u> alcohol (even in the smallest amount) and <u>I was aware</u> of all possible consequences of consuming even the smallest amount of alcohol – 1 answer;
- during pregnancy, <u>I did not consume</u> even the smallest amount of alcohol, <u>I was aware</u> of all possible consequences of consuming even the smallest amount of alcohol – 51 responses;
- during pregnancy, <u>I consumed</u> alcohol (even in the smallest amount), <u>I was not aware</u> of the negative consequences for my child resulting from the consumption of alcohol – 4 responses;
- during pregnancy, <u>I did not consume</u> even the smallest amount of alcohol, <u>I was not aware</u> of the negative consequences for my child resulting from the consumption of alcohol – 3 answers.

Analysis of the research

90 out of 130 women knew the definition of FAS and could identify what the disorder was. 33 respondents did not attempt to answer the question, 3 people admitted the lack of knowledge in this respect, and 4 people defined FAS incorrectly. 38 women admitted having met a person with FAS once. The others replied that they had not met such a person or did not know what FAS meant.

Various answers were given to the question of where or in what circumstances the respondent first encountered the term FAS. The most common of them are presented in Chart 2.

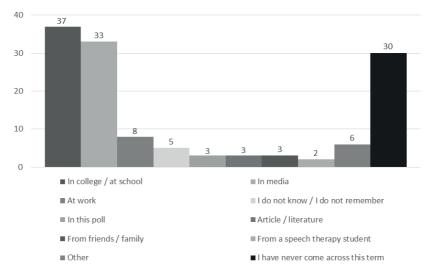


Chart 2. Circumstances of the first meeting of the respondents with the FAS term. Source: own study.

6 people gave answers that did not fit into any of the narrow categories, which is why they were placed in the chart under the name "other", and they were: a course for a rest teacher, speech therapy clinic, banner at the bus stop, situation in the family or heard somewhere, special school attended by my daughter.

Of the 130 women surveyed, 103 answered correctly, indicating the reason for the FAS. 16 women did not know the answer, 8 answered too broadly, which could not be treated as a correct answer, 3 answers were incorrect.

Alcohol consumed in moderation during pregnancy was judged as safe by 2 women, and 3 showed ignorance in this regard. The remaining 125 women considered alcohol consumed during pregnancy, also in moderation, to be dangerous. 81 women considered each dose of alcohol harmful to the fetus; 17 women showed ignorance in this regard; 7 people decided that drinking alcohol is forbidden during pregnancy (regardless of the dose); 2 respondents indicated that it all depends on a given case, and 6 women decided that there

was no specific harmful dose. The remaining 17 people administered specific doses that should not be exceeded – these responses ranged from 5 ml to 4 per mille. There were also statements that it all depends on the type of alcohol and the frequency of its consumption and among the respondents, the wine was considered to be the so-called "Healthy alcohol", the respondents allowed drinking a glass of wine from daily to once every several months.

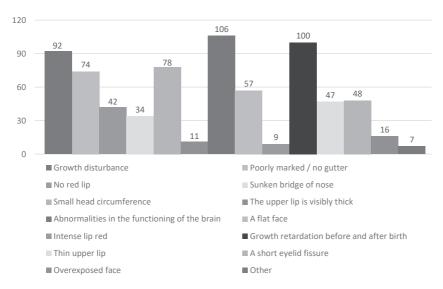


Chart 3. Respondents' answers about physical symptoms indicating Fetal Alcohol Syndrome.

Source: own study.

The participants' task was also to list the physical symptoms indicative of Fetal Alcohol Syndrome. The most common symptoms of FAS turned out to be brain abnormalities (106 responses), pre- and postnatal growth retardation (100 responses), and growth failure (92 responses). More than half of the women filling out the questionnaire considered a small head circumference (78 responses) and a poorly marked subnasal ridge or lack of it (74 responses) as

a symptom of FAS. This means that the respondents' awareness of the symptoms of Fetal Alcohol Syndrome is quite high. The most numerous answers are correct, however, the symptoms of FAS also include answers that were indicated by a few respondents, e.g. a short eyelid fissure. It is worth noting, however, that incorrect responses, such as intense red lip, thickened upper lip or excessively prominent face, were given only a few times.

100% of surveyed women admitted that FAS influences the further development of the child, however 21 people declared that they did not know what impact it was. 104 women listed the following FAS effects:

- psychophysical development delay / disorder 36 responses,
- learning difficulties 13 answers,
- impaired intellectual development / intellectual disability / lowered IQ - 10 responses,
- social maladjustment / disturbance of functioning in society 7 answers,
- brain disorders 6 responses,
- executive function disorders 4 responses,
- cognitive development disorders 4 responses,
- speech and communication disorders 4 answers,
- depression / personality disorders 3 answers,
- physical fitness disorder 2 responses,
- physical defects / disturbed appearance 2 answers,
- emotional development disorder 2 answers,
- CNS functioning disorders / damage 2 responses,
- tendency to drink alcohol 1 answer,
- ADHD 1 answer.

There were also responses regarding the short stature of children with FAS, problems with impulse control, visual, hearing and kidney function impairments, withdrawal syndrome and withdrawing.

The next part of the study concerned the assessment of the impact of FAS on the development of speech and communication in the later stages of a child's life. Proper speech development is the key to knowledge and an important factor in shaping the personality. If

the child's speech development process is correct, then the thinking process also becomes correct, and thus communication takes place properly⁴. Language difficulties resulting from memory impairment and deficiencies caused by damage to various structures in the brain have a major impact on the communication of people with FAS⁵. 22 people admitted ignorance of the influence of FAS on the development of speech and communication in the later stages of the child's life, and one person stated that FAS had no influence on it. 30 people confirmed the effect but did not mention any further consequences. The remaining people confirmed that FAS influences the development of speech and communication and indicated possible symptoms of these disorders. Among the most common answers were:

- delayed speech development 28 responses,
- not understanding jokes 11 answers,
- speech impediments / slurred speech 13 answers,
- problems with establishing contacts 8 answers,
- stuttering 8 answers,
- difficulties in recognizing and expressing emotions 7 answers,
- concentration disorders 6 responses,
- low vocabulary 4 answers,
- speech therapy problems (not specified in detail) 4 answers,
- total speech development disorder 3 responses.

Single responses turned out to be numerous, including: mental deficits, disturbed thought processes, illogical ordering, aphasia, linguistic errors, low muscle tension, inadequate education of the speech organ.

⁴ H. Pawłowska-Jaroń, *Sfery zaburzonego rozwoju u dzieci z FASD*, [in:] *NOWA LOGOPEDIA.Biologiczne uwarunkowania rozwoju i zaburzeń mowy*, vol.2, eds. M. Michalik, A. Siudak, Collegium Columbinum, Kraków 2011, pp. 123-139.

⁵ M. Krakowiak, Postępowanie logopedyczne w przypadku dzieci z zespołem poalkoholowym (FAS), [in:] eds. J. Panasiuk, S. Grabias, T. Woźniak, Logopedia. Standardy postępowania logopedycznego, Wydawnictwo UMCS, Lublin 2015, p. 426.

The surveyed women also emphasized in their responses that it all depends on the degree of damage to the fetus, as well as the place and degree of damage to the central nervous system.

The participants' task was also to list the four main diagnostic features on the basis of which FAS is determined. According to the 4-Digit Diagnostic Questionnaire, it is a shortage of height, the facial system characteristic of FAS, abnormalities in the central nervous system and confirmation of alcohol consumption by the mother (during pregnancy). The responses are presented in Chart 4.

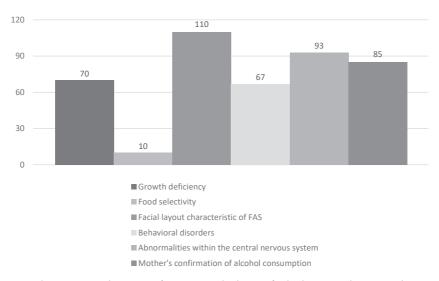


Chart 4. Main diagnostic features on the basis of which FAS is determined.

Source: own study.

Most of the selected responses were correct, but there were also inappropriate indications, e.g. behavioral disorders or food selectivity.

They were also asked about problems specific to children who had been exposed to alcohol in utero. The responses are presented in Chart 5.

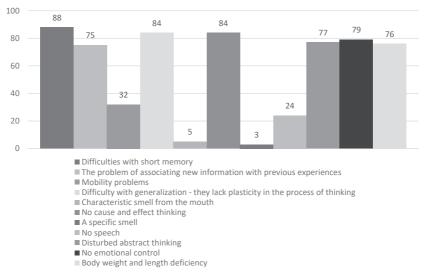


Chart 5. Problems specific to children exposed to alcohol in utero.

Source: own study.

Most of the respondents gave the correct answers. As many as 88 women were aware that exposure of a child to alcohol in utero may cause difficulties with short memory. 84 respondents knew that children of mothers who drink during pregnancy have difficulties with generalization, which means that they lack plasticity in the process of thinking and also have problems in the field of cause-and-effect thinking. The 70 correct answers also include: disturbed abstract thinking, lack of emotional control, weight and length deficiency. 64 incorrect answers were given, including: problems with movement, characteristic smell from the mouth, lack of speech, specific smell.

Summary

For the purposes of this article, a survey was conducted with 130 women. The knowledge of women about Fetal Alcohol Syndrome and its consequences for the future life of the child is quite large, however,

among the respondents there were women who, despite this awareness, consumed alcohol during pregnancy. The conducted survey showed that the awareness of women aged 18-50 about FAS is selective.

"As can be seen from the list above, problems in children with FASD are disorders of a complex and multidimensional form"⁶. As a consequence, the above-mentioned effects of FAS cause health problems that hinder functioning, problems in school education and difficulties in achieving independence. In addition, they often lead to depression, addiction, conflicts with the law, thoughts and suicide attempts, as people with FAS are unable to cope with "otherness" without the help of specialists.

When analyzing the consequences of FAS for a child, it is important to consider the time the child's mother consumed alcohol. Consuming alcohol in the first trimester of pregnancy causes brain damage, facial deformities, damage to the heart and liver, and consequently, miscarriage. Drinking alcohol in the second trimester of pregnancy may cause: damage to the baby's brain, damage to its muscle, bone, skin and gland cells. A mother drinking in the third trimester may cause her child to experience delays in weight gain, may develop brain structure and functioning disorders, and may lead to premature birth⁷. FAS manifests as primary and secondary disorders. "Primary disorders are the result of brain damage in children with FASD. Secondary disorders need not arise. They are the result of a lack of adequate help for children with FASD"8. In addition to all the abnormalities and disorders in the development of children mentioned above, complete damage to the fetus may also occur, and consequently its death.

⁶ M. Banach, J. Matejek, W trosce o zdrowie dziecka i twoje. Płodowy zespół alkoholowy (FAS) – kompendium wiedzy, Wydawnictwo «scriptum», Kraków 2016, p.44.

⁷ J. Klimczak, *FetalAlcoholSyndrome – czyli skutki oddziaływania alkoholu na płód,* [in:] ed. M. Banach, *Alkoholowy zespół płodu. Teoria – Diagnoza – Praktyka,* Wydawnictwo WAM, Kraków 2011, pp. 147-155.

⁸ T. Jadczak-Szumiło, K. Kałamajska-Liszcz, K. Liszcz, *Jak wspomagać dziecko z FASD w edukacji*, Państwowa Agencja Rozwiązywania Problemów Alkoholowych PARPA, Warszawa 2018, p. 23.

The summary of the answers given in the questionnaire allows us to draw conclusions that a large proportion of the surveyed women are aware of the symptoms, problems and consequences of Fetal Alcohol Syndrome caused by the mother's alcohol consumption during pregnancy. However, it is worth disseminating information about this syndrome to the few women who have not heard of it, and to those who consumed alcohol during pregnancy, exposing their children to possible tragic consequences.

References

- Banach M., Dzieci wymagające specjalnej opieki zdrowotnej, Fundacja Oświecenia Publicznego, Kraków 2004.
- Banach M., Matejek J., W trosce o zdrowie dziecka i twoje. Płodowy zespół alkoholowy (FAS) kompendium wiedzy, Wydawnictwo «scriptum», Kraków 2016.
- Hryniewicz D., Specyfikacja pomocy psychologiczno-pedagogicznej dzieciom z FAS, Wydawnictwo Edukacyjne PARPAMEDIA, Warszawa 2007.
- Jadczak-Szumiło T., Kałamajska-Liszcz K., Liszcz K., Jak wspomagać dziecko z FASD w edukacji, Państwowa Agencja Rozwiązywania Problemów Alkoholowych PARPA, Warszawa 2018.
- Jadczak-Szumiło T., Problemy diagnostyczne dzieci z Płodowym Zespołem Alkoholowym (FAS) – możliwości wykorzystania testu WISC-R w diagnozie różnicowej, Unpublished doctoral dissertation written under the supervision of prof. E. Hornowska, UAM Poznań 2014.
- Klecka M., Janas-Kozik M., *Dziecko z FASD. Rozpoznania różnicowe i podstawy terapii*, Wydawnictwo Edukacyjne PARPAMEDIA, Warszawa 2009.
- Klimczak J., Fetal Alcohol Syndrome czyli skutki oddziaływania alkoholu na ptód, [in:] red. M. Banach, Alkoholowy zespół ptodu teoria diagnoza praktyka, Wydawnictwo WAM, Kraków 2011, p. 147 155.
- Komorowska M., Potrzeby edukacyjne dzieci z FASD, "Remedium" 9, 2007, s. 24-25.
- Krakowiak M., Postępowanie logopedyczne w przypadku dzieci z zespołem poalkoholowym (FAS), [in:] eds. J. Panasiuk, S. Grabias, T. Woźniak, Logopedia. Standardy postępowania logopedycznego, Wydawnictwo UMCS, Lublin 2015, s. 419-435.
- Pawłowska-Jaroń H., *Płodowy zespót alkoholowy zagadnienia mowy i percepcji*, "Szkoła Specjalna" 2, 2010, p. 113-120.
- Pawłowska-Jaroń H., Sfery zaburzonego rozwoju u dzieci z FASD, [in:] eds. M. Michalik, A. Siudak, NOWA LOGOPEDIA. Biologiczne uwarunkowania rozwoju i zaburzeń mowy, vol. 2, Collegium Columbinum, Kraków 2011, p. 123-139.