Rozensztrauch Anna, Świątoniowska Natalia, Tomaszewska Kinga, Kołtuniuk Aleksandra. A child with Fetal Alcohol Syndrome (FAS) – nursing care. Journal of Education, Health and Sport. 2018;8(7):67-77. eISNN 2391-8306. DOI http://dx.doi.org/10.5281/zenodo.1278942
http://ojs.ukw.edu.pl/index.php/johs/article/view/5552

The journal has had 7 points in Ministry of Science and Higher Education parametric evaluation. Part b item 1223 (26/01/2017).
1223 Journal of Education, Health and Sport eISSN 2391-8306 7

The authors declare that there is no conflict of interests regarding the publication of this paper.

Received: 10.05.2018. Revised: .02.06.2018. Accepted: 05.06.2018.

A child with Fetal Alcohol Syndrome (FAS) – nursing care

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Abstract

Fetal Alcohol Syndrome (FAS) is the group of conditions observed in children who happened to be exposed to the effects of alcohol in their prenatal development. Some very characteristic symptoms, belonging to three groups, such as: craniofacial abnormalities, physical development deficiency and the central nervous system damage, can be distinguished in people with FAS. It also significantly affects the person's behaviour. The main objective of the research is to present the problems that a girl suffering from a fetal alcohol syndrome has to struggle with. The work has been prepared on the basis of the available literature analysis as well as of the nursing process. A method of an individual case study has been applied. The nursing care of a child with FAS should definitely involve routine caring activities, however with particular attention paid to their psychological aspect. The child suffering from FAS

must be treated in a very individual way, basically due to his/her cognitive disorder. A nurse should strictly follow 8 precisely fixed principles.

Key words: FAS, nursing care

Introduction

Fetal Alcohol Syndrome (FAS) is the group of conditions observed in children who happened to be exposed to the effects of alcohol in their prenatal development [1,2,3]. As its name suggests, the main reason for this syndrome to appear is the fact that a mother drank alcohol during pregnancy. So far, the amount of alcohol that a mother must drink to cause irreversible damage to the fetus has not been precisely determined. It is assumed that any amount has a teratogenic effect on a child's life and his/her future development, regardless to a pregnancy trimester, however it is said that the biggest effect can be observed in the first trimester when the process of forming internal organs and extremities is taking place and, in particular, forming of a child's face, on which several characteristic, for individuals with FAS, craniofacial abnormalities will be visible in the future.

Statistically, fetal alcohol syndrome (FAS) is believed to occurs in 2 out of 1000 live births, however this number may vary depending on the place of birth, social status or ethnic origins of a mother [4].

Some very characteristic symptoms, belonging to three groups, such as: craniofacial abnormalities, physical development deficiency and the central nervous system damage, can be distinguished in people with FAS. It also significantly affects the person's behaviour [5,6].

The primary role of a nurse caring for a patient with FAS is to show a holistic approach to the problem. The most important issue at the very early stage of the diagnosis is the appropriate knowledge defining the challenges that might appear to us in our everyday life. First of all, the nurse's task should be to help the patient develop self-care abilities and instruct his family how to interact with such a person, since it is possible to prevent FAS. The only certain way to do this is to avoid drinking alcohol during pregnancy or even while planning a pregnancy, the latter to avoid damage even in the earliest stages (even weeks) of a pregnancy. Therefore, it is crucial to develop and improve knowledge about the problems that can result from prenatal alcohol exposure, not only among pregnant women, but also those who are likely to get pregnant due to the fact of being in maternal age, and even among teachers at schools. Here comes the nurse's turn. Women have to be aware of the fact that it is not necessary to be an alcoholic to give a birth to a baby with FAS. The effects of alcohol are observed significantly longer in a baby's body rather than in a mother's body. Since the fetus's liver is not completely developed yet, it is impossible to get rid of the toxins that get into its bloodstream through the maternal placenta [6].

Case study

The girl was born at due time weighing 2350g. However, intrauterine growth restriction was

diagnosed in her fetal life. As medical records show, the girl's mother used to consume quite an amount of alcohol up to the third month of her pregnancy. A problem with alcohol drinking in the girl's family house has been present for a few generations, thus greatly disturbing the family life and leading to a significant decline in the material status of the family. Several characteristic craniofacial abnormalities, such as: a wider than normal space between eyes accompanied by small eye opening, thinner than usual upper lip and a smooth philtrum, could be easily observed in the girl.

Several characteristic features typical for FAS - short height, low body weight (at or below the 3rd percentile) and a small head size, have been easily perceived since the very moment the girl was born. Moreover, the girl suffers from clinodactyly of the fifth finger of both hands, asymmetrical and lower than usual position of both ears and altered palmar creases. In her infant life, the girl had problems with eating. All the food had to be crumbled. Up till now, the child happens to suffer from occasional diarrhoeas. The girl has also been found to have difficulties with attention since she became 3. In the kindergarten, the girl was very sociable and outgoing and willingly played with other children and she was quite liked by her peers. She could easily start a relationship with strangers. She demanded attention and interest. However, at the age of 6, the girl started to display first problems concerning appropriate interactions with her mates. At the same time, difficulties with controlling her physiological needs including urinary incontinence, started to occur. Additionally, the girl's tutors observed a significant decline in her ability to understand and respond to simple commands as well as the fact that she could get easily distracted. The girl was also diagnosed with hypoaesthesia. Since the age of 4, she has been a permanent patient of an allergological and neurological clinics. In this particular case, FAS was diagnosed when the girl was 5.

At the moment of being admitted to a hospital, the girl was restless. She did not allow the doctors to examine her and all the time she was hyperactive. She asked lots of questions and frequently grunted. The cough was also present at the moment of doing the research. On the basis of what her mother admits, it may be concluded that the girl's relationships with her peers are far from the correct ones. She does not feel comfortable at school, speaks quickly and unintelligibly. Due to the way she articulates the sounds, her schoolmates as well as her teachers hardly find her communicative. Once or twice a week, the child suffers from diarrhoea, she does not want to eat, has a low body weight and wets herself at night. According to the opinion prepared by experts from a psychological-pedagogical clinic, the girl shows functional intellectual deficiency, sensory processing disorder, visual perception disorder as well as verbal fluency and cognition deficiency as far as her age is concerned. In the area of communication and adaptive behaviours the girl also goes below the level appropriate for her age group.

Methods

A method referred to as „an individual case study" has been applied to do the research. The whole description presented in the work, was based on medical records for an 8 year old female patient who was admitted to a Paediatrics Ward of a hospital in order to diagnose appropriately the reasons for her chronic cough accompanied by a big amount of mucus present in her throat. The girl was diagnosed with FAS three years earlier.

A plan of adequate medical care for several potential diagnosis that might indicate the

risk of the occurrence of a particular case, was prepared. Unfortunately, the prepared plan of medical care cannot be described as the integrated one, since it is based only on the accessible records, i.e. the history of nursing, the observation card, temperature records, doctor's recommendations records, medical history and opinions expressed by medical personnel. The description of the case is the effect of the analysis of medical records done in the hospital ward during the girl's 7 day stay there.

Results

During the girl's 7 day hospital stay at the Paediatrics Ward, the following nursing problems were observed:

1. **Diagnosis**

   The child's discomfort caused by a chronic cough

   Aim: To minimize discomfort

   Nursing activities:

   - Assessment of airway
   - Administer bronchodilators as ordered
   - Monitor VS every 2 - 4 hrs.
   - Perform chest physical therapy
   - Instruct patient/family to notify nurse if the client is experiencing shortness of breath or air hunger
   - Instructing the parents how to provide the child with an appropriate microclimate and how to perform chest physical therapy
   - Application of postural drainage
   - Advising the mother to lay the child in half-high position
   - Providing the appropriate microclimate in the hospital room by means of maintaining right humidity 40-60% and temperature 18 – 21 °C
   - Ensuring peace and quiet
   - Teaching the girl how to expectorate mucus effectively and reminding her about the necessity of slow and deep breathing while lying in half-high position, holding a breath for a while (about 3-5 seconds) and then breathing the air out through the mouth
   - Reminding the girl about the necessity of expectoration hygiene and instructing her how to get rid of sputum properly
   - Providing appropriate conditions for hygienic coughing – sufficient number of tissues and amount of lignin as well as a kidney-shaped bowl for used tissues
   - Providing appropriate liquids intake, at least 1.5 litre per day
   - Informing the patient about some negative stimulants intensifying the cough
   - Applying nebulisation according to a doctor's recommendations

   Justification for taken actions:

   Applying inhalation aims at attenuating mucus whereas therapeutic and nursing actions aim at making expectoration easier, thus bringing the child bigger comfort.

2. **Diagnosis**

The child's bedwetting as the effect of psycho-emotional disorder

Aim : To decrease the child's discomfort resulting from uncontrolled urinating.

Nursing activities:

- Suggesting possible treatments.
- Teaching the child and her family how to eliminate stressful situations.
- Showing kindness and support to the child. It is definitely forbidden to shout at the child or make her feel sorry for bedwetting.
- Supporting the child to cope with the problem.
- Teaching the child and reminding her parents about getting the habit of going to the toilet before sleep.
- Making the child and her parents aware of the necessity of restricting the amount of liquids intake before going to bed. The child should not drink anything later than 2-3 hours before sleep.
- Encouraging parents to avoid giving the child, before her going to bed, any drinks or food that show strong diuretic properties (fizzy drinks, apple juice or vegetables and fruit).
- According to a paediatric surgeon's recommendations, the child should be woken up at night, basically by means of an alarm-clock, in order to get the habit of voiding urine in regular time intervals (every three hours)
- Keeping records of and 'wet nights'.
- Rewarding the child for each 'dry night'.
- Encouraging the child to do particular types of physical exercise, e.g. squats or tighten and unclench thighs alternately, in order to get the habit of voiding urine at night in regular time intervals every
- Preventing urinary tract infections.
- Instructing the child how to keep the crutch hygiene and suggesting the use of appropriate underwear.
- Instructing the child and her parents how to deal with wet underwear and sheets.
- Provide access to regular control visits to a paediatric surgeon.

Justification for taken actions:

All the taken actions aim at reducing or even eliminating totally the child's uncontrolled bedwetting caused by psycho-emotional disorder. The main aim of the conversation with the child is to decrease the feeling of guilt as well as to give help to cope with the problem.

3. **Diagnosis**

Body weight deficit in the process of lacking appetite.

Aim: To provide the child with essential nutrients.

Nursing activities:

- Providing the child with 5 meals a day.
- Adjusting the meals to the child's taste.

- Introducing balanced diet
- Serving the meals at equal time intervals, every 3 or 4 hours.
- Ensuring appropriate atmosphere while having meals
- Caring for tasteful look of the served dishes.
- Talking to the child in order to explain the importance of following an appropriate diet.
- Regular observation of the child – daily weight control.
- Instructing the parents how to cut down on the number of sweets the child consumes
- Making the parents aware of negative effects of malnutrition.

Justification for taken actions:

Serving 5 meals a day at regular time intervals provides the child with a constant level of insulin, thus assuring her better comfort. Introduction of balanced diet adjusted to the child's taste and the tasteful look of the served dishes are supposed to persuade the girl to eat the served food. Educating both, the parents and the child, basically aims at affecting positively the further process of good nutrition and making the child put on weight.

4. **Diagnosis:**

   Difficulties related to appropriate communication with the girl due to the articulation disorder she suffers from.

   Aim: To begin the right and effective interaction with the girl.

   Nursing activities:

   - Providing the girl with a constant assistance of a speech therapist.
   - Conducting regular conversations with the girl.
   - Persuading the child's mother to get involved in her daughter's speech therapy.
   - Providing the child and her parents with emotional support
   - Showing the child a lot of understanding, patience and kindness. Avoiding to hurry her while uttering her statements..
   - Increasing the feeling of safety and decreasing the feeling of fear.
   - Giving consideration to the girl's routines and habits.
   - Communicating the girl short and precise pieces of information.
   - Regularly telling the child about significant things which are difficult to understand. Speaking slowly using simple sentence constructions. Always making sure that the girl understood what she was told about.
   - Avoid introducing changes to the girl's environment.
   - Observing the girl thoroughly.
   - Encouraging the girl to read books she likes.
   - Enabling the girl to have the access to watching educational cartoons.
   - Organizing group activities.
   - Persuading the girl's mother to read books to her daughter in order to practice and improve her pronunciation.
   - Informing the mother about institutions where she could get appropriate assistance in her daughter's speech therapy.

Justification for taken actions:

The actions described above, basically aim at starting the right interaction with the girl. Because of FAS occurrence, the girl must be approached in a very individual way. Reading books and watching cartoons will result in the improvement of the girl's pronunciation and her vocabulary enrichment. The fact of informing her mother about appropriate institutions dealing with speech impediments and a constant assistance of a speech therapist, are both likely to improve the girl's pronunciation, which will make her life in the society easier in the future.

5. **Diagnosis:**

FAS occurrence as the main cause of problems related to getting adapted to school environment.

Aim: To increase the girl's self-confidence.

Nursing activities:

- Talking to the girl about her problems.
- Providing emotional support and understanding
- Ensuring peaceful atmosphere, showing empathy and acceptance.
- Respecting the girl's feelings.
- Providing regular assistance of a psychologist and a pedagogue
- Organizing fun and games as the form of free time activities.
- Encouraging the girl to play with her room mates.
- Persuading the girl's mother to discuss her daughter's school problems with her tutor.
- Encouraging the girl to speak out about her problems.
- Organizing a meeting with the girl's school mates in order to discuss the possible adaptation related disorders the children might face at school.

Justification for taken actions:

Children diagnosed with FAS are often found to show very low self-confidence, feel rejected by the society and show low level of adaptation into their peers environment. Therefore, it is essential to talk to such a child a lot and show respect to his/her feelings. Taking appropriate nursing actions, is really likely to increase the child's self-confidence level, at least by minimum.

6. **Diagnosis:**

The child's mother's FAS related knowledge deficit.

Aim: To improve the parent's knowledge about FAS and its effect on the child.

Nursing activities:

- Diagnosing the mother's knowledge about FAS.
- Educating the mother about the main causes of FAS.
- Providing useful information about the essence of the illness and the FAS diagnosed child's needs.
- Defining the acceptance stage of disorders occurring in a child.
- Assessing the mother's attitude towards the child's condition.

- Defining caring and nursing possibilities and restrictions with respect to coping with a child with FAS.
- Persuading the mother to co-operate with the therapeutic team.
- Assisting the mother with her stress management. Showing emotional support, kindness, tolerance and empathy by means of frequent conversations.
- Providing educational materials concerning the ways of supporting a child with FAS.
- Pointing out additional support sources, e.g. getting in touch with children suffering from a similar condition.
- Defining and communicating 8 steps for a carer of a child with FAS [6]:
  - ✓ Clear objectives
  - ✓ Steadiness
  - ✓ Repetition
  - ✓ Routine
  - ✓ Simplicity
  - ✓ Detail
  - ✓ Principles
  - ✓ Supervision
  - Recommendations to follow the above rules
  - Making the child's mother aware of the problem with alcohol abuse observed in the family.
  - Providing the family with the opportunity of getting in touch with a specialist treating addictions.
  - Showing the family possible ways of increasing life quality and improving their social and economic conditions.
  - Introducing the family to support groups dealing with fighting against addictions, e.g. Anonymous Alcoholics

Justification for taken actions:

The actions taken in this point aim at appropriate assessment of the mother's knowledge level about a particular case and help her to accept certain disorders observed in her child. The key issue here is a conversation with the woman since she is supposed to be the greatest support to her daughter in her adult life.

Discussion

The most frequently occurring effect of alcohol drinking by a mother during pregnancy is fetal alcohol syndrome (FAS), which is considered to be the most severe form of the condition, however other types of the condition including partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) can also be observed. In the described case, as the mother admitted, alcohol consumption took place during the first three months of the pregnancy. According to Paley et al. one of the first visible abnormalities observed shortly after a birth is a low body weight (below 2500g) [7]. In the case described above, the situation looked identical – the baby was born with the body weight reaching only 2350g. Another abnormal

feature that can be observed is, as described by Campo et al. significant growth deficiency both, intrauterine growth as well as after the birth [8]. In case of the girl described in this work, small head size, growth and weight deficiency defined as significantly below average (at or below the 3rd percentile) were observed and in her fetal development intrauterine growth restriction was diagnosed. The patient also shows other characteristic for FAS features easily visible in her appearance, such as clinodactyly of the fifth finger of both hands, described by Baranowska [6], or several characteristic craniofacial abnormalities, emphasized by Szwedowska et al [9]. Most visible facial deformities are: wider than normal space between eyes accompanied by small eye opening, thinner than usual upper lip and a smooth philtrum, short nose, low nasal bridge as well as small flattened midface. According to Szwedowska, the most characteristic for FAS, craniofacial abnormality is wider than normal space between eyes, the feature which is also easily observed in the discussed case.

As it can be found in literature, apart from visible physical deformities, some other conditions typical for those affected by FAS, are said to occur. The girl, described in the work, often happened to suffer from middle ear inflammation, as mentioned in the works by Bąbała et al., mukofagia and other digestive system disorders, described by Brosowska [10,11]. Baranowska points out frequent difficulties with food intake that occur at neonatal and infant age [6]. On the other hand, Janas – Kozik et al. mention deep sensibility disorder as quite likely to occur [12]. The patient, described in this work, often happened to hug others in a very strong way, however being completely unaware of that. Further tests confirmed the occurrence of hypoaesthesia, the condition being a neurological impairment, however in this case, caused also by prenatal alcohol exposure. Another neurological impairment that is observed, is patients' oversensitivity to numerous stimulants appearing at the same time, thus making them unable to be coped with. This phenomenon is mentioned by Jessica [13].

As Paley et al. claim, children diagnosed with FAS, tend to have difficulties with appropriate interaction with their peers [7]. In the discussed case, the girl was fully taken up by her mates up to the kindergarten age, whereas in further years when the differences between her and her peers started to deepen, the situation got significantly worse. In spite of her age, the girl often behaved like a stubborn 2-year-old child and tried to impose her opinions by means of shouting or crying. She often got furious. Because of her strange behaviour she was gradually made separated from the group. Unfortunately, such a child eventually becomes an object of taunts and her peers start teasing her. Such a situation is observed and described by Szczupał [14]. His opinion is shared by Przyłożyńska who additionally makes an assumption that such children are often found dysfunctional, both at home and at school [15]. Moreover, these children find making friends and maintaining existing friendships really hard and due to the fact of being different, their self-esteem goes below average, which also negatively affects the relationships with their peers. It frequently happens that such children close up and are considered to be extremely shy by the society that is completely unaware of their condition. As Szczupał admits, another effect of FAS is the right management of emotions or even recognizing them correctly [14]. All these problems proved to be found in the presented case. The girl shows discomfort of being together with her school mates since she is unable to build up proper relationships with them. According to Janas – Kozik et al. patients diagnosed with FAS appear to be very sensitive to rejection, have problems with attention, memory, judgment and abstract thinking, which especially in case of

children, leads to learning disabilities thus, problems at school [12]. This is also observed in the presented case. Additionally, due to the fact that she speaks quickly and unintelligibly her schoolmates as well as her teachers hardly find her communicative. Dębski et al. claim that speech and intellectual impairments are also direct effects of prenatal alcohol exposure [16].

Literature analysis does not prove the occurrence of bedwetting, which was observed in the discussed case The fact that there is very little information found about the problem which concerns not only the patient but also his family and even his close environment, can be surprising. Only Baranowska mentioned and presented 8 steps regarding treatment of a child with FAS. These are basically tips, since there is no single precisely described cure that might be applied to treat all the children diagnosed with FAS [6]. Therefore, each case must be perceived very individually and the care must be of a holistic character. In case of a recurrent problem concerning alcohol consumption, it is crucial to make the patient as well as his family aware of a destructive effect of alcohol on their daily life, since not everyone seems to realise how serious the situation might be. In order to solve the problem with alcohol overconsumption, the nurse should be able to persuade the patient to find extra help of a specialist.

It is possible to prevent Fetal Alcohol Syndrome. The only certain way to do this is to avoid drinking alcohol during pregnancy or even while planning a pregnancy, the latter to avoid damage even in the earliest stages (even weeks) of a pregnancy. Therefore, it is crucial to develop and improve knowledge about the problems that can result from prenatal alcohol exposure, not only among pregnant women, but also those who are likely to get pregnant due to the fact of being in maternal age, and even among teachers at schools.

Nursing Implication

While looking after a patient diagnosed with FAS, it is really important not to forget that routine caring actions should be accompanied by those including a psychological aspect. Two fundamental problems a child with FAS has to struggle with are adaptive behaviour and social communication. Due to this fact, the child must be approached in a very individual, adjusted to his/her needs, way. In such a case, the patient must be gradually provided with knowledge that is necessary for being able to look after himself, especially as far as elementary hygienic activities, are concerned. The most important issues while interacting with a FAS diagnosed child, are steadiness, simplicity, detail and following some fixed principles.

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