

Sexual Health Issues in Women with Intellectual Disabilities Preliminary Analysis of the Problem

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Abstract

INTRODUCTION: Women with intellectual disability have a low level of competencies that would allow them to better manage their sexuality; consequently, they have a low level of control over their own health.

OBJECTIVES: The article describes the results of author's own research into selected aspects of sexual health of women with intellectual disability (ID). The focus has been on issues such as menstruation, health and gynecological care, pharmacologization, contraception, STDs, and menopause.

METHODS: The research was conducted with 11 women using structured interviews.

RESULTS: Results suggest that these women have a low level of competencies to manage and control health problems in an optimal way. Their behavior is determined by people from their living environment to a large extent. Women with ID report various abnormalities in the course of developmental phenomena and in their own health, indicating potentially serious diseases and disorders.

CONCLUSION: Women with intellectual disability require lifelong support in meeting their health needs. Such support should be provided by institutions of care, health and social assistance.

Key words: *sexual health, intellectual disability, gynecological care, contraception, STD*

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1. Introduction

Sexual health of people with intellectual disability (ID) is more and more often the subject of research. Problem exploration proves that women with ID have menstrual periods and experience similar problems and discomforts to those seen in the general population (Ibralic, Sinanovic & Memisevic, 2010; Mason & Cunningham, 2008; Rodgers, 2001). The differences found in this respect are mainly quantitative (range and frequency) rather than qualitative (Chou, Lu & Pu, 2009; Kyrkou, 2005; Rodgers, Lipscombe & Santer, 2006). The increasingly longer life expectancy of these women makes them experience menopause with its characteristic symptoms (McCarthy & Millard, 2003; Seltzer, Schupf & Wu, 2001; Willis, Wishart & Muir, 2010; 2011), but neither they, nor the people around them are conscious of it (McCarthy & Millard, 2003; Willis et al., 2011). Women with ID have a low level of competencies (especially knowledge) that would allow them to better manage biological processes and, more broadly, their sexuality (Borawska-Charko, Rohleder, Mick & Finlay, 2017; Wilkinson, Deis, Bowen & Bokhour, 2011); consequently, they have a low level of control over their own health. To a large extent, their behavior in the sphere of health is determined by the attitudes of their carers – especially informal carers (Mason & Cunningham, 2008). There are many environmental barriers (socio-cultural, legal, economic and organizational) which have an impact on poor access to preventive healthcare in terms of preventing STDs, cancer, and dysfunctions in natural biological processes such as menstruation (Greenwood & Wilkinson, 2013; Thompson, Stancliffe, Broom & Wilson, 2014). Low awareness of health service representatives in the area of disability results in lack of individualization and personalization of their services. The very extent of the incidence of health problems specific to women (such as cervical and breast cancer etc.) is heterogeneous in this population. It should be noted that the more favorable tendencies towards women in the general population, found in some studies, may be due to shorter life expectancy, limited access to

health screenings or concentration on a selected group of women with ID, e.g. institution residents, with the exclusion of those living in open communities, who have greater opportunities to lead an active sex life (Gribben & Bell, 2010; Rurangirwa, Van Naarden Braun, Schendel & Yeargin-Allsopp, 2006; Patja, Eero & Livanainen, 2001; Wilkinson & Cerreto, 2008). Problems in obtaining informed consent for participation in medical procedures (such as sterilization and a Pap test), understanding information communicated by the specialists, and the capability of using public information, such as invitations to free health checkups can also be found in the population of women with ID (Broughton & Thompson, 2000; Gribben & Bell, 2010). Not only the cognitive ability, but also the involvement of carers and specialists play a significant role here.

The aim of this research is to learn about experiences of women with ID in the sphere of sexual health. Sexual health is very broad topic, hence the focus has been on selected issues fundamental in this area. Respondents' knowledge, declared skills and behaviors, motivations, emotional and physical sensations, problems and needs were taken into account.

2. Materials and methods

Structured interviews conducted in direct contact were used in the research. Interviews were carried out using the own structure questionnaire. The questionnaire was divided into 7 problem areas: 1) menstruation (occurrence, duration, hygiene measures used, difficulties, menstrual ailments, menarche onset, previous preparation, significance of menstrual periods); 2) contraceptives and hormonal substances (use of contraceptives, awareness of their intended use, use of hormonal substances, their effectiveness); 3) use of healthcare (frequency and autonomy in using medical care, types of specialists, motivations); 4) use of gynecological care (frequency, self-reliance, motivations, assessment of contact with the gynecologist - preparation for examination, physical and mental sensations, understanding of information, participation in cytology tests and breast cancer screening); 5) STDs (knowledge of the STDs, knowledge of

HIV/AIDS, awareness of ways to protect oneself against STDs); 6) sex education (sex education at school, in the family, autonomous activity in search of information, the need for education); 7) biological changes over time (awareness of changes in the body and new ailments, knowledge of the term menopause). Interviews were 15 to 40 minutes long depending on the duration of the women's utterances. Each interview began with the respondent's general assessment of their own health and wellbeing, an indication of the experienced problems and medication used.

The research was carried out with 11 respondents (table 1), all of whom are residents in institutions providing care and social and occupational rehabilitation (daily activity center and occupational therapy workshops). The selection criteria of the respondents were primarily their ability to establish verbal contact and their motivation to share their own experiences with the researcher. Preliminary consent, allowing the researcher to enter the institution, was obtained from the institution management in oral form, after prior notification of the purpose of the research and presentation of the subject matter of the interviews. Women who were recruited for the study could give their consent after they had been informed about the purpose and the general subject matter of the study. Each time they were asked for permission to record the interview. Women stay in daily support agency (occupational therapy workshops and daily activity centre), therefore, consent to conduct the research was obtained from the management of the institution, who were presented with the research goal and method, and the interview questionnaire.

3. Results

Assessing one's own health and wellbeing is often independent of the real problems that women face. The respondents (especially older women) report suffering from diseases such as hypertension, osteoporosis, spinal disorders, disorders of the thyroid gland, epilepsy, allergy, asthma, mycosis, mental problems such as diagnosed depression, and neurosis. As a result of these diseases women are on long-term

control medications. In the course of the interviews serious problems that require medical treatment were indicated, such as breast tumors (the woman underwent surgery), huge cysts on ovaries (before making a decision about possible surgery), and ovarian apoplexy.

Not all the women menstruate. Some report that they stopped having periods "long ago" (difficulties in assessing time, the woman suggests it may be caused by a growing cyst and surgery for appendix Woman 8), about 2-3 years ago (the doctor suggested menopause-related changes, Woman 10), a few months ago (relates it to the time she started taking psychotropic medication, Woman 7). According to two respondents, menstruation "sometimes comes, sometimes doesn't" (Women 3 and 4). The others said they menstruate regularly. Overall, taking into account the retrospective assessment of the women who do not menstruate, menstrual flow lasts from 3 to 10 days. Giving the exact number of days was difficult for the respondents, only two women (Woman 4 and 6) mentioned they recorded the duration of their period. One of the women in her youth (Woman 10) was hospitalized due to amenorrhea and doctors attempted to restore her menstrual cycle pharmacologically.

Respondents reported abdominal pain, sometimes very strong, with the need to use drugs which are not always effective. Bleeding varies in intensity, some of the women indicated very intense bleeding (they have to use two pads at the same time) with blood clots. One of the women (Woman 1) during period must limit activity and stay at home due to accompanying vomiting, abdominal pain and severe bleeding. Woman 6 has had frequent (as she reports) hemorrhages for several years but it is not known whether they are related to her monthly bleeding. Morphological examinations revealed numerous abnormalities in the blood, however, according to the respondent, neither her mother nor she reported the hemorrhages to the family doctor. It is tragic in this case that the woman has never been to a gynecologist – "she is supposed to go there with her mother soon". Another respondent (Woman 5) reported that her long, abundant period with clots

Table 1.

Characteristics of the examined women

Woman 1	Woman 2	Woman 3	Woman 4	Woman 5	
Cannot state her age (about 30 years old), lives with her parents and her sister, has a boyfriend, does not plan to have a family or children	39 years old, lives in a sheltered housing (training form), no partner, does not plan a family or children	24 years old, lives with her parents, no partner, would like to have a partner, would like to have a family	28 years old, lives with her parents, no partner, no need to have a family or a partner	36 years old, lives with her sister and her sister's family, currently has no boyfriend (she used to have one), she does not want to have a partner in the near future (because of negative experiences in the relationship), but does not exclude having a family	
Woman 6	Woman 7	Woman 8	Woman 9	Woman 10	Woman 11
27 years old, lives with her mother and her sister, no partner, does not plan to have a family or children	46 years old, lives in a sheltered housing (training form), no partner, would like to have one in the future, does not plan family or children	36 years old, lives in a sheltered housing (training form), would like to have a friend (stresses the nature of the relationship), does not plan to start a family	36 years old, lives in a sheltered housing (training form), would like to have a friend (stresses the nature of the relationship), does not plan to start a family	42 years old, lives with her mother, no partner, would like to start a family	39 years old, lives with her father, no partner, would like to have one, does not plan to start a family

was commented by the doctor as a symptom of true femininity: "He said I had a period like a real woman". In other respondents their period was typical with more pronounced initial bleeding and abdominal pain, which passed with time. All the women use pads. They have never used tampons. One woman (Woman 1) said, "My mother would kill me if she knew that I was wasting money on it." She heard about tampons from her partner, who is educated by his mother, but is afraid of using them for fear of not being able to remove the tampon. The respondents have no difficulty in using pads, but they do not always buy them on their own. Sometimes they are supplied with hygiene products by their mothers or father.

The ability to assess the time of menarche is difficult for the respondents, who indicated grade 2, 4, and 8. One woman (Woman 3) said she was 21. The respondents were not usually prepared for the first menstrual period, but remembered that it aroused fear and surprise. Mothers or guardians at the orphanage (where Woman 7 was brought up) or the dormitory

(Woman 9) did not even attempt to prepare the girls for adolescence. One woman (Woman 3) said that her mother had told her that she would not be able to go to the swimming pool at that time. Only one respondent reported that her first period meet with a positive reaction from her mother, who emphasized she was "becoming a woman" (Woman 5). Some respondents learned about menstruation from a friend that had already matured in the child care home, at a dormitory, or at school. One respondent (Woman 1) talked about it with her sister. Lack of awareness about the significance of menstruation is visible among the respondents. One respondent stated that women menstruate so that they "do not get pregnant", presumably voicing a popular opinion of the possibility of "safe sex" during menstruation. Only one woman associates menstruation with fertility ("To have children", Woman 11), other women do not know that, nor have they ever considered it ("you have it, just because"), treating period as just another gender-specific characteristic. During the interview they showed considerable

interest in this issue. In this context, a statement made by Woman 3 seems quite significant, “Children come from the abdomen” – the woman was not able to answer how they get there in the first place (!).

The respondents do not have a broad knowledge of the purpose of contraception. One said that they prevent pregnancy (Woman 9), another stated they are used “so as not to have children”. At this point it may be worthwhile to present some of the respondents’ experiences related to sexual intercourse. Although no direct questions were posed in the interview, this subject was raised by the respondents themselves. One has a partner, but claims that they do not have sexual relations (Woman 1); another two had sexual relations in the past. Woman 10 in her youth was in a relationship with a partner with ID and they shared a deep bond. This relationship was not accepted by her environment. The couple’s sexual activity resulted in the woman’s pregnancy and the child was aborted. The experience of abortion, which was justified by the carers’ by the fact that the woman and her partner have epilepsy, still awakens great negative emotions in the respondent. This woman was also a victim of rape. Another respondent (Woman 5) talked about her behavior many years ago as “drinking with friends and having sex”, which – as one might judge from the context – was caused by lack of family acceptance and psychological problems. She used condoms at that time.

The respondents, not knowing the use of contraceptives, were unable to give examples. One woman mentioned condom, noting that it was a kind of “balloon” which prevented pregnancy and adding that she saw one thrown out on the street (Woman 2); another claimed that condoms are not a contraceptive (Woman 11). Woman 7 used the term “tablets” and colloquial “safety” for condoms, knowing that the former are taken by women and the latter are used by men. One woman who was asked about the purpose of contraceptives, explained that they should be used “during sex”, they can be purchased at the kiosk, but gave tampon as an example (Woman 8).

Five respondents use or used hormones (Women 1, 3, 7, 9 and 10) prescribed by the

gynecologist or endocrinologist, but they were unable to give their exact name, knowing only their general use – to regulate their monthly bleeds. Lack of awareness of one’s own health situation, but also no control over it, was clearly evident in one of the subjects who had severe pain associated with the presence of large cysts. In the course of the interview, she denied using contraceptives or hormones to regulate her menstrual period. At the same time she reported that she was receiving gynecologic injections every three months without knowing their name or use (probably Depo-Provera) (Woman 8). Her gynecologist is a friend of her aunt. The psychologist reported that her family arranged for the use of contraception “just in case”. The respondent also reported her accidental visit to another doctor (substitute), expressing indignation that he was trying to obtain information about her life. Presumably the specialist was trying to find justification for using Depo-Provera which has many side effects.

The respondents use the services of general practitioners, and in case of having specific medical conditions they seek specialist assistance. Sometimes visits are motivated by an acute ailment or by the need to obtain a prescription for long-term control medications. Most often they visit their doctor alone, sometimes they also sign up for appointments on their own.

Two respondents have never been to a gynecologist (Woman 4 and 6). One, as abovementioned, has serious problems which seem to have been ignored by her mother for years. Another sees no need for gynecological advice, stating that her mother goes to a gynecologist. The others report routine or rare visits, which, as recorded in the interviews, results from their carers’ attitudes. The declared motivation to visit a gynecologist are routine checkups. However, respondents also state elsewhere that they have infections (“burning”) and inflammatory states requiring medical advice. The respondents have a female gynecologist, and they are strongly opposed to visiting a male gynecologist. In one case, the gynecologist is a man chosen by the respondent’s mother (Woman 3), in another

also a man, but the woman does not have routine checkups with him (Woman 7). Some respondents visit their doctor alone, others with their mother (Woman 10), father, or aunt. Sometimes the mother and daughter are treated by the same specialist, who is chosen by the mother based on her own preferences and evaluation of service quality. None of the women feel ashamed during the visits at present, although in retrospective such a feeling occurred during the first visit. The examination usually does not generate negative physical or mental sensations. In one case, the position on the chair leads to dizziness and difficulty in standing up (Woman 1); in another, there is a strong pain which, according to the respondent, can result from a specific body structure (“The doctor told me that I have a very narrow uterus”, Woman 5). One of the women sits on the gynecological examination chair with the help of her mother (Woman 3). Respondents stated that the information provided by the gynecologist is understandable to them. The first visit to a gynecologist was usually organized by other people, including family carers (mother, aunt), institutional specialists or carers from the child care home. The women were not previously prepared for gynecological examinations by carers or physicians. Only in one case did the doctor describe the diagnostic activities before proceeding with them (Woman 2).

Not all the women have had cytology tests, but if they had the results were negative. The respondents are not aware of the usefulness of such tests, except for Women 5. She also knows the risk of ovarian and breast cancer due to her family circumstances. Woman 11, who did not have cytology tests, pointed to her chest when she was asked about these tests clearly not knowing what they were. Asked about the gynecologist’s breast exam the women sometimes confirmed they have had them, but none of the respondents received instructions on how to carry out breast self-examination at home. Some only received a general suggestion to self-exam e.g. in the shower. Neither of the women conducts this type of self-observation, saying they do not know how. One of the respondents reported that her mother asked for a referral for a mammogram (Woman 10), but the

gynecologist refused stating the daughter was too young. A 46-year-old respondent asked about breast-checks replied, “my doctor told me to go somewhere” (Woman 9). Woman 5, who had a family history of breast cancer, asked for a breast cancer test but only received a suggestion to self-examine at home.

The respondents do not know the term sexually transmitted diseases, although some could give examples of HIV and AIDS. One knew of gonorrhea and explained that it is possible to “get infected by having sex” (Woman 9). Another said that “you can get infected during sex” (Woman 7). One woman declared that “one sometimes hears things said on television” and then gives an example: getting cancer due to air pollution; asked what HIV is, she replies quickly, “AIDS” (Woman 11). Woman 8 gave gastrointestinal complaints as an example. Woman 10 who experienced rape referred to her own example, indicating that she had been infected with “a venereal disease.” Awareness of HIV transmission is relatively better: the respondents knew that HIV is transmitted via blood and sexual relations; but they also thought the stereotypical drinking from one mug or airborne contact can result in HIV transmission. One woman said that one way to prevent STDs is sexual abstinence (Woman 9), another pointed to the need for using condoms (Woman 7).

Each of the respondents, without exception, assured that in the course of school education (primary school) they obtained some information on sexual health and sexuality. In no case, however, were they able to specify the nature of this information. Only some women stated, also not providing any details, that the subject was touched on by their mothers. One of the respondents (Woman 3) declared that she looked online for information about procreation. The problem of changes in the body is difficult, and the terms “organism” and “physical” (changes) requires additional explanations during the interviews. The women do not see these changes, they do not refer to adolescence, maturation or aging. They rather focus changes in how active they were in the past and how their temperament and efficiency have changed (“I used to be more active”, Woman 11). Most respondents do not know the term menopause,

but they know it refers to women. Sometimes they have some associations with it, such as “you get hot flashes, you don’t have period” (Woman 11), one feels “hot flushes, amenorrhea, organism is deregulated” (Woman 9) or that older women experience it. Knowledge of the subject comes from conversations with women from the environment, colleagues, and from television (advertisement of medication for menopause).

4. Discussion

Generalizing the results of the exploration into women’s experiences related to their sexual health it is important to point out that they are in many ways similar to those obtained by other authors. Author’s own research confirms low level of competencies of adult women with ID as far as dealing with their own health issues is concerned, visible in poor knowledge of underlying developmental and gender-specific phenomena (puberty, menstruation, menopause), potential risks (STDs), and contraception methods. Similar trends have been found by other authors. It has been shown that women with ID do not associate menstruation with its procreation function, but some see menstruation as an indicator of female puberty (Mason & Cunningham, 2008). Qualitative and quantitative analyzes have shown that women with intellectual disability (1) rarely know what menopause is (they do not know the term), or the changes that are related to it; (2) have no knowledge about the expected time of menopause; (3) are not aware of the link between menopause and fertility; (4) have limited ability to observe and record changes in their organisms over time (Chou, Lu & Pu, 2013; McCarthy & Millard, 2003; Willis et al., 2011).

Other authors confirm that persons with ID (both sexes) often know the terms or concepts of HIV and AIDS, but have little knowledge about the ways HIV is transmitted and the risks involved (Conod & Servais, 2008; Dawood, Bhagwanjee, Govender & Chohan, 2006). Still other authors have found that the knowledge of people with ID of both sexes in terms of contraception varies but it is usually selective and superficial, and it is not accompanied by

specific skills (such as the use or acquisition of contraceptives). What is well-known is the term and some of the most common contraceptives like condoms for men. Very few persons with ID are aware of other methods of contraception (Jahoda & Pownall, 2014; Murphy & O’Callaghan, 2004).

A positive tendency resulting from author’s own analyses shows the participation of women in cytology tests which are used to detect abnormal cervical cells. Many studies reveal disproportions compared to women in the general population in that in the case of women with ID these tests are ignored since these women are assumed not to engage in sexual relations (Gribben & Bell, 2010; Ramessur-Marsden, Huges, Tomlinson & Corfield, 2008 et al., 2008; Rurangirwa et al., 2006). Negative tendencies are observed in author’s own explorations of breast examination and self-examination. Women are not instructed how to perform these exams. Willis, Kennedy and Kilbride (2008) write, based on a review of numerous explorations, that many women with ID do not have the competencies to do breast self-examination or understand its meaning, and so it is the carers who have a decisive role to play in this respect. Author’s research with women with ID confirms this conclusion (Willis, 2016).

Women examined here are aware of their own state of health in that they notice cyclical symptoms, disorders and abnormalities to some extent. However, they find it difficult to precisely record them, which may be associated with the specific nature of their disability. They experience ailments or even serious disturbances in the functioning of their organism, which can indicate diseases requiring advanced therapies (uterine fibroids, polyps, ovary cysts). Unfortunately, these problems do not always raise the concern of their carers (despite the fact that are aware of them) or of the professionals who examine them. It is difficult to explain why the problems referred to by women in the course of menstrual period (such as severe abdominal pain, vomiting, abundant bleeding) are not the subject of a detailed advanced diagnosis. Perhaps women do not reveal this information to the specialist during

the visits. Periodic abnormalities of monthly bleeding or excessive bleeding (menorrhagia) may be more common among women with ID (Mason & Cunningham, 2008; Rodgers et al., 2006) due to the medications they take such as antiepileptic and antipsychotic medication (Quint, 2008).

The own research included a small group of women, therefore the results obtained should be treated with due caution. The issue requires further research taking into account many variables, such as the functional status of women, social environment, the objective aspects of healthcare (including health care services available).

5. Conclusions

Women with ID require lifelong support in meeting their health needs. The competencies they have acquired at school must be constantly maintained and strengthened in daily life, so that they do not fade away. For adult women, institutions providing social services such as daily activity centers and occupational therapy workshops are important. Organizational policy of these institutions must be geared to the comprehensive needs of adults, including their health needs. The support they provide must be both educational and instrumental. It is important to monitor the health status of participants by: arranging individual conversations (e.g. with a psychologist), organizing meetings with health service representatives (e.g. nurses, midwives, sex therapists), assisting these individuals in signing up for examinations, and accompanying them during these appointments. Cooperation with families is essential. For adult women, issues related to the correct monthly cycle (e.g. additional bleeding), symptoms accompanying menstruation (severe ailments), changes in breasts (structure, exudation), changes related to menopause are important. It should be noted that women with ID are not always aware of certain abnormalities and do not report them to the specialist. For some women it may be important to consider the use of medication to regulate and perhaps reduce bleeding. It is also important to bear in mind that women with ID have sexual needs (of varying intensity) and

tend to pursue them in various forms, such as masturbation and intercourse. People offering support, whether on a daily basis or during various forms of rehabilitation, must be aware of this to strive for rational support in meeting these needs – taking into account the best interests of the person with disability. The task of health professionals, whom women with ID have first contact with, is first of all to gain more in-depth information to take into account not only the issues that are strictly within their professional competence. Comprehensive evaluation will entail: taking into account women's needs and expectations, motivations and opportunities e.g. related to various forms of life activity, including family activity; identifying experiences relevant from the perspective of their current behavioral and functional status; obtaining information on diseases and disorders (relatively more common in this population, such as epilepsy), and prescribed medicines, their side effects and potential interactions with other drugs.

Conflicts of interests

The author declares no conflict of interests.

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