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Case Study

Pregnancy and Postpartum Experiences of Women with Impaired Physical Mobility Facing Challenges within Their Surrounding Physical and Social Contexts, Alongside Interventions from Occupational Therapy

Marika Merits[1*], Kadi Lubi[2], Anneliis Aavik[1]

[1]Leading lecturer, Tallinn Health Care College, Health Care Education Centre, Estonia.

[2]Tallinn University of Technology, Department of Health Technologies, Estonia.

Marika Merits ORCID 0000-0002-5434-6117

Kadi Lubi ORCID 0000-0002-2546-0682

[*]**Corresponding author:** Marika Merits,Tallinn Health Care College, Health Care Education Centre, Estonia; Email: marika.merits@ttk.ee

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Abstract

Being a mother is a human right and an experience that many women want regardless of their health. For women with impaired physical mobility (IPM), however, this experience can be a major physical, social, and health challenge, including during pregnancy and postpartum. In Estonia, the pregnancy, and postpartum experiences of IPM women's challenges within their surrounding physical and social contexts, alongside interventions from occupational therapy. have not been previously studied. This is a case study, where a first insight into the topic is given. **Results**: IPM women are mostly satisfied with the social context, but bottlenecks are seen in physical access to health care both during pregnancy and in the postpartum period. Little is known about the possibilities of using the services of an occupational therapist. **Conclusions:** Awareness of the possibilities of occupational therapy interventions is limited and therefore the service needs to be more effectively introduced to the target group. It is also necessary to improve the human-centered social and physical context of IPM women to ensure the quality of healthcare services.

Keywords: Impaired physical mobility; Pregnancy; Postpartum period; Physical and social contexts; Occupational therapy intervention

Background

Pregnancy and childbirth are a unique and physically, psychologically, and emotionally challenging life event for every woman. All women with a desire to become mothers need a functional support system in the face of family, friends, and specialists from various areas [1-3]. For a woman with Impaired Physical Mobility (IPM), pregnancy and/or the experience of childbirth can cause further and complicated challenges for the whole length of parenthood [4]. Research has highlighted that focusing primarily on handling the social and physical obstacles can achieve the inclusion of people with disabilities in society more efficiently [5,6,24] than focusing on the disability itself or the social stigmas related to it [7]. Prior research conducted among women with IPM has shown that the women evaluate the evidence-based information targeted at people as limited [8,6,4], the attitudes and/or availability of specialists as problematic [9,10,4], and their knowledge of the specificities related to impaired mobility as superficial [11,8,12]. Access to buildings of healthcare service providers and/or necessary medical equipment is problematic for a person with mobility disability, including a woman with IPM in need of maternity care [13,9]. In case of limitations and problems either pre-existing or occurring during pregnancy and after childbirth, women with IPM need support interventions, which in several countries are offered by occupational therapists [14,1,8,15,4]. In Estonia, the pregnancy, and postpartum experiences of IPM women with the physical and social environment and with occupational therapy intervention have not been previously studied. In Estonia, occupational therapists whose role includes evaluation of occupational capacity and environment, modifications to the environment, and intervention depending on the capacity of the client, have the relevant competencies [16]. However, some specific competencies of occupational therapists need more utilization in Estonian health care, for example in maternity care of women with disabilities [17]. Occupational therapy interventions in Estonia for supporting women with IPM during pregnancy and the postpartum period have not been previously researched in the occupational therapy context. The only case study of Braschinsky et al. [18] with a similar theme was published in the Journal of Eesti Arst (Estonian Doctor) in 2002. The case study described the effects of mobility disability stemming from Sclerosis Multiplex on pregnancy, the dangers, and risks during pregnancy and postpartum, and the importance of identifying the problematic areas and developing efficient support systems. This research paper provides the first look into and a new perspective by handling the problems related to physical and social environments, awareness of the services of occupational therapists, and the possible occupational therapy interventions to support women with IPM during pregnancy and the postpartum period.

Aim

To analyze problems related to the physical and social environment, as well as occupational therapy interventions to support women with IPM during pregnancy and the postpartum period.

Methods

Study design

The method of the present research is qualitative. It is a case study because it is an appropriate way to describe human experiences and attitudes in a situation where there are few subjects, and therefore convenience sampling is used [19]. Convenience sampling is used because the inclusion of subjects in the study is difficult due to the sensitivity of the topic and the specificity of the target group, etc. [20]. Three women with IPM with whom interviews were conducted participated in the study. The women were aged 37-45 years, and all women had a partner and an average of two children. One subject has been in a wheelchair since adolescence, and the other two use crutches and/or supporting armrests for movement. The criteria for inclusion in the study were IPM, reproductive age, and childbirth that took place within the last ten years. The time limit for giving birth was set to ten years because, in the case of previous pregnancies and births, the conditions and possibilities may differ too much from the currently functioning system. To find subjects who met the criteria of the present study, the authors cooperated with the Estonian Union of Persons with Mobility Impairment (ELIL) which forwarded an invitation to participate in the study to potential participants.

Ethical consideration

The study has been approved by the Ethics Committee (TAIEK) for Human Research of the Institute for Health Development, Estonia by decision No. 2635 (21.02.2019). In addition, the consent of the research subjects is required to conduct research. Participation in the research was voluntary for the participants. Interviewees had the right to withdraw from participating in the research at any stage of the research. Subjects digitally signed an informed consent form before the start of the study and were introduced to the objectives, methodology, and benefits of the research in advance. Study participants were informed about the use, storage, and destruction of data.

Data collection and settings

The interviews took place between 1 July 2020 and 14 October 2020. The interviews were conducted by telephone to provide an anonymous environment for the research subjects and to consider limitations due to mobility impairments. Three women

with IPM with whom semi-structured interviews were conducted participated in the study. The interviews were recorded and later transcribed verbatim. The length of the interviews varied between 30 and 36 minutes. An introduction to the study, an interview schedule, and an informed consent sheet were sent electronically to the interviewees in advance for perusal. Qualitative content analysis was used to analyze the transcribed interviews. Qualitative content analysis is a text analysis that considers the background in which systematic rules are followed for coding the meanings and content of the text [21].

The present study was based on the experiences of women with IPM, the context related to during pregnancy and postpartum period (hospital and at home), and the need for occupational support and intervention. During the content analysis of the text, a scheme for the formation of categories and codes was formed (Table 1).

Pregnancy	Postpartum period	Need for Occupational Intervention
Path to Pregnancy Support of Social Environment	Physical aspects	Pregnancy
Problems Related to Physical and Social Environment	Social aspects	Postpartum period

Table 1: The formation of categories and codes.

As can be seen in Table 1, three main categories were formed: pregnancy, the postpartum period (in-patient and home setting), and the need for Occupational Intervention. Codes emerged as the result of the content analysis. The pregnancy category consisted of the following codes: Path to Pregnancy, Support of Social Environment and the postpartum period category consisted of the following codes: Physical and Social aspects. Need for Occupational Intervention category consisted of the following codes: Pregnancy and Postpartum.

Results

Pregnancy

Path to Pregnancy Support of Social Environment

Addressing pregnancy was important because, for anatomical and physiological reasons, women with IPM may have difficulty conceiving. One of the women in this study also mentioned that she had had multiple miscarriages in the past, but this fact was not medically related to the diagnosed mobility impairment. Pregnancy or the experience of pregnancy may not be directly related to disability, but the experiences can be traumatic and affect quality of life.

Also, the participants mostly did not highlight anything negative in the attitudes of the surrounding people towards the desire of women with IPM to get pregnant. "*Everyone has always been very positive, that I haven't received any bad, like negative attitudes towards it. "[I2]* One interviewee pointed out that the attitude towards people with disabilities has improved at the societal level.

I3: "The attitude in society has improved, in the sense that they are no longer looked at in the same way as in the past, maybe, I don't know (...) That there are a lot of them everywhere, well (...) working people... in the sense of the disabled in the sense that (...) that in shopping centers, everywhere that, well, in my opinion, I personally don't look down on them like that.

The medical staff and my relatives and everyone have been very supportive, no one has said that don't become a mother now or don't plan for this child /.../ Maybe myself, my fears have been greater." (I1)

As this quote highlights, the real situation was more positive than the women themselves expected, and women's insecurity or fear of having a child and being a mother can be perceived as a bigger problem than somatic health. This suggests that women with IPM may need additional emotional and/or psychological counselling and support during the journey of motherhood.

According to the interviewees, the attitude of society and medical staff, and the support of relatives towards women with IPM and their motherhood are mostly positive.

Problems Related to Physical and Social Environment

Access to various services is a constant problem for women with IPM - both before and during pregnancy.

The interviewed women pointed out that the main problem that they encounter daily and that needs to be solved at the national level is the accessibility of healthcare services.

I1: *" /.../ it would definitely be good to be accessible everywhere, so that even when I go to the family doctor, the doors can open by themselves, so that I can, era, without tearing those doors, get in there with a stroller or to the elevator or well. That this accessibility is really poor."*

In one case, the interviewee pointed out that during her pregnancy she went to a healthcare facility where the building had stairs, no elevator, and the examination room was very narrow for a wheelchair user. It proved difficult to get from the wheelchair to the examination chair because there were no adaptations to ensure accessibility. Another interviewee mentioned the lack of environmental adaptations, such as suitable seating options for disabled patients, safe access to rooms, etc.

I2: *" /.../ I'm like this, well, lighter in weight and it's easier to lift me, but who is it more difficult to help, or towards the end of pregnancy, when my body weight naturally, well, like increased (...) So then in fact it was difficult, (...) that it was immediately like at all (...) there is also [name of institution] (...) no adapted examination chair, (...) there is no scale, (...) to weigh a person in a wheelchair."*

The interviewee pointed out his fears related to difficult movement and falling.

I1: *" /.../ It's still related to movement, that er, that I tend to trip, that I was afraid of it. This falls, for example, yes. With a big belly, I also fell a few times (↑). /.../ Just the last pregnancy times that (...) (background noise) That it was, it was like the scariest thing. /.../ my ankle doesn't move, mhh (laughter). /.../ And then I seem to get my toe stuck somewhere behind (laughter). /.../ That if my leg is tired, just a little bit then (...) then I have to think carefully about my walking."*

According to the interviewees, physical accessibility to healthcare services and medical equipment is a big problem.

The interviewees did not experience a negative attitude towards the decision to become a mother from loved ones or healthcare professionals. However, one interviewee pointed out the negative attitude of the local social worker.

I3*: (...) it was somewhat surprising that the social worker of the region did ask these questions, that how /.../ are you going to have this child now? That it was planned or not? That, /.../ that he didn't seem to understand anything, that (...) I wasn't ready for that."*

The interviewees did not perceive a negative or dismissive attitude when communicating with the medical staff during pregnancy. Women emphasized on several occasions that it was more about their feelings and prejudices.

I2: *".../ where I was perhaps afraid at the beginning that they would be bigger, well I was just afraid of those prejudices, well, for example, somewhere, well, at a gynecologist or in a maternity hospital or, or at such special services, that the attitude there was actually very open. "*

Postpartum period

In this period, IMP women's experiences are discussed both in the hospital context and at home. *In terms of physical aspects*, several specific bottlenecks emerged during the postpartum period. As the interviewees' experiences revealed, the need for help at this time is very great, both in the hospital and at home.

The interviewee pointed out that when they were in the hospital after giving birth, they could use the family ward because the toilet in the general ward was not wheelchair accessible and there was also no possibility of using the disabled toilet. The toilet in the family ward was also not adapted for wheelchair access, but there the room was more open, and thanks to that it was possible to use it.

I2: *" /.../ it all boils down to accessibility, that /.../ [facility name] is generally accessible, but /.../ later, when I was there to give birth and then in the postpartum ward, where there is no disabled toilet. . there are regular toilets with poor accessibility..."*

I3: *" /.../ after giving birth, movement is already difficult, and if you still have a disability, then... try to manage in the room... "*

Here is a place for thinking and a development opportunity for healthcare institutions, how to plan and design strategically important and central principles to ensure a human-centred approach to patients with disabilities, including during pregnancy and the postpartum period.

After giving birth, problems and bottlenecks also appear at home, which are a challenge for the IPM woman and mother. After giving birth, various aids and learned techniques on how to hold, lift, place, and transport the baby more safely played an important role for women at home. For all women, holding a baby in their arms was problematic to some extent. For one woman, holding her baby in her arms and moving with her like this was scary because she had previously fallen during her pregnancy.

I1: *"Well, holding the baby at all, holding it in your arms and that, it was scary for me."*

To make everyday life easier, one of the women needed assistance services. She was helped with various household chores and taking care of her child.

I2: *„Well anyway, well still the same way, just that, uh, just, um, actually I have a personal assistant next to me, because what will happen, you never know, helps me do various jobs, it also helps, of course it also helps if he was a baby, then he also helped a lot, a lot, then we were together... "*

The previous quotes show that IPM women may have a greater need for help after childbirth in the form of various aids, techniques, and personal assistance.

Based on the social aspect, it appeared that, according to the interviewees, hospital staff are not used to helping IPM women after childbirth and rather avoid situations.

I2: *" /.../ How was it in my case, well, it was obvious that they were trying, themselves, to stay very far away, that, that (...)"*

I3: *" /.../, that these care workers, well, in their case, I have to say that they were not ready for a patient like me (laughter). /.../ Yes, that, well, help would have been needed for example, when washing there, or even if they must help post-emperor women without disabilities, well, they still have to help /.../"*

Undoubtedly, this may indicate the need to draw attention to women with special needs in the hospital's rules and regulations, because the usual practice may not always be the right choice with them. In part, it may also be a situation where the hospital worker has limited skills in helping IPM women.

Social aspects at home after childbirth were not challenging for IPM women. Positive support from loved ones was perceived.

I2: *"Well, help from loved ones, yes. (Sigh) Well (stuttering) I walked next to him, so he was a support or longer things, I took roads, journeys by car at all."*

I1: *"/.../I had emotional and moral support... laugh...always. "*

V3: *" /.../ (sigh) I don't, I can't say, I don't know. I was really good (laughter), I don't know. That, er, well, I can't say. I lived in a country house, in the sense that these, er, trees and things were brought to me by my husband, that I was able to handle the child beautifully by myself, er... that, well... "*

Better coping in the postpartum period of the IPM who participated in the study was ensured primarily by the help and support of family members and loved ones.

Need for Occupational Intervention

When asking the interviewees whether they would have needed the services of an occupational therapist during pregnancy and in the postpartum period, two interviewees answered that they were not directly aware of who an occupational therapist is and what exactly they do, having organized their life arrangements independently. When asked what kind of support they would have expected from an occupational therapist and whether they were aware of this profession, one interviewee answered:

I1: "*Yes, it is. " /.../ "But well, I, mm, I don't think they can offer me anything more."*

When asking the interviewee what kind of support or help she would have needed from an occupational therapist to organize her life better during pregnancy, or whether occupational therapy intervention would have helped, the answer was vague.

The interviewee, who had previously contacted an occupational therapist as part of rehabilitation services, pointed out that it is not possible to see an occupational therapist on an outpatient basis. Added then during pregnancy.

I3: "*You could do things like that, no, not any crap ... maybe you should really do occupational therapy now, you can't get an occupational therapist on an outpatient basis anyway."*

When women were asked about the possibility of using a paid occupational therapy service if it were made available, they would be happy to use it.

I2: *„ "I think so, I definitely would."*

One of the three women interviewed would be interested in paid occupational therapist services during pregnancy. Another interviewee found that she did not need or want the service of an occupational therapist for home adaptations but thought that it could be a necessary service for other new mothers with mobility impairments and pregnant women.

I3: "*Mhmh. (pause) Well, simple things (home adaptations) could be like in the sense that, er, well. Well, I can manage, but I think that, er, that, er, maybe there are women who are worse it was like, uh, who needs that much more help that (...)"*

The shortcoming is the lack of specific counseling for first-time mothers with IPM.

I2: *"And well, maybe it's a little bit that neither /.../ There was no more specific advice to ask that (...) and this, well, this (...) well, it's embarrassing, of course, in this to be old and, and all, but well, is there something like, (sigh) that works as a result of the fact that you are in a wheelchair and maybe you need more help yourself, that I can talk, what to prepare for more or read how others are doing, that it has been done, which is (...) people are helpful, used and it's actually positive to know."*

The interviewees pointed out which activities an occupational therapist could offer help to IPM mothers/parents as part of the home service.

I2: *„ /.../ what concerns this child, but why do we say the occupational therapist can't teach them, any thoughts, how, how to hold better, how to hold in your arms when the child is bigger or so, oh no (squeezing the child in the background), easier to do some activities, games, if mom and dad's movement is hindered?"*

The need lies in the recommendation, availability, and use of aids based on occupational therapy intervention.

I1: *" /.../ if there should be a need for help, then these aids should definitely be available."*

The interviews show the IPM's lack of knowledge about the occupational therapist as a specialist who can help and support them in other aspects related to pregnancy. It is also important to intervene in occupational therapy after childbirth, based on aspects such as the use of aids, adaptation of the home, etc. According to the interviewees, there is a lack of specific occupational therapist counseling aimed at women (mothers) with special needs.

Discussion

In this case study, the pregnancy, and postpartum experiences of women with IPM with the physical and social environment and influencing factors related to occupational therapy intervention were discussed. Even though mobility disabilities can be very

different in origin and nature [22], it is a serious challenge for women with IPM who want to become mothers, and therefore they face several obstacles.

There is a need to address limitations arising from the physical environment, such as lack of ramps, too narrow doorways, and non-adjustable medical equipment and equipment in examination rooms, which make it difficult, if not impossible, for women with IMP to access services. The interviewed women found that access to health care is difficult both before pregnancy, during pregnancy, and after childbirth. For example, the lack of special toilets in the health care facility was mentioned, which prevents basic coping and requires asking for help if it is not needed or if it is not recommended. Based on an extensive study by Sakellariou and Rotarou [9], it also appears that physical access to health care or buildings and social inclusion are difficult for people with disabilities, especially women, which in turn threatens their health indicators. Based on a large, systematic study of women with disabilities [23], it can also be confirmed that the vulnerable target group has difficult and limited access to health services, where they encounter various structural barriers. The limited accessibility of the physical environment is also analyzed in their research by Malouf et al. [6] and Bradbury-Jones et al. [24], who point out the challenges faced by women with disabilities in accessing healthcare services. Agaronik et al. [25] emphasize in their study that access to medical equipment and facilities is difficult for a disabled patient and needs improvement. Therefore, it is important to develop the physical environment and medical equipment of healthcare facilities to ensure the availability and use of services for women with IPM.

The assessment of the interviewees in this case study regarding the social environment both during pregnancy and in the postpartum period was rather positive. However, personal examples of a social worker and hospital caregivers were mentioned, whose indifferent and repulsive attitude towards the pregnancy of a woman with IMP or helping her after childbirth was perceived as rather negative. The interviewees expect more knowledge, help, and an empathic attitude from the social sector and hospital staff. Previous studies have also highlighted a similar social attitude or stigmatization, where a woman's capacity during pregnancy and after birth is questioned [7,6] and the lack of specialist knowledge of health professionals [13,9,10,4,23, 26,27]. Therefore, social and healthcare workers must have access to additional information and training and an empathic attitude that would increase the implementation of the human-centered service for IMP women in the work environment. Positive support, involvement, and help of family members are important in supporting women with IMP disabilities to become mothers. In the current study, the interviewees highlighted the help and support of family members. Powell et al. [28] have pointed out the importance of family members' attitudes and involvement in supporting motherhood for women with IMP, emphasizing that doubting it inhibits actual coping. Family members need relevant information and should be provided with training where necessary.

The intervention of an occupational therapist as a supporting specialist was considered important by the women with IMP who participated in the current study precisely because of their disability, not just because of their pregnancy and postpartum needs. Wint et al. [29] have confirmed the same because of their study. In Estonia, there is a great shortage of occupational therapists in the healthcare field, which is why it is not always possible to provide the necessary service [16,17]. In the future, healthcare facilities should include an occupational therapist in interdisciplinary teams, whose competence is to provide recommendations or interventions for the implementation of universal design principles in the planning of buildings and rooms, which would ensure patients with touch, including women with IMP, the best possible adaptations in coping in the environment.

Limitations of the study

This is the first study in Estonia reflecting the experiences of women with IMP during pregnancy and postpartum period. The main limitation of the study is the number of participants. Despite this, important institutional problems emerged, as it is a topic that has not been studied much so far. It is also necessary to note the limitations of the study methodology (the total number of women with IMP in combination with the time limit of the last pregnancy). Based on the methodology, the fact that the interviews were conducted over the phone, and it was not possible to observe the non-verbal expression characteristic of the qualitative method and necessary could also have a limiting effect. Unfortunately, the research subjects have limited knowledge about the possibilities of occupational therapist interventions in maternity care, while this is an input on how the occupational therapist can introduce the service more effectively and network cooperation with other healthcare professionals in supporting IPM women. Despite the limitations, this is important and valuable information that provides a first insight into the bottlenecks, the focus of which is the availability of healthcare services, and physical and other obstacles, that women with IPM experience during their life and every day.

Conclusion and Recommendations

Awareness of the possibilities of occupational therapy interventions is limited and therefore the service needs to be more effectively introduced to the target group. The topic needs continued research to ensure the best possible occupational therapy interventions shortly to support IPM women during pregnancy and the postpartum period, networking with other healthcare professionals and women's loved ones. It is also necessary to improve the human-centred social and physical context of IPM women to ensure the quality of healthcare services.

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