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Midwives' work and attitudes towards contraceptive counselling and contraception among women with intellectual disability: focus group interviews in Sweden

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ABSTRACT

Objectives: Family planning counselling is an essential part of sexual and reproductive health care; however, health care professionals often fail to offer sexual and reproductive health services to women with intellectual disability (ID), based on a misconception of inactive sexuality. The aims of this study were to gain a deeper understanding of midwives' perceptions of sexual health and contraceptive use of women with ID, and of midwives' practices in providing contraceptive counselling to women with ID.

Methods: Five focus group interviews were conducted with 19 midwives at five antenatal/family planning clinics in central Sweden between December 2016 and February 2017.

Results: The findings are presented in a paradigm model comprising the following components: context, causal conditions for women with ID needing contraception, intervening conditions, action and interaction strategies based on the midwives' approach and performance during the consultation, and finally consequences. Midwives strived to enhance informed choice, whenever possible, and tried to maintain a neutral attitude during counselling. They wanted to provide the most suitable contraceptive method balanced against any risk of long-term use and possible side effects. Midwives raised the need for teamwork and inter-professional support to improve health care, security and access to other related services for women with ID.

Conclusions: Few women with ID request contraceptive counselling, which limits midwives' knowledge, experience and competence. Midwives, therefore, plan consultations carefully and strive to enable women with ID to make informed contraceptive choices. Increased teamwork could be a way to strengthen the role of midwives and thereby improve counselling.

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Introduction

The World Health Organization states that family planning is essential to promote the well-being and autonomy of women, their families and communities [1]. Moreover, quality of care in family planning is paramount for ensuring progress towards achieving high standards of health for all. Whether or not to use family planning is a choice based on knowledge, attitude and decision making by women and their partners. Family planning counselling thus plays an important role in making an informed contraceptive choice [1]. Expansion of access to contraception and reduction of unmet family planning needs are key components to improve reproductive health. Worldwide, contraceptive prevalence has increased from 54.8 (1990) to 63.3% (2010), and unmet needs for family planning have decreased from 15.4 to 12.3%, respectively [2].

Contraceptive counselling should be an integrated part of abortion and post-abortion care to avoid another unplanned pregnancy or abortion [3] and must include information about the fertile window, effective contraception and the emergency contraceptive pill [4]. Recent studies recommended improved counselling and access to long-acting reversible contraception (LARC) for nulliparous women of all ages [5, 6].

Previous research has stated that health care professionals often fail to offer sexual and reproductive health services to people with disabilities, based on a misconception of inactive sexuality [7]. Provision of contraceptive services for people with disabilities is complex and may require decisions based on appropriate contraception for the individual, considering the nature of the disability and the specifics of different contraceptive methods [7].

Few studies have focused on contraceptive counselling and contraceptive use among women with intellectual disability (ID) [8–12]. A 1991 study by Haefner and Elkins [8] reported that female adolescents with ID needed counselling on sexual activity, sexual abuse, temporary contraception and sterilisation, in relation to their mental and physical capabilities. Servais et al. [10] found that most women with ID receive sexual health care in primary care settings, where providers receive very little to no formal education in caring for them. Moreover, they found that 40.8% of women with ID (aged 18–46 years) did not use any contraceptive method, 22.2% were sterilised and 18.4% used oral contraception, 17.6% used depot medroxyprogesterone acetate (DMPA) and 1% used an intrauterine device. Institutional factors, such as living environment (i.e., institutional or parental), as well as the

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sexual and contraceptive policy of the institution, were strong influences [10]. One study showed that requests for contraception were initiated mainly by physicians and parents [12].

Greenwood and Wilkinson [9] found that women with ID faced significant barriers to care, including health care providers who lacked the knowledge and skills to help them. Moreover, they described hesitancy to broach the topic of sexual health, lack of sexual knowledge, limited opportunities for sexuality education, disability-related barriers, higher prevalence of sexual abuse and assault (often underreported), lack of dialogue regarding the human right to consensual sexual expression, undertreatment of menstrual disorders, as well as legal and systemic barriers. Women with ID thus face multiple health disparities and challenges to accessing health care, and little is known about how to optimise reproductive health among such women [9]. In Sweden, there are no particular guidelines related to contraceptive counselling and contraceptive use for women with ID [13].

The aims of this study were to gain a deeper understanding of midwives' perceptions of sexual health and contraceptive use of women with ID, and of midwives' practices in providing contraceptive counselling to women with ID.

Methods

The study had a descriptive design using qualitative focus group interviews. The study was carried out in central Sweden. Nineteen midwives at five midwifery clinics were recruited between December 2016 and February 2017.

Midwives in Sweden are all nurse-midwives, but in this article are referred to as midwives. They are responsible for most contraceptive counselling, either at youth clinics or midwifery clinics [14, 15]. Contraceptive counselling has been free of charge since 1974, and contraceptives are free of charge to women under 21 years and are subsidised up to the age of 25. According to national guidelines from the Medical Products Agency in Sweden, contraceptive counselling should be easily accessible. It should emphasise informed choice and encourage the formulation of a reproductive life plan. Moreover, the provider should address what constitutes a healthy lifestyle, offer screening for sexually transmitted infections (STIs) and perform Pap smear tests as recommended in national guidelines. Local guidelines generally complement the recommendations from the Medical Products Agency. Other professionals, such as a physician, a psychologist and a social worker, should be associated with each youth clinic and midwifery clinic and be available for consultations when needed. The researcher contacted the head director and local directors of the midwifery clinics who gave permission for the study. The principles of focus group research were followed [16]. Data were collected from midwives providing contraceptive counselling and contraception. All approached midwives agreed to participate. Experience of counselling women with ID varied from wide to very little experience. However, all midwives had met women with ID in other caring encounters, such as during pregnancy and childbirth.

A semi-structured topic guide with open-ended questions was developed. The topic guide covered broad areas

related to women with ID, such as sexual health, contraceptive counselling and informed choice. Each focus group included four or five midwives, and the interviews lasted on average 83 min, ranging from 63 to 111 min. The recruitment information stated that participation was equally important regardless of previous experience of counselling women with ID. The midwives were informed that they could withdraw from the study at any time without explanation. All the midwives signed a consent form and confidentiality was assured. The interviews were performed in a relaxed atmosphere and all midwives participated in the discussions. All participants had the opportunity to express their opinions to others who listened; the perspective broadened when others contributed their opinions. The interactions were vivid, deepened the opinions expressed and provided illustrations from different perspectives. The first author (BH) conducted all the interviews and the second author (ML) took notes. Both authors are researchers and midwives and have worked clinically at midwifery clinics. The interviews were tape-recorded after obtaining permission from the participants and were transcribed verbatim.

Content analysis was used to analyse the data [17, 18]. The analysis was a stepwise process of categorisation based on expressions of feelings, thoughts, attitudes, actions and experiences described throughout the text. After careful reading of all transcripts, the text was divided into meaning units, i.e., a piece of text related to the aim of the study. All meaning units were then condensed while preserving the core content. The condensed meaning units were shortened into codes, which is labelling that allows the data to be understood in relation to the context. The codes were then grouped into subcategories and thereafter to mutually exclusive categories. The emerging categories were then closely examined, discussed with the second author and organised according to a paradigm model [19]. A paradigm model is an analytical strategy for integrating structure with interacting processes to understand the data. Identifying contextual factors and linking them with processes provides the paradigm. A paradigm has four basic components: (1) causal and intervening conditions, (2) action and interaction strategies, (3) context and (4) consequences.

The first author (BH) performed the analysis throughout the whole analytical scheme, and the second author (ML) participated in all steps after the coding process. Since participation was entirely voluntary, no ethical review was needed, according to Swedish law. The procedure followed the ethical principles outlined in the Declaration of Helsinki.

Results

This section describes what the midwives said about sexual health among women with ID and their practices during contraceptive counselling of women with ID. The findings are organised according to a paradigm model, where each category relates to one component of the model. The context is related to contraceptive counselling in a midwifery setting. The causal conditions are related to the women with ID themselves and their contraceptive needs. The intervening conditions are more related to the midwife. The action and interaction strategies included the midwife's

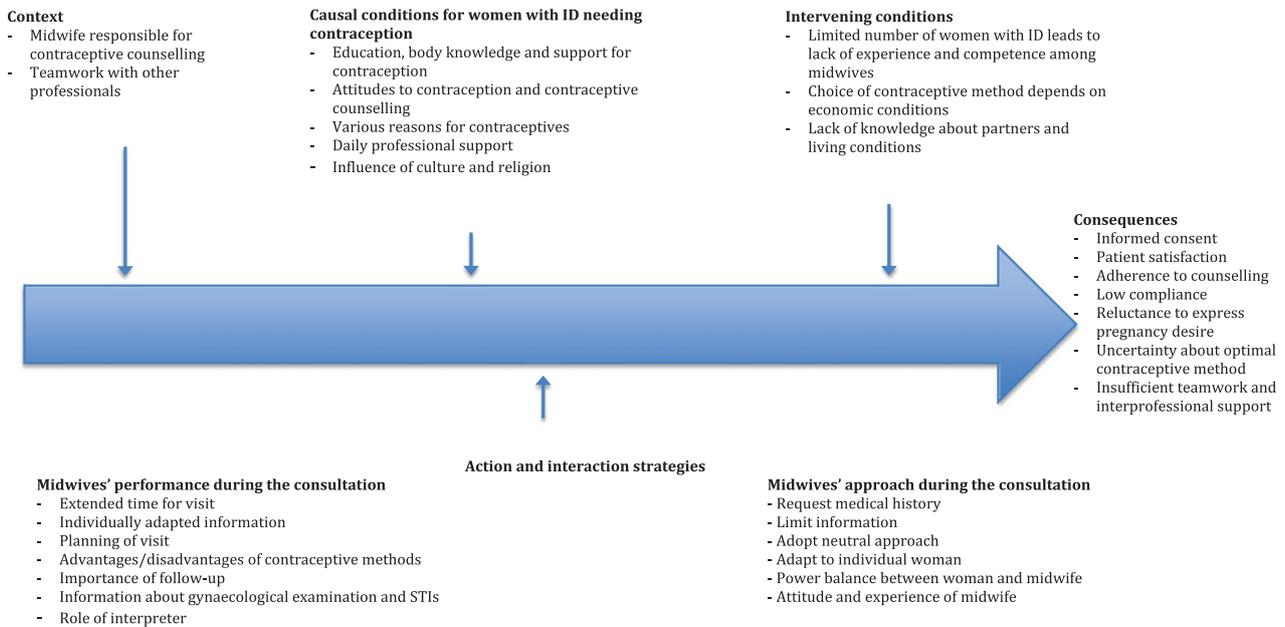


Figure 1. Findings presented in a paradigm model.

performance and approach during the consultation, and the use of an interpreter. The outcome category explored the consequences arising from all the other categories (Figure 1).

Context

Despite the model of organisation in which midwives have autonomous responsibility for contraceptive counselling, the midwives in our study described deficient teamwork in regard to women with ID. They were uncertain about where to turn for support. The midwives requested a strategy for teamwork with other professionals to improve health care and security and ensure access to other services closely related to women with ID. There should be an extended strategy of inter-professional support for close backup when a woman with ID has a need.

Causal conditions for women with ID needing contraception

The midwives discussed various reasons for women with ID to use contraceptives, such as preventing pregnancy, avoiding menstrual bleeding and pain and for reasons of hygiene. The midwives felt that culture and religion added to the multifaceted challenge in contraceptive counselling. Some immigrant women might have different attitudes and experiences of contraceptives. Those who perceived that monthly menstrual periods were necessary would be excluded from methods that caused amenorrhoea or irregular bleeding. Another challenge was language issues in combination with ID, requiring the services of a professional interpreter. It could be a cultural and religious aspect that [makes] foreign women with ID want their monthly periods.

When they visited a midwife, women with ID often had little or no knowledge about their own body and existing contraceptive methods. Others, such as friends, mothers, school nurses and midwives influenced their knowledge.

Occasionally, but not always, midwives knew whether the woman had daily professional support or not.

Midwives had the feeling that women with ID were eager to satisfy the health care provider by following instructions and complying with the suggested method of contraception. Midwives felt that to get to know the woman before a counselling situation facilitated the encounter, enhanced trust and limited the risk of choices based on social desirability.

The woman wants to satisfy the midwife and do the right thing, and so on.

Intervening conditions

Since few women who visit a midwifery clinic have an ID, midwives had limited experience and competence in counselling such women.

It is just this lack of knowledge. ... I have no knowledge or experience in meeting women with ID. What is my responsibility, should I push her, should I just accept her choice, are there other things regarding this? If she says no, should I do something more or just let her go? It is so difficult.

Another problem, according to participants, was the limited information they had about women's partners and their living conditions. Some women, however, were proud and happy to talk about their partner or boyfriend. Midwives seldom had any information about the partner's knowledge of or use of contraception, and wished they knew more about this aspect in order to get a more complete picture of the woman's circumstances.

Is she living alone? Does she have a partner? Is she living with parents or in other accommodation? You [midwife] have to create an extended map of her life conditions to give her optimal and realistic support.

A woman's financial situation could also play a significant role in her contraceptive choices; women with ID might be excluded from optimal, safe, modern and user-friendly hormonal contraception because of the higher cost.

Action and interaction strategies

Midwives' performance during the consultation

The midwives had a goal that the same midwife should counsel a woman with ID every time she sought contraceptive counselling. The midwife extended the appointment time to ensure that the woman received optimal information and support and gained a feeling of trust and security. Midwives adapted individual counselling according to the woman's ability and needs. This included determining the level of ID and the woman's current knowledge of and wishes for contraception, as well as her medical history. Midwives used pedagogical methods, such as clear, simple words and questions, repetition, short sentences, pictures, models, easy to read brochures and a review of what was said. Midwives carefully planned the consultation for women with ID, but there were no clear methods to guide them. Some midwives asked questions such as: What do you know about contraceptives? What kind of information would you like? Other midwives started with discussions about the menstrual period. Relatives, friends, staff and other people often accompanied and supported women with ID, but the midwives believed it was easier to hold intimate and private discussions alone with the woman.

The midwives talked about the advantages and disadvantages of different contraceptive methods to women with ID. LARC methods were considered to be safe contraceptive methods. However, insertion of an intrauterine device or implant was sometimes felt to be too much of an intrusion, especially if the woman's cognitive ability was limited. DMPA injections had been and still were sometimes used. The midwives prescribed DMPA to a lesser extent than they did 10 years ago, since it is a highly potent drug with a risk of decalcification of the skeleton in the long term. Instead, they recommended other safe and convenient contraceptives, such as the intrauterine device and the implant if it suited a woman with ID and her situation.

Midwives gave information about and offered gynaecological examination and screening for STIs as well as cervical cancer (Pap smears). This was an option if the woman wished it and an explanation served to prepare her so, she might feel more comfortable having an examination and screening later on.

At a gynaecological examination, I am always generous with STI screening and Pap smears.

An interpreter facilitates communication in the woman's native language, but midwives expressed a risk that information could be misunderstood and even influenced by the interpreter's own values.

The interpreter could talk very little to very much – it is uncertain and extra difficult if this person adds his or her own values about contraceptives.

Midwives' approach to the consultation

Midwives did not always explain every contraceptive method to a woman with ID, in contrast to counselling women without ID.

I think that information about all contraceptives at the same time is confusing; two to three suggestions are enough ... small doses ... and not too much talk.

The midwives' talked about the complexity of counselling if the woman had no current sexual partner but wanted contraception 'just in case'. This potential future need had to be balanced against any risk of long-term use and possible side effects. It was clear that midwives, through information sharing and discussion, tried to gain a clear understanding of a woman's previous contraceptive use and the current need for contraception in her specific circumstances. Midwives' overall strategy was to be as neutral and clear as possible in providing information and counselling. Occasionally, the midwife had to be extra clear and attentive, so the woman with ID understood the mode of administration as well as the effectiveness and benefit of her chosen method. Mostly, midwives enabled women with ID to make their own informed choice. However, sometimes they needed to direct a woman to an appropriate method if she was not capable of deciding for herself. Midwives expressed difficulties in identifying the level of a woman's ID, which was important in order to adapt the counselling accordingly.

I cannot take for granted ... I should remain indifferent and ask questions so that a woman with ID can tell me how she is doing and if she is thinking about a special contraceptive method. ... I try to find out her level of ID.

Consequences

The goal was that every woman with ID should be able to make an informed choice about contraception. In reality, this was not possible with every woman with ID; thus, sometimes, a midwife had to make the decision on her behalf. Consequently, it was difficult to know whether every woman was optimally satisfied with her contraceptive method. Mostly, midwives offered a follow-up visit within 3 months, focusing on compliance, well-being and satisfaction. Midwives felt that discussing contraception was an important area but were uncertain whether it might create a pregnancy wish among women with ID. One midwife felt that pregnancy in a woman with ID was a failure of health care. Inter-professional support benefited both women with ID and also all involved professionals.

The social worker participated once when a woman with ID came for contraception, and she [the woman with ID] also talked about other problems. This teamwork opened up a door for me.

The midwives wanted education and supervision from other professionals who had experience and knowledge about women with ID.

It feels that there are so many things to address around a woman with ID, and we need education about that ... you cannot be updated in everything.

Discussion

Findings and interpretation

The main findings of the study were that midwives considered access to contraception to be a human right and an essential factor in reproductive health for women with ID. Midwives strived to enhance informed choice, whenever possible, and tried to maintain a neutral attitude during counselling. They considered it important to preserve their

own professional knowledge and sensitivity and focus on the woman's wishes and decisions. Participants agreed that women with ID were a small target group for contraceptive counselling, which led to limited knowledge, experience and competence among midwives.

In women with less capability or who had no opinion of their own about a contraceptive method, a balancing act was needed. This interpersonal balance between the woman with ID and the prescribing midwife was a fine line which required professional knowledge and sensitivity. Occasionally, a midwife had to choose the most suitable contraceptive method for an individual woman. McCarthy [20, 21] and Walmsley et al. [22] found that women with learning disabilities did not make their own contraceptive decisions, including when to start contraceptive use, which method to use, the duration of use and the decision to discontinue.

Some midwives expressed uncertainty about whether contraceptive counselling opened women's mind to the possibility of a future pregnancy; one midwife referred to a pregnancy as a health care failure. In accordance with previous research, midwives have mixed attitudes and different experiences about pregnancies in women with ID [23].

When an interpreter was used, midwives described the risk of misinformation and influence of the interpreter's own values. Previous studies concerning interpretation in psychiatric care found a need for more training for interpreters in understanding feelings and emotions rather than simply interpreting what was explicitly stated [24, 25].

Since there are no national guidelines for contraceptive counselling among women with ID and no recommended pedagogical method, midwives adapted their counselling to women's ability and needs. Overall, midwives considered that it was necessary to create a trusting atmosphere for women with ID. Trust was essential, both in the short and long term, and especially when midwives asked private questions about lifestyle, living conditions and sexual partners. Swedish studies found that women with ID generally trusted the midwife when they were kindly treated [26], received practical and emotional support and were offered a trusted and safe environment [27].

The midwives wished to work in a stable team with other involved health care professionals. They felt that education and supervision from experienced co-workers could improve expertise. Similarly, in previous studies, midwives have requested accessible resources, professional support and supervision [23, 28].

Strengths and weaknesses of the study

The judgement of trustworthiness in qualitative research is based on credibility, dependability, confirmability and transferability [29]. To ensure credibility, we have described the entire process in detail and inserted quotations to strengthen the credibility of our findings. Dependability was created by recruiting midwives from different midwifery clinics in central Sweden, using the same topic guide. To establish confirmability, we created an open dialogue. Interpretation of the data was discussed until consensus was reached [17, 18]. Finally, transferability refers to the extent to which findings can be applied by other health care professionals at family planning clinics. We have

reasons to believe that the present findings are transferable to providers in a society with a sociodemographic structure and organisation of reproductive health care similar to those of Sweden.

One obvious weakness is that by talking to midwives we only obtained second-hand information about women with ID. The information must, therefore, be regarded with caution. Further research should focus on the women themselves and their knowledge of, attitudes to and experiences of contraceptive use and counselling.

Clinical implications

National guidelines about contraceptive counselling for women with ID are needed, as is expanded teamwork and continued education for midwives and other health care providers who provide care to women with ID.

Conclusion

Few women with ID request contraceptive counselling, which limits midwives' knowledge, experience and competence. However, the midwives planned the consultations and strived to enable women with ID to make informed contraceptive choices. Increased teamwork could be a way to strengthen the role of midwives and thereby improve counselling.

Disclosure statement

The authors report no conflict of interest.

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