

“It Gives Me, as her Caregiver, a Sense of Security.” Young People with Intellectual Disability and their Experiences with Sexuality, Menstruation, Gynecological Treatment and Contraception: A Follow-up Analysis of Parents’ and Caregivers’ Perspectives

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Abstract

Background

Research shows that caregivers support but also impede people with intellectual disabilities from developing intimate relationships. People with intellectual disability experience coital sex later and less often compared to adolescents without disabilities. Caregivers often request hormonal contraception from gynecologists on their behalf. Their main motives are pregnancy avoidance (either as a result of consensual sex or sexual abuse) and menstrual suppression.

Method

The sample included 42 primary caregivers of young people with intellectual disability aged 14 to 25. Interviews were evaluated with qualitative content analysis.

Results

Nine of the main caregivers assumed that sexual intercourse had taken place. Half of the carers evaluated the importance of sexuality for the young people with intellectual disability as high. The main reason for seeing a gynecologist was the prescription of hormonal contraceptives; the outcome of which was arbitrary and dependent on the individual gynecologist. The majority of young women took general hormonal contraceptives as a preventive measure or due to heavy bleeding, regardless of sexual activity. One-fifth took hormone depots as a form of long-term contraception.

Discussion

A trusting relationship with the gynecologist favored the compliance and well-being of the young women. The administration of hormonal contraceptives seems to be controlled by third parties. Caregivers used hormonal contraceptives to simplify the regulation of menstruation and felt relieved by it. Carers view the sexual activities of the young women more critically because they fear a pregnancy and the responsibility for a potential grandchild. The use of hormonal contraceptives made carers clearly more tolerant of sexual activity.

Current State Of Research

Caregivers are an essential source of support for people with intellectual disabilities in forming intimate relationships [1–3]. They teach social skills and help in the shaping of sexual identity [21]. Research also suggests that caregivers are sometimes preventing people with intellectual disabilities from developing intimate relationships [1, 2, 4–6]. The private lives of people with intellectual disabilities are often characterized by strict boundaries [7], constraints and prohibitions to having intimate relationships [4, 8]. Consequently, there is a lack of learning and experiential spaces [9] and social networks are limited when it comes to meeting potential partners outside of work. This lessens the chances of intimate relations with peers [10]. Young people with intellectual disability also tend to be lonelier, as they spend more time under the supervision of adults [11, 12].

One explanation for these limitations is the caregiver's personal attitude. When caregivers are open-minded and have a positive attitude about sexuality, adolescents are more likely to have the capacity to decide for themselves [7]. If their caregivers infantilize them and do not think of them as individuals with sexual needs, people with intellectual disabilities are prone to adopt that view [13]. In addition, caregivers often view the sexuality of people with intellectual disabilities as being more inappropriate than their own [14]. Caregivers also report feeling ambivalent regarding intimate relationships of people with intellectual disabilities. On one hand, caregivers want them to be happy sharing intimacy with their partners increasing their independence. Yet, on the other hand, they fear sexual abuse and unwanted pregnancies restricting their independence and control [1, 7, 15, 16]. Women with intellectual disabilities, in particular, face more restrictions from staff and family [17, 18]. The limitations and scarcity of privacy [19] forces people with intellectual disabilities to experience intimacy with their partners in secret in order to avoid the disapproval and anger of caregivers [1, 4], as well as further prohibitions and punishments [8].

Parents tend to have a more conservative attitude towards the sexuality of people with intellectual disabilities than professionals do. Professionals tend to be more supportive when it comes to partnerships and to supervise relationships less stringently [20–22]. Mothers are especially cautious when it comes to the sexuality of their children with intellectual disability. The protective nature of their relationship causes them to believe that their children are less interested in sex than parents of children without disabilities [23]. Moreover, people with disability appear to have little sexual knowledge due to insufficient sex education and avoid discussing this matter with their caregivers for fear of disapproval [24]. Parents consider it more difficult to explain sexual issues to their child with intellectual disabilities and do so less frequently than with their children without disabilities [1, 25–27]. Mothers are more likely than fathers to discuss sexual issues with them [28].

People with intellectual disabilities experience intimate relationships similarly to people without disabilities: starting with infatuation, then flirting, and progressing to hugging, kissing and petting [7]. Research shows that people with intellectual disabilities have significantly more experience with socially acceptable sexual activities such as kissing, hugging, and petting than with sexual intercourse [24, 26, 29, 30]. People with intellectual disabilities experience coital sex later and less often compared to adolescents without disabilities [27, 29]. Masturbation and petting are their most common sexual activities [29]. In addition, men appear to have more sexual experience than women with intellectual disabilities, to experience higher sexual desire, and to hold a more positive attitude toward sexual activity [30]. Having sexual intercourse experiences later and less frequently may be because their caregivers consider them sexually vulnerable. This can result in overprotection which can interfere with sexual autonomy and sexual competence [31]. Research indicates that women with intellectual disabilities experience difficulties developing a sexual identity, view sex as a painful, inappropriate and pleasureless activity and rarely expect to feel sexual desire [17].

Caregivers, particularly mothers, often request hormonal contraception from gynecologists and decide when their daughters will begin taking it [16, 32–34]. Some caregivers request a contraception prescription for their daughters without their consent [35]. Pregnancy avoidance, menstrual suppression, fear of sexual abuse and worries about sexual activity were the main caregivers' reasons for requesting contraception [36–38]. Caregivers often approved of and considered sterilization to be a viable option for their daughters with intellectual disability [39, 40]. One study shows that health care providers convinced some caregivers to sterilize their female relatives; the women with intellectual disability were often not involved in the decision-making process [41]. The main motives were pregnancy prevention, menstrual suppression and the fear of pregnancy resulting from a sexual assault [16, 41]. Current research indicates that gynecologists do not know about human rights concerning sexual and reproductive health of women with intellectual disability and that they support and prescribe hormone depots and sterilization as routine practice [42].

Women with intellectual disability often have difficulty dealing with menstruation management [43, 44]. Mothers support their daughters with menstrual hygiene, sometimes taking complete care [43]. Women with intellectual disability have limited knowledge about the menstrual cycle [43]. Heavy periods are one of the main menstruation problems [43, 45] and, along with menstrual hygiene concerns, a reason for menstrual suppression in the form of hormonal and surgical contraception [44, 45].

A German study [46] shows that gynecologists learned how to care for people with intellectual disabilities from experience rather than from academic training. They articulate the need for further education and training opportunities in communicating with women with intellectual disability. The interviewed gynecologists report that their female patients with intellectual disability are often very agitated during the examination and sometimes do not allow it at all. Then it is often up to the gynecologists to decide whether a purely external examination is sufficient or whether a pelvic examination is required. They continue to report communication problems due to the intellectual disability of their patients, which limits contact, preparation and explanation for the examination. They additionally describe that their patients with intellectual disability find it difficult to reflect on their own health situation and to make their own decision as to whether they wish to undergo an examination. Consequently, the shared decision-making sought by physicians is only possible to a limited extent and treatment decisions are often made by gynecologists. The main caregivers were predominantly perceived as supportive during communication and transfer to the examination chair [46].

To the best of the authors' knowledge, this is the first German survey that questions a relatively large number of primary caregivers of young people with intellectual disabilities about their experiences with sexuality, contraception, and gynecological treatment. Reports on the perspective of the interviewed young people with intellectual disability from this survey [47] and the primary caregivers' perspective on the young people's experiences with intimate relationships [48] have already been presented. The aim of this article is to examine how primary caregivers describe the experiences with sexuality, contraception, menstruation and

gynecological treatment of young people with intellectual disability. In particular, differences between the perspectives of the primary caregivers and the interviewed young people with intellectual disability towards these topics will be discussed in this context.

Method

Participants

The sample was comprised of 42 primary caregivers of young people aged 14 to 25 years with mild to moderate intellectual disability, 23 male and 19 female participants. Thirty-three of the primary caregivers were parents and nine were professionals caring for these individuals. In our sample, primary caregivers included 29 mothers, four fathers, four female and five male professional caregivers. All primary caregivers and the young respondents with intellectual disability identified themselves as heterosexual.

The 33 parents were between 41 and 63 years old; the average age was 50 years. Three parents had immigrated to Germany. Twenty-eight young people with intellectual disability lived with their parents and three with their grand- or foster parents. Twenty-five parents lived in a partnership, including 16 interviewees in a partnership with the child's other parent.

The nine employed caretakers were between 26-60 years old; the average age was 46. Eleven young people lived in assisted living or a residential home for people with disability; among them were two in their own homes with supervision. The professional group of caregivers consisted of pedagogically qualified specialists in the form of legal guardians, occupational therapists, early childhood teachers, educators, and social workers. All of them were German. Six had completed vocational training and three had a university degree.

Criteria for participation included being 14 to 25 years old, having the diagnosis of intellectual disability and the ability to verbally converse. The participation of a primary caregiver in the study was an additional criterion. Consent was obtained from each primary caregiver and each young participant with intellectual disability. They were informed about the content of the study, the voluntary nature of their participation, confidentiality and the right to withdraw their participation from the study at any time. The participants and their primary caregivers received together a compensation of 25€.

Instrument

The semi-structured interview guide of the caregivers was adapted from the earlier studies "Youth Sexuality and Disability" [49, 50] and "Family Planning for Young Adults with Disability" [51, 52]. The interview guide was revised based on feedback from a focus group. In addition, a pilot test was conducted. The interview guide was wide-ranging and included questions about sex education, attitudes about sexuality, the young people's experience with relationships, sexuality, and contraception. The appendix contains the formulated questions on sexuality, menstruation, gynecological treatment and contraception from the caregiver's perspective.

Data Collection

The study, "Sexuality of Young Adults with Intellectual Disability in Saxony," was conducted from 2014 to 2017. The Ethical Review Committee of the Medical Faculty of the University of Leipzig approved the study prior to data collection (AZ: 015-15-26012015).

The young study participants (n =42) including their caregivers (n=42) were recruited from seven schools for students with intellectual disability (n=19) and nine sheltered workshops (n=23) in Saxony, Germany. Caregivers could choose between a telephone interview (n=8) and an on-site interview (n=34). The face-to-face on-site interviews took place mostly at the caregivers' homes (n=26). In exceptional cases, the interviews were carried out at the request of the main caregivers in other locations (n=8), such as in a park or café. On average, the interview duration was one hour. The amount of total time for each respondent varied from 22 minutes to 115 minutes.

Data Analysis

The interviews were digitally recorded and fully transcribed. The names of the respondents were anonymized. Transcripts were analyzed thematically using both summary and structuring content analysis [53]. The deductive category formation was based on

the questions in the interview guide. Text passages were inductively coded using summary content analysis every time they could not be assigned to a defined category. Coding was carried out using the qualitative data analysis software MAXQDA. After a first category system was created, two authors analyzed it independently. They jointly reviewed and revised the coding framework. Subsequently, the authors coded the remaining interviews. In addition, data were analyzed using SPSS version 22.

Results

The results of the interviews with the main caregivers are presented thematically. First, the experience with sexuality of the young people with intellectual disability is presented, next their experiences with menstruation and gynecological treatment and finally their experiences with contraception.

Experience with sexuality

This section deals with the following issues regarding the sexuality of young people with intellectual disability from the perspective of their main caregivers: their attitude and knowledge about the sexual activity of the young people, their subsequent reaction to it, masturbation, the sexual needs of the young people and the carers' evaluation of the importance of sexuality for the young people.

The **carer's attitudes** towards the sexual activities of the young people with intellectual disability varied. About half of the main caregivers supported them having a sexually active life while simultaneously expressing limitations in the young people's cognitive and psychological maturity. A common strategy of the parents was to shift the concept of their sexual acts and needs into the not too near future: "But that is still a long way off. Far into the future," says the mother of Roman (17 years old). This strategy allows them to not deal with the issue and its consequences while simultaneously showing openness. The main caregivers determined kissing to be the most common and, at the same time, the most unproblematic sexual act among young people with intellectual disability. Sexual intercourse is viewed more critically in a large part because of the potential of pregnancy.

Few of the main caregivers had precise **knowledge of the sexual activities** of young people with intellectual disability. Often there were only guesses and vague statements that the carers expressed about the sexual activities of the young people: "At least she says she is still a virgin. So nothing happened supposedly," according to 23 years old Astrid's mother. "He spins quite a yarn sometimes. I can't be sure," said the mother of Nils (23 years old). The statements of the carers reflect the young people's desire for a romantic relationship in which kissing and cuddling are allowed. From the point of view of the carers, this corresponds most closely to the needs of the young people. Only nine of the main caregivers could safely assume that sexual intercourse had taken place. There were, in some cases, discrepancies between the statements of carers and those of young people about the experience with sexual intercourse (table 1).

Table 1: Experience with Sexual Intercourse [n (%)]

	Young people	Male	Female	Carers	Male	Female
Yes	12 (29)	4 (17)	8 (44)	9 (22)	3 (13)	6 (33)
No	29 (71)	19 (83)	10 (56)	26 (63)	16 (70)	10 (56)
Don't know	0 (0)	0 (0)	0 (0)	6 (15)	4 (17)	2 (11)

(N=41)

The main caregivers became aware of the sexual activities of the young people in different ways. In nine cases, the respondents received the information from the young people themselves. Five carers were informed from third parties, and three respondents reported having accidentally witnessed the young people having sex. Jana's mother said that Jana (22 years old): "...asked about condoms. Then we basically knew what was going on. And we noticed it because her door was locked. And through her sister of course."

The **reactions of the carers** to the young people's first sexual experiences varied. The interviewed mothers, in particular, expressed rejection and difficulties in accepting the sexual needs of the young people throughout their detachment process. The mother of Helen (20 years old) said her own reaction was "terrible." She continued: "Let us find another supervised workshop immediately. I

calmed down after that. Helen came home and wanted to talk to me in private in her room. And she said, 'I'm so happy, I had sex.' And I thought, 'that's my baby.' Normally mothers are more excited." Parents showed significantly more acceptance of the sexual activities of their children when certain reliable contraception methods were used.

With regard to **masturbation**, there was a significant gender gap. Carers of young men presented themselves as open to this issue. They judged masturbation as normal behavior and a common means of pleasurable satisfaction. They engaged in conversation with the young men, informed them about appropriate behavior and respected their privacy. Most main caregivers were aware of their masturbation habits, partly from their reports, but also from their own observation. The mother of Simon (25 years old) said, "He shouldn't do it in public, [...] always at home. There he can do it if he feels like it. Suppressing it, that's not good. If he closes the door to his room, then I know that I shouldn't come in." However, young women were hardly ever or not at all recognized by the carers as having a need for masturbation. The mere idea about it did not seem to exist and was in some cases also not welcomed. "I can't imagine that," said the mother of Ina (25 years old). The pleasure aspect of female sexuality is practically non-existent in the eyes of the carers.

There are carers who are available contact persons for the **sexual needs** of the young people. According to the caregivers, the young people longed for the exchange of affection and intimacy with a partner and considered starting their own family. Tanja's mother says her daughter (20 years old), "...wants to be in a partnership. And to have normal sex. Just normal sex. Without any unusual stuff. Just a lot of affection and tenderness. But not necessarily that intercourse is center stage all the time." Mostly, the young men express that they want to have sexual intercourse. The caregiver of Björn (16 years old) described him talking about his sexual desires like this: "He does talk about it. Pretty crude most of the time. 'I want to fuck. Oh, I'd like to screw her.' Like that. But there's something behind it. He is able to talk differently about it. I think he wants to have a girlfriend."

Contrastingly, there are carers, especially mothers, who had little to say about the sexual needs and desires of young people. "Well, he is very reserved," described Malte's (22 years old) mother reflecting a typical lack of communication between carers and young people about this topic. The main cause for this was that the young people did not want to talk to their caregivers about sexual matters; they preferred to talk to their peers. The carers increasingly sought an exchange when measures such as contraception or an appropriate retreat for togetherness became necessary.

The carers evaluated the **significance of sexuality** for young people differently. Half of them determined it as high: "I'd say quite high, especially affection, sex with her boyfriend, that is quite important," said Jana's mother. One-third rated the significance of sexuality rather low, about which the mothers in particular showed relief: "None at the moment. I, for one, am happy about it. Doesn't have to be so early," said Stefan's (15 years old) mother. Only a small proportion of carers described the importance of sexuality as varying or average.

Experience with Menstruation

This section deals with the following issues regarding the experience of the young women with menstruation: their reaction to menarche and menstrual management.

The majority (10 of 18) of the young women's **menarche** began between the ages of 10 and 13, on average at 12.9 years according to caregivers. A large proportion of them reacted "calmly" and "quietly" to the onset of their menarche. This response is directly related to the maternal education about the female cycle and related hygiene and organizational measures that were provided in advance. "We have prepared her in advance that all women get it once a month. And that it is quite normal, that it is not a disease. It's part of life. She was not afraid when it happened" (mother of Alice, 22). In caregivers' recollection, a smaller group of women tended to react with surprise, fear, and insecurity to the onset of menarche due to a lack of education beforehand. In some cases, mothers were equally surprised by the early onset of menarche and had failed to educate their daughters in time. However, even in these cases, the initial shock at the physical reactions due to inexperience soon turned into routine, capable behavior. Elisa's mother describes the reaction of Elisa (18 years old) like this: "She was freaked out. What's going on? So, I explained it to her. She then understood. [...] I explained it to her and managed it and talked. Well, until she finally understood."

After the onset of their first menstrual period most caregivers informed their daughters about the need for **menstrual management**. The mothers tried to teach them how to handle the hygiene articles themselves as soon as possible, which the young women

learned at different speeds. Influencing the learning process was, on the one hand, the severity of the mental disability and, on the other hand, the extent to which the young women were prepared for menstrual management in the lead-up to menarche. In part, the learning process was characterized by anxiety, reluctance, and initial problems. The mother of Jana (22 years old) said about this process: "I had always told her, there are tampons, there are pads in the bathroom. Use them when needed. It was a process to learn how to deal with this, because she already had trouble using the hygiene products due to her disability. She had her share of problems at the beginning. She sometimes forgot to take things with her and found herself without them. But in the meantime, she has become really good at it. She used to provide for half of the sheltered workshop." In conclusion, most mothers were very pleased with their daughters' safe and independent handling of hygiene products, which was learned with varying levels of effort.

Experience with Gynecological Treatment

This section deals with the following issues regarding the experience of the young women with gynecological treatment: the first gynecologist visit, the reasons for seeing a gynecologist and the experience of the first gynecologist visit.

Fifteen out of 19 caregivers reported that the young women had already seen a gynecologist. The age of the **first gynecological visit** varied between 12 and 20 years; on the median, the young women were 15.7 years old. Half of the young women made their first visit to a gynecologist between the ages of 12 and 15, and the other half between the ages of 16 and 20. Almost all 15 caregivers said they had accompanied the young women to their first appointment with a gynecologist.

Obtaining information about possible contraceptive measures was cited as the **reason for seeing a gynecologist** in the majority of cases (8 out of 13). Hormonal contraception as pregnancy prevention was important to caregivers when the young women began menstruating or entered a relationship. Other reasons for the first visit to the gynecologist were medical measures due to cycle irregularities, menstrual cramps, HPV vaccination and preventive medical care. Contraceptive measures were subsequently initiated in as many as 11 of the 15 women following their first gynecologist visit.

One-third of the caregivers said the young women had a positive **experience at their first gynecologist visit**. The positive experiences were largely related to the empathy and respectful approach of the physicians in responding to the fears and needs of their patients. Sandra's mother describes the gentle familiarization of her daughter (15 years old) with the gynecological examination, which took place both through conversations with her mother and through the kind gynecologist herself. She says: "The gynecologist really took an hour just for Sandra. She explained everything to her. She explained about the chair. And what happens there. And she also had a big doll there, it was lying on the chair. She showed her everything. I thought it was excellent." One-third of the caregivers rated the experience of the visit as being rather average and in two cases as negative: "She was not too thrilled about that. She said that it hurt so much," reported the mother of Elisa (18 years old). Three young women refused vaginal examination. In two cases the gynecologists performed an ultrasound examination through the abdominal wall as an alternative. One gynecologist prescribed the pill without a pelvic examination; another refused, even though the young woman was sexually active. Alice's mother (22 years old) described it this way, "As soon as Alice loses grasp of what they're doing to her, it's over. That's when she panics and when she gets up and leaves." In response, the gynecologist refused to prescribe the pill because, according to Alice's mother, "she doesn't prescribe the pill off lightly, 'I have to examine her or it will be a no go.'" The opposite experience was reported by two other mothers who were issued prescriptions without pelvic examinations. One young woman had been taking the pill for five years before her first visit to the gynecologist at age 16. According to the mother of Elisa (18 years old), "I just went to the gynecologist and said, 'yes, so, what do you say, my little girl is disabled, 70 percent disability – I mean regarding the pill.' First asking about the injection. 'It's not possible under 18,' he said. But he immediately prescribed the pill, and she wasn't even there."

Experience with Contraception

This section deals with the following issues regarding the experience and attitudes with contraception of young people with intellectual disability from the point of view of their main caregivers: use of condoms, use of hormonal contraception, caregivers' reasons for administering hormonal contraceptives, the side effects of hormonal contraception, and ethical considerations about hormonal contraceptives and sterilization.

Seventeen primary caregivers stated with certainty that the young people had used a contraceptive. Hormonal contraceptive methods are, by far, the preferred method among respondents (n=13) contrary to condoms (n=4). This may be explained by the fact

that only a small number of the young men had ever been sexually active. The young men's main caregivers were uncertain about the consistent use of condoms. Unlike hormonal contraceptives, the correct **use of condoms** cannot be verified by third parties. The caregiver of Arne (23 years old) said: "I mean there was talk of condoms. I think he'll use them too. But he has not actually said that he will take them." The answers of the participants showed that there was very little communication about contraception between the male young men and their caregivers.

According to the caregivers, only five of the 13 young women who **used hormonal contraception** had already had sexual intercourse. Three of them had only recently experienced their first sexual intercourse. The remaining seven young women were taking a hormonal contraceptive as a preventive measure or due to heavy menstrual bleeding. Two young women could not take hormonal contraceptives because of interactions with other medications. Of the women who took the contraceptive pill, two had taken it in the past. In a single case, it was suspected that the use of the pill was associated with a severe pulmonary embolism; therefore, hormonal contraceptives were not used anymore. In four cases, the caregivers preferred hormone depots such as the three-month injection or the contraceptive implant (table 2).

Table 2: Used Hormonal Contraception

	Current	Prior	Total
Used hormonal contraception	11	2	13
Contraceptive pill	7	2	9
Three-month injection	3	0	3
Contraceptive implant	1	0	1

The lack of regular intake monitoring and the compatibility with other medications was experienced as relieving for the caregivers. For example, the father of Sonja (21 years old) mentioned: "The pill was usually the first thing the doctor recommended, but because of the disability and also the forgetting and not taking it the right way, we decided together with the doctor that using the three-month injection makes sense." The use of hormonal contraception was started at a very early age in some cases. One young woman has been taking a hormone medication since age 11 and two young women since age 12. Two of them started using a hormonal contraceptive immediately after the onset of menarche (11 and 12 years). Two other young women started taking hormonal contraceptives at age 14, the remaining young women began after age 18.

Some of the caregivers cited the intention to regulate heavy menstrual bleeding as **the reason for administering hormonal contraceptives**. The duration, intensity and level of pain were reduced through it; in some cases, menstruation was completely suppressed. This made menstrual management much simpler and easier to plan, which provided noticeable relief and a high level of satisfaction for the main caregivers. "I am very happy with the pill because Sandra had a lot of trouble with her period. She really bled without end. Sometimes even for three weeks without a break. [...] And I have to say that Sandra got used to it very quickly. And above all, I know when she gets her period. It's convenient for me." (mother of Sandra, 15 years old). The cessation of menstruation is described unanimously as a positive effect of hormonal contraception, which simplifies the complex handling of monthly menstruation. Ina's mother reports that Ina (25 years old) was not in charge of her own menstrual management: "She couldn't control and change it herself." Stopping menstruation "makes it more comfortable, you don't have the stress anymore. It takes a whole chunk out of it."

For some, hormonal contraceptives functioned foremost as pregnancy prevention because future pregnancy could be precluded with a very high degree of certainty. The caregivers who see the main purpose of hormonal contraceptives as pregnancy prevention could be further divided into two groups. One group that acts on the basis of the current sexual and relationship related activities of the young people and one group that administers contraception in the absence of a relationship (table 3).

Table 3: Used Hormonal Contraception and Sexual Activity

	Sexually active	General	Total
Used hormonal contraception	5	8	13
Contraceptive pill	2	7	9
Three-month injection	2	1	3
Contraceptive implant	1	0	1

The mother of Elisa (18 years old) described her intention like this: “And I had also gotten her the pill right after the first menstruation started, just to be safe. And they told me at school that it was for the best. ‘We can’t always be running after her.’ And if some boys do something they don’t notice, anything can happen. I took precautions, just to be safe.” It is this group that reports especially high levels of satisfaction with their daughters’ hormonal contraception, because protecting their daughter from becoming pregnant is their top priority. Most notably, positive associations such as “safe,” “good,” “better,” “reassuring” were evoked with the administration of contraceptives. “I feel like Sonja is content with the current situation. I’m prepared for things to come, like her boyfriend she wants to bring over at the weekends. I can provide a little bit of safety. The three-month injection is a comfortable thing for her. She doesn’t have her menstruation anymore, and she doesn’t have to bother, and it gives me, as her caretaker, a sense of security.” (father of Sonja, 21 years old).

Possible **side effects of hormonal medication** were mostly tolerated by caregivers: “She has gained a little weight. But the doctor said that is normal. We have no problem,” said Helen’s (20 years old) mother. Caregivers criticized the administration of hormones only slightly. The mother of Tanja (20 years old) expressed doubts about the choice for the pill, but lacked realistic alternatives: “She is on the pill. [...] I think she is not ready yet. I think the pill just does a lot to a woman. And that along with her other medications. But how can we do it differently?” Only one of the caregivers made a conscious decision not to use hormonal contraception for her daughter (Tabea, 15 years old), even though she was in a relationship and her first sexual experience was imminent: “We agreed that we would just try it for a while without. Because at that time the boyfriend was not yet so relevant and you do not need to mindlessly flood in the hormones.” Tabea’s mother, on the one hand, is the only caregiver who explicitly advocates for condoms as the preferred contraceptive and supports her daughter in using hormone-free contraception for her first sexual intercourse. On the other hand, she is worried that Tabea and her boyfriend might have difficulties using your condom. As a possible cause for the suspected application difficulties, she explicitly mentioned the intellectual disabilities of the couple: “The problem is just whether they both are able to like just get it done when it comes to it.”

According to the caregivers, the majority of young women had **knowledge about the fact they are taking a hormonal contraceptive**. However, several statements suggest that some young women take the pill purely at their parents’ directive. There is also the case where a young woman had no knowledge that she was taking a hormonal contraceptive: “She doesn’t know that. It has never interested her before. I don’t believe she knows what it’s for.” (father of Sandra, 15 years old).

Despite legal prohibitions, two mothers were in favor of the possibility of **sterilization** surgery for their children. They justify their position with their own life situation and the consequences that a grandchild would bring with it. The mother of Jan (21 years old) described her years as the mother of a child with intellectual disability as a difficult time during which she had to give up her job for the demanding and time-consuming care of her son: “You really sacrifice yourself. Like I haven’t done much for myself over the years, privately, I gotta say. You fall through the cracks.” She feared that her son is not fit to use contraception and that she “would have to sacrifice the rest of her live also to raise her grandchild.” She generally denied her son the role of a father since, in her opinion: “He can’t raise a child consciously and reasonably. And Jan says he would like to have children. But, as sorry as I am, he can’t have children. He shouldn’t have any.” The mother of Jana (22 years old) also did not consider her daughter and her boyfriend as possibly competent parents. “She can’t even figure herself out and she basically can’t read. She can’t even read on a milk carton to make a bottle for a little kid. She can’t read a fever thermometer. She can’t take a kid to the doctor; it doesn’t work like that.” Because Jana cannot take hormonal contraceptives due to her other medications, Jana’s parents advocated “a general resolution of the problem” because they, too, feared taking over the parenting role for a potential grandchild. They were aware of the legal regulations regarding sterilization: “However, the law simply stands in the way. If Jana doesn’t agree and says, ‘No, I want it that way,’ we don’t stand a chance. In theory, Jana is entitled to have children. And that’s really a big worry for us. [...] If the two of them join forces, then we have a serious problem.”

Discussion

The results show that direct communication between main caregivers and their children and clients about sexual activities was rather rare. In some cases, not all primary caregivers had knowledge of sexual interactions from the young people with intellectual disability or received this information indirectly through third parties. This result is consistent with the findings from Pownall et al. [25] and Isler et al. [26]. Parents consider it more difficult to explain sexual issues to their child with intellectual disabilities and do so less frequently than with their children without disabilities. The culture of communication between parents and children can be strengthened and improved with a positive and open-minded attitude towards adolescent sexuality [7]. Professional caregivers can be more neutral conversation partners than parents because of their emotional distance from the client. As mentioned earlier, they also tend to be more supportive regarding the partnerships of their clients and allow them significantly less supervised relationships [20–22].

The main caregivers of young men were open to the topic of masturbation, however young women's needs were denied sometimes because carers did not classify it as a common form of sexual experience. The topic of female masturbation is still shameful and taboo, while male masturbation is widely accepted as a common sexual practice. This attitude is reflective of social norms in which young men can confess lust and demonstrate it to the outside world, but reserved young women do not touch themselves and have low libido. Previous research [29, 54] found that masturbation is the most common sexual practice performed by people with intellectual disability, mostly among men. This is similar to young people without disabilities with young men having more and earlier experience with masturbation [55].

The mothers accompanied their daughters at the first visit to the gynecologist and at all subsequent visits. They emphasized the importance of a trusting atmosphere fostered by the gynecologist: calmness, patience, and empathy during the examinations favor the compliance and the well-being of the young women. They described that their daughters were often anxious about their first gynecological examination because they did not know what to expect. The young women who were carefully prepared by their mothers for the first gynecological examination and for whom the gynecologists had patience and time to explain the examination had positive experiences. However, if the fear of the gynecologist is ignored, the first visit to the gynecologist can be remembered as a negative and sometimes painful experience. Hornberg et al. [46] also describe that gynecologists experience their female patients with intellectual disability often as very agitated during the examination in some cases not allowing it. Then it is the decision of the gynecologist if an external or internal examination is required. Gynecologists articulate to not have been prepared to treat women with intellectual disability. Because medical school education does not typically include this topic, these competencies have to be learned on the job, further education on this topic would be welcome [46].

The prescription of hormonal contraceptives was most common the reason for the first visit to a gynecologist. The prescription of hormonal contraceptives for young women with intellectual disability was described by their caregivers as arbitrary and dependent on the individual gynecologist. Some women received a hormonal contraceptive from their gynecologist despite refusing a pelvic exam, while others did not. In some cases, gynecologists prescribed hormonal contraceptives through the mothers without any direct patient contact. There is no evidence of a uniform and regulated prescription practice. This is consistent with the findings of Eastgate et al. [16] and McCarthy [32] that caregivers, particularly mothers, often demanded hormonal contraception from gynecologists deciding when their daughters would start taking it. McCarthy's study [35] also demonstrated that some caregivers wanted a contraception prescription for their daughters without their consent. Research [46] has also described gynecologists having difficulties with shared decision making with patients with intellectual disability because of communication problems leading to physician led treatment decisions. Previous research findings [42] also showed that not all gynecologists knew about human rights concerning sexual and reproductive health of women with intellectual disability concerning supporting and prescribing hormone depots and sterilization as routine practice [42].

The interviewed primary caregivers used hormonal contraceptives to simplify the regulation of menstruation of the young women with intellectual disability. They felt relieved by the simplification of menstrual management tolerating the side effects of hormonal contraception. Women with intellectual disability often experience difficulty dealing with menstruation management [43, 44] and are supported by their mothers who sometimes must take complete care [43]. Hormonal contraceptives can suppress heavy periods which is a common and difficult to manage problem [43, 45]. Previous research [36–38] demonstrates that menstrual suppression was one of the main caregivers' reasons for requesting contraception. Caregivers were predominantly perceived as supportive by

physicians during gynecological appointments but it is important to note that communication should still be mainly between doctor and patient [46]. Female patients with intellectual disability need to be informed about their options and make their own decision as to whether they wish to take hormonal contraception to suppress their menstruation.

The majority of the main caregivers supported a sexually active life for the young people. Contraception was their central focus when dealing with the sexuality of the young people but with gender-specific restrictions. They show a clearly unequal treatment towards the young women and view their sexual activities more critically because of their fear of pregnancy and responsibility for a potential grandchild. If the young women took hormonal contraceptives, this monitoring made carers more tolerant of sexual activity. Overall, the contraceptive measures taken by young men seem to attract less interest. Previous research [36–38, 56] also mentioned that pregnancy avoidance and fear of sexual abuse was one of the caregivers' main reasons requesting contraception.

The study results show that a large proportion of young women take general hormonal contraceptives, regardless of their current relationship status or potential sexual contact intention, sometimes from the onset of menstruation. One-fifth of the young women surveyed are taking or have taken a so-called hormone depot as a form of long-term contraception. For the carers, hormone depots offer long-term safety in preventing pregnancy and regular control measures are no longer required. In young people without disability, hormone depots play a minor role due to the high number of side effects [55]. A German study [56] also concluded that the female respondents with intellectual disability were prescribed hormone depots much more frequently than women without disability. The associated side effects seem to be accepted as a matter of course by women with intellectual disability in favor of high and long-term security compared to women without disability, who are quite critical of hormone depots. In general, the impression is created that the administration of hormonal contraceptives is controlled by third parties and that the women concerned are not given a say. The young women lacked background and detailed knowledge about taking hormonal contraceptives in some cases and they were not informed about the differences in hormonal contraception in comprehensible language. A mother's fear of an unwanted pregnancy for her daughter should not be a determining factor in the provision of hormonal contraception. All women should consult a gynecologist before being prescribed hormonal contraceptives and gynecologists must be informed that women with disability have the same rights as women without disability in accordance with the United Nations Convention on the Rights of Persons with Disability.

Practical implications

Gynecologists articulate the need for further education to better communicate with female patients with intellectual disability [46]. It is therefore important to also address and practice the gynecological care of women with intellectual disability in their education in order to prepare gynecologists well. Female patients with intellectual disability should be fully informed and educated about the mode of action, side effects and function of hormonal contraceptives. Easy language should be introduced and explained to gynecologists as a form of communication with women with intellectual disability. If gynecologists observe that caregivers are trying to act in opposition to the patient's will, they should communicate with the woman alone and ask exactly the background for the need for hormonal contraception and whether she agrees to take it. For the education about hormonal contraceptives at the gynecologist's office, graphic informational materials in easy language that can be taken home are needed.

In addition, education about the female cycle and the use of hygiene products should start early for girls with intellectual disability so that they can correctly classify the onset of their menstrual period. The appropriate hygiene articles (panty liners, pads, tampons) should be presented to the girls and integrated into a menstrual management concept. Dealing with the female cycle can have a de-dramatizing, de-tabooing and identity-building effect and thus contribute to positive body awareness.

Because of the masturbation gender gap, it is important to provide more sex education on the topic of female sexuality and female masturbation. Informational materials about these topics should help young women with intellectual disability to develop a sense of sexual self-awareness, free of shame and guilt. Sex educators should preferably teach within gender-homogeneous groups using easy language. Authentic discourse regarding desire would be important for adolescents with disability to define what feels desirable and undesirable on the basis of their needs, experiences, and limitations [57]. Parents should also be informed that girls and women have a right to sexual self-determination and should be allowed to live it out (e.g. through masturbation). Specific information materials are available for this purpose, as are parent initiatives and thematic school-parent evenings. Primary caregivers should also be motivated to communicate directly with their children or clients about sexuality.

Limitations

The current study has some limitations. Study participants consented to be interviewed and to talk about intimate relationships and sexuality. Consequently, they may represent a more progressive and engaged segment of the population. In addition, consent was obtained from the primary caregiver and each young participant with intellectual disability. Hence, potential participants could not participate in the study unless both consented, and results may be missing from caregiver and young participant reports. Criteria for participation included the young people having the diagnosis of intellectual disability and the ability to verbally converse. This excluded all potential participants that were not able to communicate verbally and their respective caregivers. A further limitation was the unintended fact that only heterosexual and cisgender caregivers and young participants participated in the study.

Appendix

The following questions were formulated regarding the topics sexuality, menstruation, gynecological treatment and contraception:

- Has your daughter/son already had sexual experiences to your knowledge? What was it? (If yes: Have you learned of any sexual acts involving your daughter/son from your child or from others? Have you observed your daughter/son engaging in sexual activity? How did you feel about it? How did you react to it?)
- What sexual practices can you imagine your daughter/son engaging in? (Examples: cuddling, caressing, touching of genitals, sexual intercourse, masturbation)
- When did your daughter have her first menstrual period and how did you and she react to it?
- Has your daughter ever been to a gynecologist? (If yes: At what age? Who accompanied her? What was the reason for her first visit to the gynecologist?)
- How did your daughter experience her first visit to the gynecologist from your perspective?
- What was the reason for the last visit to the gynecologist? Who accompanied her?
- Has the topic of contraception ever been brought up at the gynecologist's appointment? (If yes: Who raised the subject? Were contraceptive measures implemented afterwards?)
- Is your daughter presently taking a contraceptive or have measures been taken to prevent contraception (e.g., pill, IUD)? Is your son currently using a contraceptive or have any contraceptive measures been taken? (If yes: Which contraceptive? When was it started?)
- How satisfied are you with your daughter/son's contraceptive? Why?
- Is your daughter/son aware that she/he is taking/using a contraceptive?
- Does your daughter/son currently have sexual contacts where she/he uses contraception?
- Has your daughter/son ever had sexual contact where she/he used contraception?
- Has the contraceptive method ever been switched? (If yes: What was the specific reason? Who decided on this?)
- How do you feel knowing that your child is taking/using a contraceptive?

Declarations

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Consent to participate Informed consent was obtained from all participants included in this study.

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