

Facilitators and Barriers of Preconception Care in Women With Inflammatory Bowel Disease and Rheumatic Diseases

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Research article

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Abstract

Background: Preconception care (PCC) is care prior to conception to optimize parental health, and health of the future child, through biomedical and behavioral changes. Providing PCC to all women with a wish to conceive will improve perinatal health. PCC is especially important for women with a chronic disease, such as inflammatory bowel disease (IBD) and rheumatic diseases (RD). However, at present PCC is not part of routine care for these women. The aim of this study is to identify facilitators and barriers on a patient and professional level regarding the provision of PCC in women with IBD and RD.

Methods: A survey study among women with IBD and RD, their treating physicians as well as obstetric professionals was performed. Patients, visiting the outpatient clinic of a university medical center and a secondary hospital located in the Netherlands with a wish to conceive, pregnant women or those with a recent pregnancy (<1 year ago) and involved physicians and obstetric professionals were eligible.

Results: A total of 71% of the IBD patients (n=22/31) and 35% of the RD patients (n=20/58) received a PCC consultation. PCC consultation was considered easy to enter, short in time and patients felt comfortable. Patients (71% IBD; 62% RD) preferred a personal PCC consultation with their disease specific specialist together with an obstetrician. Patients specifically wanted to receive information about the safety of medication use and disease activity following delivery. A total of 67% (n=31) of the included healthcare professionals agreed PCC was applicable to their patients. Main barrier to providing PCC was lack of time and unavailability of professionals. In total 41% (n=16) of obstetric professionals felt they had the knowledge and skills to provide PCC compared to 33% (n=1) and 75% (n=3) of gastroenterologists and rheumatologists, respectively.

Conclusion: Facilitators and barriers have been reported both on a patient and healthcare professional level. Despite the positive attitude towards PCC on both levels, realization of PCC remains difficult. In the future, in order to facilitate optimal PCC to high risk patients as standard of care, it is necessary to remove these barriers.

Trial Registration: not applicable.

Background

Preconception care (PCC) is care prior to conception for all women or couples to optimize parental health and the health of the future child through biomedical and behavioral changes (1). General PCC involves counselling, health promotion and risk reduction. General practitioners (GPs) and midwives are usually responsible for providing general PCC. Women receive advice about folic acid supplementation and optimal lifestyle (2–4). For women suffering from chronic diseases specialized PCC should be offered by a gynecologist or disease specific specialist. Patients should be counseled on how their disease can affect pregnancy and the risks of pregnancy associated with their disease (5).

Specialized PCC is especially important for women with chronic diseases, like inflammatory bowel disease (IBD) and rheumatic diseases (RD). IBD, Crohn's disease (CD) and ulcerative colitis (UC), is often diagnosed at a reproductive age, 50% being diagnosed before the age of 35 (6). The presence of active disease during pregnancy is one of the most important risk factors for adverse pregnancy outcomes like spontaneous miscarriage, preterm delivery and low birth weight (7). Ideally, the disease should be in remission at least six months before conception. Lack of knowledge results in incorrect beliefs regarding pregnancy. The study from *Ellul et al.*, showed that > 60% of the patients believed IBD might lead to a complicated pregnancy and the disease itself or medication use could cause harm to the fetus (8). Providing PCC in women with IBD is associated with medication compliance, reduced disease relapse during pregnancy and a protective factor for having children with a low birth weight and therefore a better outcome of pregnancy (9).

PCC is also essential for women with rheumatoid arthritis (RA). Despite the remission of this auto-immune disease during pregnancy, more than half of the RA patients experience active disease during the third trimester. Low disease activity before pregnancy is associated with low disease activity during pregnancy (10). Whereas, high disease activity in women with RA can be associated with infertility and low birthweight of their child (11, 12). Therefore, it is important that the disease is in remission before conception.

A study by *Chakravaty et al.*, regarding family planning in women with systemic inflammatory diseases, like IBD and RD, reported that patients had a preference for receiving PCC from a gynecologist. A disease specific specialist should only be involved for the treatment of the underlying chronic condition. Only a minority of the disease specific specialists reported providing PCC to female patients of reproductive age (13). Hence, women with systemic inflammatory diseases are in need of consistent information about disease specific pregnancy risks which their disease specific medical specialists will not routinely provide.

It is important to improve the quality of specialized PCC and to ensure that PCC is available for patients with a chronic inflammatory disease at risk of pregnancy complications due to their underlying disease. The aim of this study is to identify facilitators and barriers on a patient and healthcare professional level regarding PCC in women with IBD and RD.

Methods

Study design

The PPCD (Pregnancy Preparation for women with Chronic Diseases) study is a single questionnaire study (MEC-2016-368). Questionnaires on a patient and professional level were used to identify the facilitators and barriers of PCC. These questionnaires were based on validated questions from the HP4All2 study (MEC-2015-182, Healthy pregnancy 4 All-2, subproject protocol C 'interconception care') which focused on the effectiveness of programmatic PCC and systematic antenatal risk assessment by

introducing and offering PCC to women visiting family clinics in the Netherlands (14). Eligible women for the current study were patients, aged between 18–42 years, visiting the outpatient clinic for their specific disease. They had an actual or nearby future (< one year) wish to conceive, were pregnant or recently gave birth (< 1 year ago). Patients with a poor understanding of the Dutch language were excluded.

Healthcare professionals (medical specialists, residents, house-officers, midwives and consultants) working in the collaborating departments (i.e. Gastroenterology, Rheumatology and Obstetrics & Gynecology) were also asked to participate.

Study setting

The departments of Gastroenterology and Obstetrics and Gynecology of a secondary hospital (Franciscus Gasthuis & Vlietland, Rotterdam) and the departments of Gastroenterology, Rheumatology and Obstetrics and Gynecology of a tertiary university hospital (Erasmus University Medical Center, Rotterdam) participated in this study.

Study procedure

Women who met the inclusion criteria were asked to participate in this study during an outpatient visit with their disease specific specialist. They received an information letter and an informed consent form. Only after informed consent did participating patients receive an e-mail with a link to the online questionnaire using Lime Survey, which is an online tool for sending out questionnaires to specific groups. The questionnaire was completely anonymous. Healthcare professionals also received an e-mail with a link to another anonymous, online questionnaire.

Both questionnaires included questions to identify baseline characteristics (client level: 27 questions; professional level: 5 questions); facilitators and barriers of PCC (client level: 25 questions; professional level: 9 questions); knowledge, attitude and actions towards PCC (client level: 13 questions; professional level: 9 questions) and the most ideal form of a preconception consultation (i.e. a personal or a skype consultation) (client level: 2 questions; professional level: 9 questions). Facilitators and barriers were reported for the domains: personal, medical, organizational and financial. Knowledge was arbitrary judged as adequate if a patient had a score of > 80% correct answers (15, 16).

Statistical analysis

IBM SPSS Statistics version 24 was used to analyze data from both questionnaires. The baseline characteristics were determined for both patients and healthcare professionals. Frequency tables were used to analyze categorical and continuous data. Cross tables were used to report the results for knowledge, attitude and actions towards PCC. Fisher's exact and Mann-Whitney U test were used to test for significant differences between several groups. By analyzing the answers to both questionnaires, facilitators and barriers of PCC in women with IBD and RD were identified. All reported answers were considered as important and contributing to the questions and therefore included for analysis.

Results

Results at a patient level

The questionnaire was filled in by 31 women with IBD and 58 women with RD. One response in the IBD group and six responses in the RD group were incomplete (missing 3.4%). The baseline characteristics of both groups are shown in table 1. The majority of our patients were of Western origin. In total 55% (n=17) of the women in the IBD group had CD and 42% (n=13) had CU. The most common RD among our patients were RA (36%, n=21) and ankylosing spondylitis (21%, n=12). Regarding obstetric history, previous miscarriages were reported in 19% (n=6) of our women with IBD and 32% (n=18) of our women with RD. At the time of enrollment 32% (n=10) of the women in the IBD group and 45% (n=26) of the women in the RD group were pregnant.

Facilitators and barriers of PCC reported by patients with IBD and RD are shown as an additional file (additional file 1). On a personal level, multiple facilitators were found. Women in both groups said visiting a PCC consultation would be easy to enter ((90%, n=28 IBD) and (86%, n=50 RD)). The majority of women with IBD and RD felt comfortable visiting a PCC consultation and did not think it took too much time. An important reason to visit a PCC consultation was a good preparation for pregnancy which was reported by 74% (n=23) of women with IBD and 74% (n=43) of women with RD.

On a medical level 4 out of 13 IBD patients with a previous pregnancy and 6 out of 36 previously pregnant RD patients had a pregnancy that was different to expectations. Further, on a medical level, referral from their disease specific specialist was considered of higher value to visit a PCC consultation in both groups compared to advice from a gynecologist, midwife or GP.

On an organizational level the majority of the patients in both groups prefer to see PCC posters everywhere. On a financial level 90% (n=28) of women with IBD and 85% (n=49) of women with RD said PCC consultations should be available for free.

In both groups the preferred healthcare professional to provide PCC was the gynecologist and in second place they would like to receive PCC from their disease specific specialist (gastroenterologist or rheumatologist). The most ideal form of a PCC consultation was a personal combined consultation from both their disease specific specialist and gynecologist (Table 2).

Knowledge, attitude and actions towards general PCC of women with IBD and RD are described in an additional file (additional file 2). General knowledge on folic-acid supplementation was up to date in both groups as more than 80% understood the benefits of folic-acid supplementation. General knowledge on the effect of smoking on fertility was not up to date as less than 80% knew about the association with infertility.

The questionnaire also focused on the content of information patients would like to receive during a PCC consultation. Most of them wanted to receive information about medication use during pregnancy (97%, n=30 IBD; 78%, n=45 RD). Other important topics to be discussed were information about their disease after delivery and breastfeeding when using medication. In total 71% (n=22) of our women with IBD and

35% (n=20) of our women with RD visited a PCC consultation. They all felt that their questions were answered adequately and the majority found the consultation useful.

Results at a professional level

The online questionnaire was sent to healthcare professionals from the involved departments. Responses were received from 39 professionals from the department of Obstetrics and Gynecology, three from the department of Gastroenterology and four from the department of Rheumatology. Not all questionnaires were filled in completely (missing 5.4%). The baseline characteristics of the respondents are shown as an additional file (additional file 3).

Facilitators and barriers of PCC were identified on an organizational and personal level (additional file 4). At an organizational level, shortage of healthcare professionals (62%, n=24) and lack of time (54%, n=21) to provide PCC were reported as barriers by respondents from the department of Obstetrics and Gynecology. Only one respondent from the department of Gastroenterology and none of the respondents from the department of Rheumatology reported lack of time. At a personal level 64% (n=25) of the obstetric professionals agreed that from a healthcare professionals' perspective, PCC was applicable to their patients which was in agreement with the respondents from the departments of Rheumatology and Gastroenterology.

Knowledge, attitude and actions of healthcare professionals towards PCC are described in an additional file (additional file 5). From the Obstetrics and Gynecology department 41% of the respondents (n=16) felt they had sufficient knowledge and skills to provide PCC. For the departments of Rheumatology and Gastroenterology this was the case in respectively 33% (n=1) and 75% (n=3).

Figure 1 (insert figure 1) shows which healthcare professionals were considered most suitable by healthcare professionals to provide PCC. In both women with IBD and RD the gynecologist and the disease specific specialist were mentioned as most suitable. Midwives and GPs were considered less suitable to provide PCC.

Discussion

Main findings

Facilitators and barriers have been reported on a patient and healthcare professional level. Despite the positive attitude towards PCC on a client and professional level, realization of PCC remains difficult.

Comparison to other studies

Studies have shown that women in general are interested in PCC and have a positive attitude towards PCC, however the uptake of PCC is low (3, 17). The majority of women are hesitant about seeking PCC themselves, because they do not consider themselves part of the target group (3). Our study found that 71% of the women in the IBD group experienced they had received a PCC consultation which is, crucial to

mention, part of standard of care for women with IBD visiting the Department of Gastroenterology of the University hospital. Only 35% of women with RD mentioned they received a PCC consultation. However, providing PCC, is standard of care in the outpatient department of RD of the university hospital (additional file 2). These findings may be explained by variations in patient experience regarding discussion of the topic “pregnancy and pregnancy preparation” with their treating doctors.

Poels et al., reported several facilitators and barriers for general PCC. Some of the barriers identified were anxiety and fears of PCC, not being offered PCC and time and effort to visit a PCC consultation (17). These were not identified as barriers in our study. The majority felt comfortable to visit a PCC consultation or thought such consultation did not take too much time. This could be due to the selected group of women who participated in our survey study on a voluntary basis following recruitment at the outpatient clinics for their chronic disease, who might be more interested in PCC.

The study from *Chakravarty et al.* showed that 32–56% of the gastroenterologists and rheumatologists spontaneously provided PCC to women of childbearing age (13). Our study found that 67% of the gastroenterologists and 50% of the rheumatologists would provide PCC to all women who visit the clinic for routine care. However, the low number of included disease specific specialists of both departments in this study could affect these results.

Studies from *Goossens et al.* and *M’Hamdi et al.* about facilitators and barriers of PCC reported by healthcare providers mentioned more barriers than facilitators, including lack of knowledge and lack of time (18, 19). This is partly in line with our findings. Some of the healthcare professionals reported to have lack of knowledge and time to provide PCC (additional files 4–5). Therefore, more information about PCC should be provided to healthcare professionals and more time should be created to implement PCC as part of standard-care.

A study regarding knowledge on folic acid supplementation showed that knowledge on this topic has increased over the years. However, knowledge remains limited. A study from *Temel et al.*, showed an increase in knowledge from 30.7–36.8% in two years of time (16). In our study knowledge on folic acid supplementation was up to date in women with IBD and RD with > 80% correct answers. On the contrary, knowledge of the effect of smoking on fertility was not up to date with < 80% correct answers. These findings were supported by another study which showed that the majority of patients thought smoking did not affect fertility (20). Several studies have shown that smoking by men and women is associated with delayed conception and adverse pregnancy outcomes (21–23). The topics of folic acid supplementation and smoking should always be addressed during a PCC consultation.

Relevance of the findings

Research has shown that women are hesitant about seeking PCC themselves and only a minority of primary caregivers in the Netherlands recommends PCC in the form of a dedicated consultation (3, 4). This study shows that only 28% (n = 11) of the healthcare professionals from the department of Obstetrics and Gynecology would provide PCC to all women of childbearing age. The majority (74%, n =

34) would provide PCC to women with known risk factors or questions about a future pregnancy (additional file 5). Hence, a considerable group of women with an increased risk of pregnancy complications who would potentially benefit from a PCC consultation, do not receive this form of care. Hence, following this survey study aiming to provide PCC to all women of childbearing age, we would like to suggest at least to disease specific specialists that mentioning PCC to their patients generating awareness of the existence and importance of this kind of care is an urgent matter. Further, GPs and midwives could play a key role during everyday practice stating the availability and importance of a PCC consultation during routine appointments. Lastly, considering the lack of knowledge mentioned by the professionals, professionals could receive training on the importance of PCC and the possibilities how to deliver PCC to all women of childbearing age.

PCC can be provided by various healthcare professionals. Our patients preferred to receive PCC from either a gynecologist or their disease specific specialist. A personal consultation with both specialists was reported as the ideal form of a PCC consultation (Table 2). We consider collaboration between the departments of Rheumatology and Obstetrics and Gynecology at the Erasmus MC as best practice, as healthcare professionals do participate in multidisciplinary consultations and preconceptional referral of patients with a wish to conceive. At the moment the department of Obstetrics and Gynecology and the department of Gastroenterology have separate PCC consultations in the Erasmus MC. We would recommend closer collaboration between both departments to improve the quality of PCC. Recent studies from *Atrash and Jack* describe several evidence based clinical interventions and guidelines for implementation which can be useful to further optimize multidisciplinary PCC consultations (24–26).

Lack of awareness of PCC has been reported in different studies as a barrier (17–19). One patient said she never knew about the existence of PCC and she would have liked to know about disease related complications before her first pregnancy. The majority of our women with IBD or RD reported that PCC posters should be used to alert women in, amongst others, the waiting room of the midwife/GP. *Sijpkens et al.*, showed that this could result in an increased number of women visiting a PCC consultation (27).

Strengths And Limitations

One of the strengths of this study was the use of validated questions (based on the HP4All2 study) to identify facilitators and barriers of PCC. Questionnaires were anonymous and easily accessible online. Questionnaires were filled in by patients and healthcare professionals, therefore facilitators and barriers could be identified on both levels. Furthermore, this study involved different areas of interest (department of Obstetrics and Gynecology, Gastroenterology and Rheumatology). The number of women with both chronic inflammatory diseases (IBD and RD) was sufficient for the identified facilitators and barriers of PCC.

There were 46 healthcare professionals who filled in the questionnaire. Unfortunately, numbers of disease specialists included were low which can be seen as a limitation of the study. Due to the anonymity of the questionnaires it was not possible to send personal invitations to fill in the questionnaires.

We found that 71% of the patients with IBD visited a PCC consultation compared to 35% of the clients with RD. The study started in the RD group, later followed by the IBD group. In the first questionnaire we used a different word for a 'preconception consultation' which could have been misinterpreted by women. Moreover, this could be the reason for missing data on this question. During the study we substituted this word to a clearer word for 'preconception consultation' aiming for improved understanding of our survey question. In addition, despite the description of PCC in the questionnaire, it is possible women are not aware that PCC can be provided by various healthcare professionals such as their disease specific specialist. Further, it is possible more women received PCC or specific preconception information that did not match our questions about a preconception consultation. Another explanation for the lower percentage of PCC in the RD group is the fact that many of the women visiting the outpatient clinic of Rheumatology were referred to the tertiary university hospital after they had become pregnant subsequently lacking the opportunity to provide PCC in this center.

Finally, women reported they had to answer questions about a previous pregnancy, even though some of them had never been pregnant. It was not possible to skip the questions, so they answered that they did not have any problems during a previous pregnancy. This limitation for data interpretation was taken into account when constructing the results.

Conclusion

Facilitators and barriers have been reported on a patient and healthcare professional level. Despite the positive attitude towards PCC on both levels, realization of PCC remains difficult. In the future, providing optimal pregnancy preparation for high-risk patients performing specialized PCC as standard of care, it is necessary to take away the identified barriers.

Abbreviations

CD

Crohn's disease; CU:ulcerative colitis; Erasmus MC:Erasmus Medical Center; GP:general practitioner; IBD:inflammatory bowel disease; PCC:Preconception care; PPCD:Pregnancy Preparation of women with Chronic Diseases; RA; rheumatic arthritis; RD:rheumatic diseases.

Declarations

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Authors' contributions

All authors, LA, AR, RD, RW, AM, prepared and performed the study, participated in discussing and interpreting results and approved the final manuscript. LA analyzed the data. LA, AR, and AM wrote the first draft.

Ethics approval and consent to participate

The establishment and data collection have obtained a license from the Medical Ethics Committee of the Erasmus MC (MEC-2016 368). Informed written consent was obtained from each participant.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Tables

Table 1 Baseline characteristics women with IBD and RD

Registration	Women IBD Frequency n = 31 (%)* (%)*	Women RD Frequency n = 58
Mean age, years	30 (25-38)	32 (27-41)
Country of origin		
Western	30 (97)	56 (97)
Education and work		
Understanding of the Dutch language	31 (100)	57 (98)
Education		
Low	12 (39)	21 (36)
Intermediate	12 (39)	24 (41)
High	7 (23)	12 (21)
Paid job	28 (90)	47 (81)
Lifestyle and medical history		
Smoking		
No	29 (94)	54 (93)
Smoking of partner		
No	24 (77)	51 (88)
Alcohol		
Yes	17 (55)	20 (35)
Drugs		
No	29 (94)	56 (97)
Folic-acid supplement		
Yes, daily	20 (65)	43 (74)
Inflammatory bowel disease		
Ulcerative colitis	13 (42)	0 (-)
Crohn's disease	17 (55)	0 (-)
Other	1 (3)	0 (-)
Rheumatic disease		
Rheumatoid arthritis	0 (-)	21 (36)

Ankylosing spondylitis	0 (-)	12 (21)
Juvenile idiopathic arthritis	0 (-)	6 (10)
Psoriatic arthritis	0 (-)	10 (17)
Spondylarthropathy	0 (-)	6 (10)
Other	0 (-)	1 (2)
Time since diagnosis		
> 12 months	30 (97)	56 (97)
Obstetric history		
Mean number of pregnancies	2.0	2.0
Complicated pregnancy	1 (43)	11 (19)
Miscarriage		
Yes	6 (19)	18 (32)
No	25 (81)	37 (64)
One of the next problems during pregnancy		
Pre-term birth (< 37 weeks)	1 (3)	4 (7)
Birthweight < 2500 gram	1 (3)	6 (10)
Birthweight > 4500 gram	2 (7)	0 (-)
Congenital malformation	0 (-)	2 (3)
Perinatal asphyxia (Apgar 5 <7)	4 (13)	4 (7)
Perinatal mortality		
No	31 (100)	58 (100)
Contraception		
Yes	14 (45)	14 (24)
Actual wish to conceive		
Pregnant at study entry	10 (32)	26 (45)
Within 3-12 months	16 (52)	16 (27)
Within > 12 months	4 (13)	7 (12)

* due to missing answers (3.4%) the numbers do not always count up to 100%

Table 2 Most ideal form of a preconception consultation regarding women with IBD or RD

Ideal form of a preconception consultation	Women IBD	Women RD
	Frequency n = 31 (%)*	Frequency n = 58 (%)*
Personal consultation with the disease specific specialist	3 (10)	6 (10)
Personal consultation with the gynecologist	2 (7)	6 (10)
Personal consultation with the disease specific specialist and gynecologist	22 (71)	36 (62)
Skype consultation with the disease specific specialist	0 (-)	0 (-)
Skype consultation with the gynecologist	1 (3)	0 (-)
Skype consultation with the disease specific specialist and gynecologist	2 (7)	3 (5)

* due to missing answers (3.4%) the numbers do not always count up to 100%

Figures

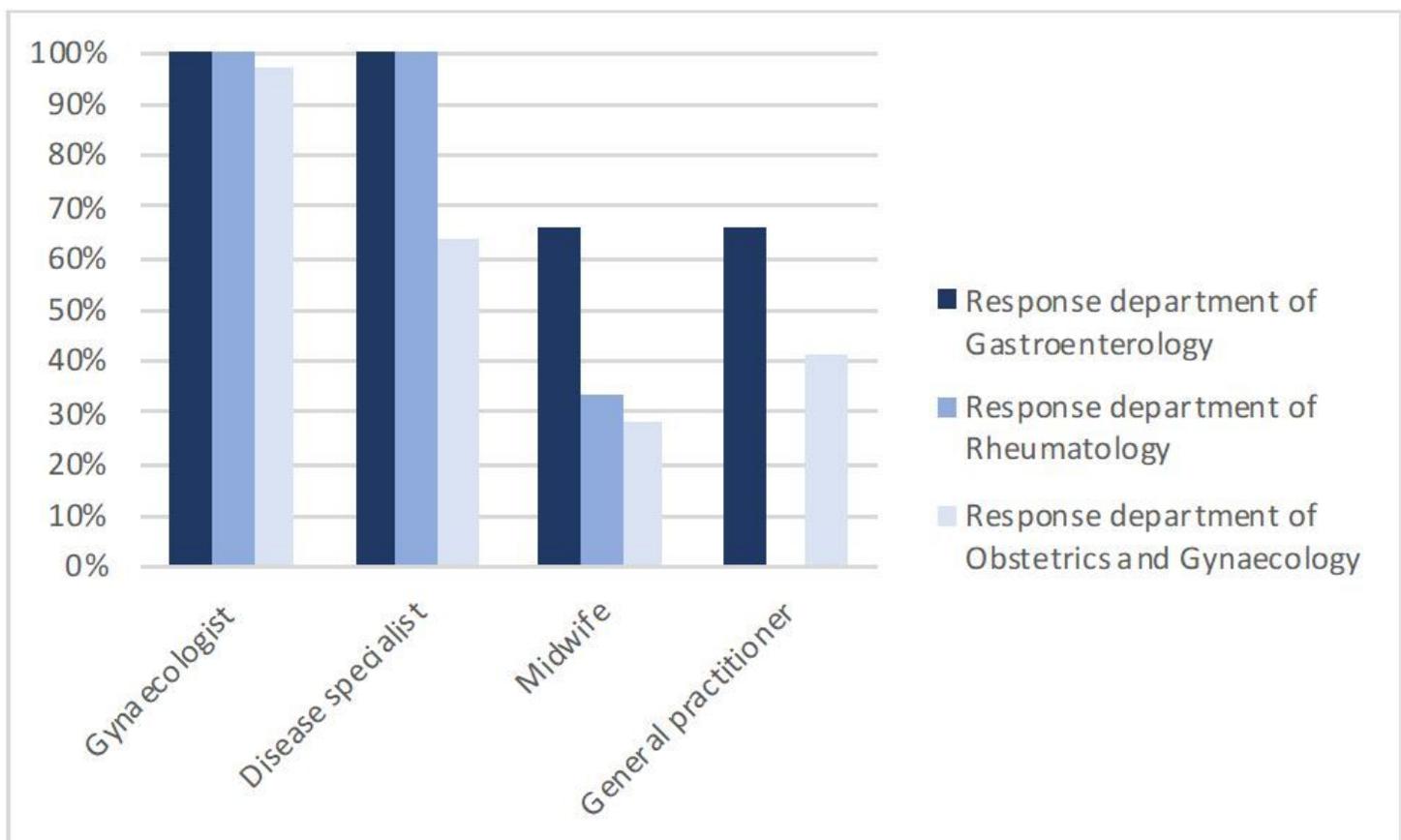


Figure 1

Healthcare professionals' point of view: professionals suitable for PCC in women with IBD/RD. Ranking according to a 5-point scale from 'most certainly' to 'most certainly not'. Percentages were calculated based on number of respondents who filled in: 'most certainly' and 'certainly'.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [AdditionalfilesfacilitatorsbarriersPCCIBDRDfinal.docx](#)