



Sexual behaviour of children and teenagers with autism spectrum disorders. Pilot study results

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In the article the results of pilot studies concerning manifestation of sexuality in a group of children and youth with autism spectrum disorder were presented. The research is divided into two fundamental parts. In the first part – the shorter one, definitions and conceptions were outlined. The subject of sexuality and functioning of people with autism spectrum disorders regarding social behaviours was also discussed. In the second part, the findings of own studies conducted on a group of mothers of children and youth with autism spectrum disorder were presented.

KEY WORDS: autism, children, sexual behaviors, youth

1. Theoretical background

1. Human sexual behaviours are not an isolated field of life which might be separated from other activities. They constitute an integral part of personality, even the one developing and manifesting itself in a non-normative and non-typical way. The more so, in the functioning of people with particular disorders, separating the

sexual sphere from other aspects of life seems impossible. It influences those aspects, which in return affect the sexuality. "A man is born with a physiological potential of sexuality which is continuously formed by life experience; sexuality is conditioned by integrated activity of biological, psychological and social-cultural factors" (Imieliński 1986 s: 28). Sexuality is a permanent human attribute, constantly dynamic – undergoing changes, both in biological (physiological) sphere, as well as in psycho-social one. Moreover also within the transactions taking place between these areas. The aforementioned assumptions underlie the ecological model of sexuality of Whalen and Schmidta (ibid.), treating sexual apetention as a disposition formed on the grounds of innate features and developed under the influence of acquired features. The first area is formed by biophysiology – with an appropriate genetic programme, proper development of organism, including cortical centres, sub-cortical centres, peripheral nerves, receptors and hormones. The other area is formed by acquired characteristics – created in the process of learning and gaining experience, related mostly to educational and culture-related factors (Imieliński 1986: 40; Gulczyńska 2009; Jankowiak 2010, Steinberg, Monahan 2010).

Applying the aforementioned assumptions to people with autism spectrum disorders we state that: dysfunctions displayed by them are non-specific, therefore it is difficult to indicate a specific damage of cortical centres or peripheral nerves connected with sexual behaviours. Given the state of the art we might presume that biological (physiological) background of sexual behaviour is similar to that of people with no development disorders. The existing differences in sexual functioning are caused rather by limited ability to establish, maintain and develop interpersonal relations, particularly by deficits within the theory of mind¹.

¹ The concept of theory of mind (related terms: *mentalizing*, – *mindreading*) refers to a system of concepts and rules, enabling people to predict and explain other people's behaviours by referring to unobservable states of mind, namely desires, beliefs, intentions etc. It is the ability to interpret one's own actions and those of

2. With regard to people with autism spectrum disorders, social functioning sphere constitutes, apart from communication and activity disorders, the area with significant deficits observed. They refer to establishing contacts with people, social understanding, recognising and understanding emotions, as well as disorders of the theory of mind – basis for proper existence among people. The area of social functioning in classification DSM-5 was combined with communication abilities of people with autism spectrum disorders and was given a term of social communication disorders (DSM- 5). Such approach shows how significant the communication sphere is within the social context thus more aptly characterising the problem which plays an important role in considerations on the sexuality of children and adolescents with autism spectrum disorders.

Analysing diagnostics criteria (see ICD-10, DSM-5) and subject literature (see e. g. Maljaars et al. 2011; Pisula 2012; Frith 2008; Winczura 2005), we might conclude that the greatest difficulty in the school years for children and adolescents with autism spectrum disorders lies in undertaking interactions, maintaining contact with another person and building relations based on mutual benefits and exchange. Such behaviour is based on proper development of the theory of mind. The ability to comprehend that a human has feelings, thoughts and beliefs which might not be a precise and realistic reflection of reality, is a significant aspect of social understanding referred to as the theory of mind (the ability of mindreading or, as referred to by other authors, the ability to metalize (see Baron-Cohen 1995; Castelli, Frith, Happe, Frith 2002). Such ability enables to approach psychological states of other people and predict their behaviour (Colle, Baron-Cohen, Hill 2006). The authors also emphasize that assessment of this particular sphere is related to verbal abilities of a person, and the knowledge of the development of this ability in speech-impaired children and autistic people with intellectual disability is scarce (ibid.).

others as driven by the states of mind (Baron-Cohen 1995; Frith 2003; Winczura 2008).

Researchers also observe that people with autism spectrum disorders displaying proper early development followed by later regression of the developed skills, contrary to children whose autism was detected already during the first year of their lives, display better skills in the early development of the theory of mind (Matthews et al. 2012).

This aspect is significant also with regard to sexual behaviours of children and adolescents with autism spectrum disorders. It indicates that social perception of reality is not only related to intellectual capacity, but to linguistic abilities of such person as well, which should considerably determine (in its wider sense) the education of children and adolescents displaying the development disorders in question.

To sum up, a person with autism spectrum disorders in the period of adolescence is subject to the same changes as a teenager at the same age displaying no developmental disorders. However, the perception of oneself and the process of accepting changes taking place in one's organism depends on many factors, not only external, but also cognitive abilities and social-emotional skills (Wojciechowska 2013a). It is by identification with a social group and assuming new roles, that a young man begins to perceive himself/herself as other people's peer or the one different from the surrounding people. A student with autism spectrum disorders functioning on the level of intellectual standards often notices his/her distinctness from their peers. And the older he/she gets, the more aware he/she is of difficulties in establishing peer relationships (Atwood 2013; Wojciechowska 2013b).

2. Research method and research sample characteristics

The original questionnaire prepared on the grounds of literature analysis was used (including: Ballan 2012; Aylaz, Yılmaz, Polat 2012; Zielona-Jenek, Chodecka 2010; Hellemans, Colson, Verbraeken, Vermeiren, Deboutte 2007; Kościelska 2004; Atwood 2013;

Bellon-Harn, Harn 2006; Castelli 2005) as well as the observation of children and adolescents with autism spectrum disorders. Since this is the pilot study, mothers taking part in it were asked to provide remarks and comments which would be taken into account while producing the final version of the tool.

Although the assumed target research sample were parents of children and with autism spectrum disorders, yet the questionnaire was filled in only by mothers. It is most probably caused by the fact that mothers have the most extensive knowledge comprising information required by the questionnaire and they spend the most time with their child.

Eighteen mothers of children from grades IV-VI of primary school and twenty mothers of junior high school (gymnasium) students. The questionnaire was anonymous - filled in in paper or through a website. Due to discomfort caused by the subject of the study as declared by the parents, 38 questionnaires were received altogether for the purpose of this pilot study.

The respondents filling in the questionnaire about primary school students were mothers - mostly of boys (69%), the oldest respondent was 55, the youngest 34, coming mostly from towns (up to 200 residents). Most of the mothers describe themselves as Catholic believers, yet irregularly practising.

The respondents filling in the questionnaire on junior high school students were mothers of boys, the oldest respondent being 51, the youngest 38, coming mostly from big cities (over 200 thousand of residents). Except for the people regarding themselves religiously undeclared, forming the smallest group, the remaining part of the results distributed among: non-believers, believers, non-practising believers, irregularly practicing believers, regularly practicing believers was the same (20% each).

The decision was made to present the result in percentage, in order to demonstrate the frequency of occurrence of a given opinion or behaviour in the sample. The Authors emphasize that the application of percentage results in such a small research sample is only supposed to indicate a certain tendency, the direction of

which shall be verified in further studies. Yet it by no means authorises to generalise about the results with regard to the whole population.

3. Research problems

The demonstration of the results of the pilot study aims at presenting of mothers' opinions on sexual behaviours of their children (grades 4–6 of primary school) and youth (junior high school – gymnasium) with autism spectrum disorders. Both their type and the frequency of occurrence was analysed.

The following research problems were stated:

1. What sources of knowledge on the sexual development are used by the mothers of children and teenagers with autism spectrum disorders?
2. What sources of knowledge on their sexual development are used by children and teenagers with autism spectrum disorders?
3. Are there any differences – and if so, what are they – according to the mothers of autistic children and teenagers, in the sexual development of their children compared to the children and teenagers with no autism spectrum disorders.
4. What symptoms of precocious puberty in children and youths with autism spectrum disorders are observed by mothers and what is their frequency of occurrence?

4. Results of the pilot studies

1. Primary school:

Behaviours described by the mothers concerned the majority of boys with autism spectrum disorders. Almost half of the children display standard intellectual capacity, and the other half is diagnosed with intellectual disability. Most of the children speak, only

some of them use alternative communication. Children attend special schools, mass education schools or integration classes. Sexual education classes are conducted in almost half of the schools, are not conducted in almost half of the schools, and a couple of respondents have no knowledge of that. Majority of children do not participate in the classes. Over half of the mothers claim that they were not asked to give their consent to the child's participation in the classes of preparation to family life (sexual education classes).

In the question about the source of knowledge on the sexual development of their children, mothers could give more than one answer (table 1).

Literature is on the first place, followed by: the Internet, other parents, teachers, therapists and other (including a lecture given by a specialist).

Table 1. The source of knowledge on the sexual development of primary schools children

| No. | Source | Per cent |
|-----|--|----------|
| 1 | Scientific literature and popular-science literature | 81 |
| 2 | Internet | 62 |
| 3 | Other parents | 50 |
| 4 | Therapists | 42 |
| 5 | Teachers | 29 |
| 6 | Other | 10 |

Source: proprietary research

According to the mothers, their children gain knowledge on sexual development from the Internet (over 80%), TV (over 50%), therapists and literature (18% each), as well as other sources, for instance parents.

Subsequently, the question was asked, what difference there is between the sexual development of non-autistic children and that of the children with autism spectrum disorders?

The answers given were classified into six categories: no difference, no awareness of the changes taking place in their organism and no sense of socially accepted behaviour (the aforementioned answers constituted 90%, with a similar distribution between groups), the remaining categories being: no symptoms of the child's sexuality observed and: "children with autism spectrum are more sensitive in this respect, more sensitive to their own sexuality" and I don't know (the answers constituted 10%).

Further on a question was asked, how often a particular behaviour is observed in a child (mothers could choose between answers from: 0 - never to 4 - permanent occurrence).

The question about observable symptoms of precocious puberty in their children was answered by 20% respondents with the declaration that they do not notice any, for 30% such symptoms are still present or quite frequent (20%), for the remaining 30% they are observed only seldom or sometimes. The answers to the question if the mothers observe the increased need for privacy in their children correspond with the aforementioned. Almost 20% answers "no", 45% seldom notices such a need, the remaining respondents - very often or constantly. Majority of mothers (over 70%) however states that they do not observe any embarrassment or increased shyness related to sexuality issue or changes in their bodies, 20% rarely notice such behaviour, and hardly 10% constantly. A similar percentage (over 70%) observes no fear of their own normality, 20% rarely notices its symptoms, and 10% quite often.

Over 50% of mothers were not asked by their children about sexuality, almost 30% rarely, 20% often and very often. Interest in the opposite sex is not observed by over 60% of respondents, and about 40% seldom notices such symptoms. 60% of the mothers notice the interest in the topic of how babies are made, namely 30% seldom, 30% often and very often. It corresponds with the observed interest in differences in the way boys and girls are built: seldom 35%, often and very often 30%.

For a majority of mothers the most difficult behaviours are those related to taking clothes off in public, cuddling and kissing other

people (30% each), followed by masturbation, and further: seeking pornographic content on the Internet and uttering comments of sexual nature aloud (almost 20% each utterance).

No respondents observe kissing or attempts made by their children from grades IV–VI of both peers – of the same sex, as well as of opposite sex. At the same time, over 80% of the mothers observed no exhibitionistic behaviour. A similar percentage of respondents noticed no masturbation symptoms of their children. Over 60% of the mothers thinks that their children do not touch their intimate parts in the presence of other people, 30% claims that such behaviour occurs very seldom, and nearly 10%, that often. When an emotional factor is added – fear or excitement – the results undergo changes only with regard to distribution of rarely (20% with such behaviour) and often (20%). 90% of the respondents states that they haven't noticed their children seeking sexual content on the Internet or TV or demonstrate their intimate parts to other children.

Including sexual behaviour in the element of play is rare (80% lack such behaviour, 20% occurs rarely). Similarly, participation in plays considered proper for the opposite sex (with over 70% it does not occur, with 20% occurs rarely, only with 10% occurs often). Majority of the mothers (over 70%) failed to observe negative comments on children of the opposite sex (e. g. girls are stupid or: boys are dumb and noisy), such behaviour being rarely observed by 10% of the respondents, and often by almost 20%. Peeping at children, when they are in the bathroom is absent from a majority (90%) of children, and 10% does it constantly. Whereas the attempts at entering a toilet with other people rather do not occur (60%), rarely occur (20%), often or very often in the case of 10%.

45% of children do not strive for being hugged and do not cuddle to other children, whereas most children demand being hugged by adults (40% very often and often, 50% seldom), yet a considerable majority (over 70%) makes no attempts at kissing adult women at school, foundation, counselling centre, and occasional behaviours are rarely observed. Over half of the respondents claim to observe imitations of teen dancing (over 30% rarely, 10% often and very often as well).

2. Junior high school:

The analysed behaviour concerned only boys, the oldest being 18, the youngest 14 years old. Majority of the respondents' children display standard intellectual capacity. All of them demonstrate verbal communication. Adolescents attend special schools, mass education schools or integration classes. Sexual education classes took place in over half of the schools, and only a couple of the respondents have no knowledge in this topic. Over half of the teenagers participate in such classes. Nearly half of the respondents claim that they were asked to give consent to the child's participation in the preparation to family life (sexual education) classes, the same number declares that they were not asked.

When asked the question about the source of knowledge on sexual development of their children mothers could give more than one answer (table 2). They enumerated in the following order: literature (scientific, popular - science), other parents, Internet, therapists, conversation with a child, TV, teachers, their own studies and training.

According to the mothers, their children learn about sexual development from the Internet (nearly 80%), from peers (over 60%), TV (over 50%) and therapists (over 20%).

Table 2. Sources of knowledge about sexual development of their junior high school children

| No. | Source | Per cent |
|-----|--|----------|
| 1 | Scientific Literature and popular-science literature | 65 |
| 2 | Other parents | 62 |
| 3 | Internet | 57 |
| 4 | Therapists | 55 |
| 5 | Conversations with a child | 29 |
| 6 | TV | 10 |
| 7 | Teachers | 10 |
| 8 | Own studies and training | 10 |

Based on author's own research

Further on a question was asked, what, according to them, is the difference between sexual development of children with no autism spectrum disorders and that of the children suffering from such disorders?

The answers were distributed into five groups: no parallelism between physical and emotional development (delayed emotional development) 50%, no differences perceived - 20%, no idea - 10%, too much sincerity and openness (10%) and difficulties in communication (10%).

Next they were asked how often a particular behaviour was observed in a teenager (parents could choose between answers scaled from: 0 - never to 4 - persistent). Questions formulated in this particular way are supposed to reflect subjective observations and feelings of mothers.

Symptoms of precocious puberty in teenage children were observed by all respondents, majority of whom claims them to be still present (60%), very frequent or frequent (over 30%). The answers given to the question if mothers observe the increased need for privacy among their children correspond with the aforementioned. Such observations were shared by all the respondents, 90% of whom declares that behaviour proving such need are very frequent and frequent, and 10% rarely observes such need. Over half of the mothers (55%) knows that their children masturbate rarely (45%) or constantly (10%), whereas 45% fail to observe the acts of autoerotism among their sons. However, over half of the mothers (55%) state, that they observe no signs of embarrassment or increased shyness related to sexual issues and changes taking place in their body build, over 30% seldom notices such behaviour, and nearly 10% does it often. Over half of the mothers observe their children fear about their normality (20% rarely, over 30% often, very often and permanently).

Over 50% of mothers were asked by their children about the issues related to sexuality. Interest in the opposite sex is absent from the observations of merely 20% respondents, they occur often or very often in over 40% adolescents, over 30% - rarely. It corresponds to

the interest in the differences between physique of boys and girls: 20% of the youth is completely uninterested, over 50% incidentally displays such interest, 30% does it often and permanently.

For the majority of the mothers participating in the survey, the most difficult behaviours are those related to masturbation (55%), uttering loud comments of sexual nature (over half), undressing in public (over 30%), hugging and kissing other people (over 20%), and further on seeking pornographic content on the Internet.

Mothers fail to observe in their maturing sons the following behaviour: entering (or attempts to enter) a toilet with other people, kissing (or attempts to kiss) their peers of the same or opposite sex in public, as well as people employed in the centres (schools, counselling centres) or showing their intimate parts. Exhibitionistic acts followed by an escape are also quite rare. Peeping at others when they are in a bathroom, is not observed in the majority (80%), and the remaining part states they do it very rarely.

Over 40% mothers declare that their children do not touch their private parts in the presence of other people, 30% claims that such behaviour occurs rarely, 20% thinks that it happens often or constantly. When an emotional component is added – fear or excitement, it has no influence with 30% of the described cases, happens often and very often in 40% teenagers, rarely with 20%.

Seeking sexual content on the Internet is observed by 55% of the mothers (including over 30% rarely, and 20% frequently), whereas on TV by 45% (including over 30% rarely, and 10% frequently).

Including sexual behaviour aspect in their activity is rarely observed (80% display no such behaviour, 20% occurs rarely). Over half of the mothers did not hear their sons speak negatively of girls.

90% of boys do not seek to be hugged or themselves hug adults of their age or does it seldom (45% each). Hugging peers is also occasional (45%) or absent (55%). 45% of the respondents' children had no experience with the first boyfriend or girlfriend, 45% has such meetings very rarely, and only over 10% often. Half of the respondents (55%) observes no imitation of teenage dance, an half observes it frequently.

Conclusions

The concept of the studies was prepared on the basis of the literature accessible in this subject, observation (including participant observation) of IV–VI grades children, junior high school students and talks with their parents. Owing to the involvement of the mothers filling in the questionnaire, the study could be extended with certain categories of answers, which previously were not taken into account.

Primary school: a majority of mothers taking part in the survey observed the symptoms of precocious puberty in their children, however rather poorly visible. The increased need for privacy occurs rather rarely. Embarrassment and shyness related to sexuality or the changes in the body build is also rarely observed. Similarly, they display no fear of their normality.

Mothers complemented their knowledge of sexuality by: reading available literature, visiting websites, talking to other parents, further on: from therapists and teachers. In their opinions their children learn about their sexuality mainly from the Internet and TV, further on from therapists and teachers. In over half of the cases they themselves were not asked by their children about sexuality issues.

The majority of the respondents state that the development of sexuality in their children with autism spectrum disorders differs from the same process observed in children who were not diagnosed with autism. The main difference, in their opinion, is unawareness of the changes in the organism and socially accepted behaviour.

The most difficult behaviour displayed in this period is for them undressing in public, hugging and kissing other people.

Junior high school: All mothers participating in the study observed the signs of precocious puberty and an increased need for privacy. Their knowledge on this subject was complemented with: reading available literature, talking to other parents, searching websites, from therapists, by talking to a child, watching TV, from teachers or their own studying and training.

In their opinions, their growing sons learn about sexuality issues mostly from the Internet and their peers, less frequently from TV and therapists, to be followed by teachers and other parents. Literature, as the source of knowledge on sexuality, is listed as the last one. A majority of the respondents claim that sexuality development of adolescents with autism spectrum disorders takes place unlike in people without such diagnosis; the main difference is delayed emotional development and their focus on physical components of puberty displayed by their sons. The most difficult behaviour displayed in this period is, in their opinion, masturbation, loud comments of sexual nature, next undressing in public, seeking pornographic content on the Internet or kissing other people. They also draw attention to shyness of the young men, related to sexual topics and precocious puberty which is rarely observed or almost absent. Over half of the mothers were invited to talk or asked by their children about sexually related topics. The important thing is that over half of the mothers notice fear related to their own normality and related dilemmas. The first experience with dating refers to half of the sons of the respondents, however their quality and duration was not subject to this study. While characterising sexual behaviours of their sons, mothers described the increased masturbation, considerable interest in the anatomy of sexual organs and differences observed in women (girls) and men (boys) and the interest in how the children are made. Other types of observed sexual behaviour are: imitating teenage dance, touching private parts in the presence of other people and touching their own sexual organs when feeling excitement or fear, seeking to be hugged or seeking sexual content on the Internet or TV.

Discussion

The analysis of the material collected in the course of the pilot studies aiming at learning the opinion of mothers on the sexual behaviour of children and adolescents with autism spectrum disorder

ders, indicated the significance of the problem and the necessity to carry on with the scientific research. They helped to detect probable difficulties with which mothers of children with autism spectrum disorders struggle and also indicated that the problem causes fear among mothers.

The replies given by the mothers of primary school children to part of the questions seem to apparently contradict themselves. Namely, mothers claim that their children learn about sexual development mainly from the Internet or TV, at the same time declaring that their children do not seek sexual content on the Internet. The achieved results become the source of hypotheses for further studies, namely: it is possible that the mothers treated children as a main category, seeking sexually related content on the Internet (there was no reference to their own children in the question) or think that children become only an unintentional recipient of sexually related content.

The signs of growing were rarely observed and adequately – mothers noticed the need for privacy. In case of junior high school children – signs of precocious puberty appear in all of them, whereas embarrassment or shyness related to sexuality and changes within their bodies – rarely, remaining on the level similar to that of children from grades IV–VI.

While analysing the literature on the subject we may observe that sexual growth, sexual behaviours and sexual education of people with autism spectrum disorders are rarely discussed in Polish publications. In 2008, foreign literature database accessible through EBSCO system contained only 20 publications on the sexuality of people with autism spectrum disorders (Sullivan, Caterino 2008). In September 2014 the search engine found 46 publications (autism, sexuality).

Physical growth in people with autism spectrum disorders usually takes place in a regular way, indicated by the appearance of secondary sexual characteristics, yet emotional growth and the accompanying sexual growth is considerably extended and delayed (Sullivan, Caterino, 2008) or happens in a way typical of a particular person, which was also confirmed by the mothers' opinions provided in the study.

Persons displaying standard intellectual capacity with autism spectrum disorders feel the need for social contacts and sexual intercourse; failure to realise such behaviours is caused by disability to properly understand and establish relationships. Behaviours of the fifteen-year-olds with autism spectrum disorders participating in the studies were corresponding to those of ten-year-olds with no such diagnosis (Stokes, Kaur 2005), which is also observed by the Polish respondents.

The difference can be perceived in the approach to sexuality issues by the parents of children with autism spectrum disorders in Poland, when compared to the results of the foreign studies. The studies proved that sexuality of autistic people was placed high on the list of main problems parents sought help and support with. (van Son-Schoones, van Bilsen 1995). It may be caused by the fact that sexuality in Poland is a taboo, and the sexuality of the disabled people is all the more the issue rarely discussed, even among specialists and in research.

In other studies (Stokes, Newton, Kaur 2007) no insight into the motives of one's action was indicated, as well as limited comprehension and awareness of social situations, limited empathy, lack of restraint and knowledge, as well as care, reduced recognition of emotions and permanent, repetitive schematic behaviour. The results achieved in the pilot studies correspond to the aforementioned conclusions.

Different studies (Henaull 2006) emphasize an increased need for knowledge of the changing body and functions of the organism of people with Asperger Syndrome. In the pilot studies in question adolescents' parents claim that physiological issues are recognised by their sons, whereas emotional development is expected to improve the acquisition of higher competencies.

The studies discussed above were aimed at contributing to deeper and more extensive analyses and exploration of the topic, and in future – also to formulating wider conclusions and translating them into practice.

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