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Educational Intervention Programme in Sexual Education of a Pre-Adolescent Boy with Prader- Willi Syndrome: A Case Study

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Abstract

A lack of educational intervention programmes is noticed in the sexual education of all children and teenagers, regardless of whether they have intellectual disabilities (ID), or not. The purpose of the present study was to create an educational intervention programme in the sexual education of a pre-adolescent with Prader-Willi syndrome (PWS). The participant was a 13-year-old pre-adolescent boy who has been diagnosed with PW syndrome. Based on the data obtained, it was found that the educational intervention was very effective and that it could be applied to other teenagers with this specific cognitive profile.

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1. Introduction

PWS is a rare genetic syndrome which can be described as a complex and genetically determined neurodevelopmental disorder (Bollerslev, 2006; Wadsworth et al., 2003). The incidence of the syndrome is between 1:15,000 births and 1:25:000. Even though every case of PWS is due to the baby failing to receive active genes from the father's chromosome 15, there are two different ways that this can happen. The first way is called paternal deletion and the second way is called maternal uniparental disomy (Bollerslev, 2006; Koenig, 2004; Lewis et al, 2002; Wadsworth et al., 2003).

Individuals with PWS have cognitive strengths and weaknesses. Some of them have good long-term memory, good receptive language, perform highly in projects that require a 'parallel' holistic processing, have good

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visuospatial perception and good visual attention. Their ability to assemble objects is beyond average and reading and writing skills are slightly better than math. So, it is better for people with PWS to use holistic, rather than successive processing, when they encounter new information which is presented visually or through visual aids. In addition, they learn better when computers, new technology, and visual mnemonic techniques of short-term memory are used (Alevriadou & Giaouri, 2009).

International data show that a large percentage of young people with ID have not received sexual education (Gomez, 2012; Löfgren-Martenson, 2012; Sweeney, 2007). There is no organized sexual education in Greece either (Apteslis, 2012). The theoretical background of this study highlights the importance of sexual education for all children and teenagers, regardless of whether they have ID or not (Anderson, 2010; Barak & Fisher, 2001; Gomez, 2012; Löfgren-Martenson, 2012; McAvoy, 2013; Schaalma et al., 2004). It is very important to involve all young people with ID, including those with PWS, in sexual education programmes (Alevriadou, Lang, & Akbuyur, 2010; Reeve, 2001; Richards et al, 2006 ; Schulze, 2001; Watson et al., 2012).

The relevant literature is limited to a few, short references about the special sexual identity of this syndrome. A lot of studies highlight the people's with PWS need for sexual education (Cassidy & Driscoll, 2009; Reeve, 2001; Schulze, 2001; Watson et al., 2012). Even though sexual urges are decreased in PWS, sexual education should not be neglected, because there is always the fear of sexual harassment and the rare possibility of an unwanted pregnancy (Cassidy & Driscoll, 2009). Guidance to teenagers and their families cannot be complete without sexual advice.

The aim of the present study was to utilize the theoretical framework that is provided by the international literature on the sexual education of people with ID and especially those with PWS. It also utilizes the strengths according to the cognitive profile of the syndrome, in order to create an educational intervention programme in sexual education for a pre-adolescent with PWS.

More specifically, the research had two objectives. The first objective was to improve the individual skills of the pre-adolescent with PWS, comparing his own skills before and after the educational intervention. The second objective was to assess the effectiveness of the educational intervention on the sexual education of the pre-adolescent with PWS.

2. Method

2.1. Case study

The methodology that was used is that of the case study. In this research an intervention programme was applied in the sexual education of a 13-year-old pre-adolescent boy who has been diagnosed with PWS. The information was gathered through an interview with his mother and through an informal educational assessment. His family consists of his father, his mother and his brother, George.

His psychomotor development was slow compared to children with typical development. He was not able to talk at all until he was three years old. At the age of three he was able to pronounce small words such as mum and dad. After a series of speech therapy sessions he was able to add some words to his vocabulary. These days he can make sentences with many errors in pronunciation and syntax. At the age of five he did not wear diapers during the day and at the age of seven during the night.

When he was five years old he attended a special nursery school and when he was seven years old he attended a special primary school. Konstantinos (this is the boy's pseudonym) adjusted to his school context without problems. His mother highlighted the fact that he has positive feelings for his school and that he really likes the curriculum.

His mother mentions that he knows basic feelings, expresses them in a civilized way and he is able to manage them. In the past he often had seizures and anger outbursts, in particular when food was concerned. During the last three years he has been able to remain calm due to the fact that he knows his daily food schedule and that the rules are steady and known. He is cooperative, friendly and happy. He can stay focused, calm and put on his chair. He does not get tired having a lesson and he is motivated to learn. He really likes playing computer games, helping his mother in the kitchen and doing physical exercise at school. He seems to love his school very much. He likes reward stickers and social appraisal. He really likes doing jigsaw puzzles and his room is decorated with framed jigsaw

puzzles consisting of many pieces which he did himself. He is better at activities that have to do with visual perceptual memory skills rather than auditory.

2.2. Instruments and Procedure

2.2.1. First Phase

The first phase included the initial assessment through the information that was collected from the informal educational assessment, from the social history of the child, from the assessment of intelligence with the WISC-III test (Georgas et al., 1997), as well as from the initial assessment in eight sub-tests of sexual education skills, before the educational intervention was implemented. Before the educational intervention, the 8 activities of assessment of sexual knowledge were:

Activity 1: The individual was given two images of a boy and two other images of a girl. He was asked to name all the internal and external reproductive organs that girls and boys have.

Activity 2: He was given 74 statements. Some of them supported wrong stereotypes and prejudices about sex and the other the right ones. He was asked to write the letter C next to every correct sentence and the letter I next to every incorrect sentence.

Activity 3: He was given images with 8 different stages of development of both sexes. He was asked to place the pictures in the correct order and describe the changes that occur in both sexes during puberty.

Activity 4: He was given 18 pictures of the reproductive cycle of life and asked to place the pictures in the correct order and then to describe every picture.

Activity 5: He was given sheets of 5 different houses, for example his family house, the house of friends, relatives, known and unknown people and was asked to put the toy people inside the appropriate house according to their social relationship.

Activity 6: He was given 24 pictures of private and public places. He was asked to find the acceptable social dressing code for each photo and group them into two folders depending on whether they were acceptable for a private or public space.

Activity 7: He read a story about his classmate's dad who invited him to dine at his house. He was asked to answer the following questions: "What's the answer? Why? Will you keep it a secret from your mum? Why? What should you do in case you refused to accept his invitation and he tried to force you into his car? What should you do in case he tried to touch your underwear?"

Activity 8: There was not a direct evaluation activity in order to evaluate Konstantinos' ability to bathe on his own. Information was gathered in an indirect way through his social history. His mother said that he forgets the steps he has to follow in order to bathe on his own. He has not required complete autonomy in this skill and he needs verbal guidance. The reason that this skill was not evaluated directly through an external observer was that it would conflict with the objective of the present study. The aim of this study was to teach the pre- adolescent to keep his privacy while undressing in private places, such as a bathroom.

2.2.2. Second Phase

The intervention programme was applied during the second phase and it included modern pedagogical methods, such as the use of new technologies, the experiential method, the multi- sensory method, the method of project analysis and the method of social story. The fifteen intervention activities lasted about 29 credit hours. The intervention took a total of 29 days, with one teaching hour each day. The teenager participated with great pleasure and excitement. The supervisory materials were attractive, interesting, original and appropriate to his cognitive profile and managed to draw his attention. The 15 intervention activities were:

Activity 1: He was given 24 pictures of private and public places. He was asked to describe and name every place of the pictures. A discussion followed about the clothes we should wear in each area and whether we can stay there alone or with company. He wrote and painted whatever he wanted next to each picture.

Activity 2: He painted, on an interactive board, the appropriate clothes for a boy and a girl according to the place in the pictures. Afterwards he played online games where boys and girls dressed up.

Activity 3: He read a picture book which provided information on how children were born from the moment of their conception until birth, the fetus in their mother's womb, the differences between women's and men's bodies, the changes that occur during puberty, the various family types, acceptable and unacceptable touches, when and how to say no, and the stages of human development. The understanding of the book was completed with questions and description of images.

Activity 4: He read several stories on sexual harassment and ways to protect himself. He was asked to describe the stories and then answer some questions that confirmed his understanding of the fairytales. The questions that followed included possible ways of reaction in case he was in the same position as the protagonists of the stories.

Activity 5: He watched many videos from the stage of conception until birth, about family formation, the evolution of life, the differences between the sexes in relation to the reproductive parts of the body, the changes that occur during puberty, who can be married to whom, socially acceptable ways in which people of the opposite sex establish relations and sexual harassment. He was asked to describe the stories and then answer some questions that confirmed his understanding. The questions included possible ways of reaction in case he was in the same position as the protagonists of the stories.

Activity 6: He read a social story written especially for his needs. The story provided information on what are socially acceptable and not acceptable touches and ways to protect oneself and seek help in the possibility of sexual abuse.

Activity 7: In this activity, a female classmate was involved. Both of them lied down on a cardboard which was on the floor and drew each other's body outline. Then he drew a female and male adolescent's body differences.

Activity 8: He placed images according to the developmental stages of both sexes.

Activity 9: He browsed the internet for pictures of men's and women's personal belongings, saving them into two different folders.

Activity 10: We had two wreaths on the floor with different indications on them: True and False. He read statements about stereotypes and prejudices about sex. Depending on whether the statement was true or false he jumped in the wreath with the correct indication.

Activity 11: He put colored circles on the pictures of a boy and a girl. Red circles were placed on the parts of the body which were not to be touched by others. Green circles were placed on the parts of the body that he can let other people touch. Finally he put orange circles on the parts of the body parts that only a doctor or a nurse can touch during a medical examination.

Activity 12: He grouped people of his everyday life into five colored groups. The groups were family, relatives, friends, known people and strangers. He made five concentric, but different in diameter, circles from paperboards which were placed according to how close they were to his picture which was stuck in the center of the circles.

Activity 13: We played the game "May I say a ... something ... in a stranger?". Instead of the word "something" we choose anything he may, or may not say to a stranger. The rule of the game was to raise his hand every time we selected a word that was not a secret for a stranger and to keep his hand down when the word should be a secret for a stranger.

Activity 14: He read three social scenarios on sexual harassment. He answered questions about the protagonists' reactions and feelings and described how they would react in a similar case. He dramatized the scenarios to confirm that he understood the stories.

Activity 15: In this activity we used the method of analysis project. He was asked to place 12 pictures of how to bathe a boy in the correct order. When he was at school he bathed a doll by using images. When he bathed himself at home, his mother urged him to properly implement the steps by looking at the pictures. Gradually the images were removed until he reached the point of full autonomy.

2.2.3. Third Phase

The third phase was that of the final evaluation, which took place right after the implementation of the intervention programme on sexual education, and aimed to assess the degree of improvement of individual skills after the educational intervention. The activities of the final evaluation were exactly the same as the initial assessment activities before the educational intervention, in order to have a reliable comparison.

3. Results

The data analysis showed that the educational intervention was very effective and that it could be applied to other teenagers with this specific cognitive profile. More specifically, all the individual skills of the pre- adolescent were improved. These skills included the recognition of boys' and girls' body parts, sex differences, changes during adolescence, false prejudices and stereotypes for both sexes and breeding circle. They also referred to the distinction between various social relations, between public and private places, as well as to the clothes we wear in each place. Some other skills were related to the understanding of the ways he could protect himself, to obtaining full autonomy in self-service and self-caring skills and thus to the improvement of the pre- adolescent's with PWS quality of life.

The percentages of correct answers were compared during the initial and final assessment. The results show that we have absolutely statistical significance ($P < 0,0001$) among the results before and after the educational intervention in all the sub-tests. The modified paired sample t-test control shows that there is a variation among the results before and after the educational intervention (Crawford, 2004). The difference between the average success rate before (16,25%) and after (98,25%) the educational intervention was so great that shows by itself that statistic rates will overall vary. T- test control shows that we have statistically significant change and more specifically a statistically significant increase in success rates.

The correlation between the rates before and after the educational intervention was also examined. This association is negative and we could characterize it as a medium linear correlation. The correlation is not statistically significant, so it is characterized as moderate or else as a weak negative correlation. There is no association between the initial and the final evaluation either. Therefore it is not possible to predict the final evaluation from the results of the initial assessment. Finally, the final evaluation that was conducted after the intervention programme on sexual education was related to the typical grades in the WISC-III sub-tests. The connection of these two variables is non- linearized, so the non- linear regression was used (Crawford, 2004). More specifically, the relationship between the two variables has an exponential form, that of power inverse regression. The equation of the two variables is: Final evaluation = $13,541 + 41,138 / \text{Standard Degrees of WISC III}$. The conclusion is that the assessment of intelligence with the WISC-III can predict performance in sexual education projects.

4. Discussion

All in all, it seems that the educational intervention in sexual education was very effective and that it could be applied to other teenagers with this specific cognitive profile. When comparing skills before and after the educational intervention it is observed that the pre- adolescent's with PWS skills were improved. Regarding the statistical findings of this study, the assessment of intelligence with the WISC-III can predict performance in sexual education projects. The theoretical framework of this study highlights the importance of sexual education for individuals with ID. They usually have either no information or misleading and inadequate information (Anderson, 2010. McAvoy, 2013. Schaalma et al., 2004). Sexual education contributes to young people's autonomy on issues concerning their body and personal hygiene and helps them acquire information about dangers, sexually transmitted diseases and birth control. Through sexual education self-esteem is boosted, responsibility is created and awkwardness about sexuality is erased. Furthermore, through sexual education young people with ID learn their

rights, how to make right, free and conscious choices, to set boundaries in their behavior, to protect themselves from sexual harassment and communicate their wishes while at the same time respecting other people (Barak & Fisher, 2001; McAvoy, 2013).

References

- Alevriadou, A., Lang, L. & Akbuyur, S. (2010, May). Special educational needs & citizenship: education for the inclusion of all students. Poster session presented at the CiCe Twelfth European Conference, Lifelong Learning and Active Citizenship, Barcelona, Spain.
- Alevriadou, A. & Giaouri, S., (2009). *Genetic syndromes of mental retardation: developmental and educational approach*. Thessaloniki: University Studio Press.
- Anderson, M. J., (2010). Sex education and rape. *Michigan Journal of Gender & Law*, 17, 83-110.
- Aptelis, N., (2012). *Sexual education for students with intellectual disabilities in school age: needs assessment and preparation intervention programs*. (Doctoral dissertation, University of Thessaly, 2012). National archive of PhD thesis.
- Barak, A. & Fisher, W. A., (2001). Toward an internet-driven, theoretically-based, innovative approach to sex education. *The Journal of Sex Research*, 38, 324-332.
- Bollerslev, M.V., (2006). *Working memory in adults with Prader – Willi Syndrome*. Oslo: University of Oslo.
- Crawford, J. R., (2004). Psychometric foundations of neuropsychological assessment. In L. H. Goldstein & J. E. McNeil (Eds.), *Clinical neuropsychology: A practical guide to assessment and management for clinicians* (pp. 121-140). Chichester: Wiley.
- Georgas, D. D., Paraskevopoulos, I. N., Bezevegis, H. G. & Giannitsas, N. D., (1997). *Greek WISC-III: Wechsler Intelligence Scales for Children*. Athens: Ellinika Grammata.
- Gomez, M. T., (2012). The s words: sexuality, sensuality, sexual expression and people with intellectual disability. *Sexual Disabilities*, 30, 237-245.
- Koenig, K., Klin, A. & Schultz, R., (2004). Deficits in social attribution ability in Prader–Willi syndrome. *Journal of Autism and Developmental Disorders*, 34, 573–582.
- Lewis, B. A., Freebairn, L., Heeger, S. & Cassidy, S.B., (2002). Speech and language skills of individuals with PW syndrome. *American Journal of Speech - Language Pathology*, 11, 285-294.
- Löfgren-Martenson, L., (2012). "I want to do it right!" A pilot study of Swedish sex education and young people with intellectual disabilities. *Sexuality and Disability*, 30, 209-225.
- McAvoy, P., (2013). The aims of sex education: demoting autonomy and promoting mutuality. *Educational Theory*, 63, 483-496.
- Schaalma, H. P., Abraham, C., Mary, R. G. & Kok, G., (2004). Sex education as health promotion: what does it take? *Archives of Sexual Behavior*, 33, 259-269.
- Reeve, A., (2001). Understanding the adolescent with developmental disabilities. *Pediatric Annals*, 30, 104-108.
- Richards, D., Miodrag, N. & Watson, S. L., (2006). Sexuality and developmental disability: obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin*, 1&2, 137-155.
- Schulze, A., Mogensen, H., Hamborg-Petersen, B., Græm, N., Ostergaard, J.R. & Brøndum-Nielsen, K., (2001). Fertility in Prader-Willi syndrome: a case report with Angelman syndrome in the offspring. *Acta Paediatrica*, 90, 455- 459.
- Sweeney, L., (2007). *Human sexuality education for students with special needs*. Kansas: MarshMedia.
- Wadsworth, J. S., McBrien, D.M. & Harper, D.C., (2003). Vocational guidance and employment of persons with a diagnosis of Prader – Willi syndrome. *Journal of Rehabilitation*, 69, 15-21.
- Watson, S.L., Richards, D.A., Miodrag, N. & Fedoroff, J.P., (2012). Sex and genes, Part 1: sexuality and Down, Prader–Willi, and Williams Syndromes. *Intellectual and Developmental Disabilities*, 50, 155–168.