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Online contraceptive discussion forums: a qualitative study to explore information provision

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Received 27 May 2020
Revised 22 July 2020
Accepted 28 July 2020
Published Online First 25 August 2020**ABSTRACT**

Background Women in the UK spend up to 30 years avoiding pregnancy, and effective use of contraception requires detailed information and support. Online forums offer opportunities to discuss contraception with few restrictions. Analysis of these discussions may generate learning on the information needs and preferences of their users. We analysed contraceptive discussions on forums to explore content, motivation for engaging, behaviours observed and outcomes reported.

Methods We selected 50 threads across five English-speaking public forums, which contained more than 1000 contraceptive-specific threads. We generated a stratified sample of these threads (n=250) and then completed a qualitative thematic analysis.

Results Forum users seek urgent help, emotional support and the detailed accounts of others. The work of posting on forums is significant and includes framing the question to generate the desired response type, managing responses and assessing their value. Conversations were consistently framed in relation to healthcare and were important for preparing for, understanding and responding to consultations. Most of the technical information was accurate or corrected within the conversation. For most users this enquiry was part of a broader decision-making process and there was no evidence that users planned to make decisions based on forum discussions alone.

Conclusions Our analysis has implications for healthcare organisations that offer or signpost to online information on contraception. It suggests that improvements in the online 'wrap around' information are needed to help decide when to consult, prepare for the consultation, understand the information given and manage post-consultation questions.

BACKGROUND

Women in the UK spend up to 30 years avoiding unintended pregnancy.¹

Key messages

- ▶ Contraceptive forums do not challenge traditional clinical care or result in decreased use of offline medical advice.
- ▶ Contrary to concerns about inaccurate information shared on forums, we found little evidence of this in the forums we investigated.
- ▶ Forums continue to provide an essential service beyond clinical consultations; however, significant work is required by the user to access this information.

Difficulty finding acceptable contraception is associated with inconsistent use which increases risk of pregnancy, and half of pregnancies in England and Wales are unintended.² High-quality contraceptive information may support the ability to find an acceptable method of contraception and, therefore, may support effective use.³

UK guidance on quality contraceptive services requires a full choice of contraceptive options, comprehensive information and decision-making support.⁴ Guidance specifies the need to discuss the risks, benefits, side effects, medical contraindications, instructions for use, and family and personal views on all methods to be considered. This is an ambitious task in a time-limited consultation,⁵ and users often supplement the information provided in consultations with their own online research.⁶

Fifty-four per cent of adults in the UK search for health information online.⁶ Discussion forums enable people to ask personal contraceptive questions or view or respond to the questions that others have asked in an interactive context that is visible by a large audience who may have relevant knowledge or similar



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To cite: Courtenay T, Baraitser P. *BMJ Sex Reprod Health* 2021;**47**:e5.

experiences to share. The value of forums as a source of health information has been questioned,⁷ particularly their role in promoting misinformation or misconceptions.⁸

Forums are a space where people can search for any information regarding contraception and may therefore be useful to understand gaps in current information provision. An analysis of these conversations may therefore be of interest to anyone providing contraceptive information online. We were particularly interested in the content of forum discussions (What is being talked about?), the reasons for having these conversations on forums (What is the motivation for engaging on forums in particular?), the characteristics of the discussion (What behaviours could be observed within these conversations?) and the reported outcomes of the discussion. To explore these areas, we analysed discussions from five online contraceptive discussion forums to inform our thinking on new options for contraceptive information.

Aim

The study aim was to explore the content of discussions, motivation for engagement, behaviours observed and reported outcomes within five large online contraceptive forums.

Ethics

Following the British Sociological Association (BSA) report⁹ we did not seek ethical approval for this study. The BSA guidelines suggest that qualitative research on publicly accessible forum data does not require ethical approval or informed consent if an adequate anonymisation process is undertaken. The ethical approach adopted by this study also adheres to wider established guidance.^{10–13} All data discussed in the study are presented following an anonymisation process, so that the initial source cannot be discovered. This procedure includes not referencing URL links of forum posts, paraphrasing quotations and the removal of identifiable information (eg, usernames and email addresses).

METHODS

Using two internet search engines (Google and Bing) TC searched the terms “contraceptive discussion forum” and “online contraceptive conversation” and identified seven active forums or subforums in English that were dedicated to contraception. Inclusion criteria were a group of posts set up as a conversation among users (a thread) that was publicly accessible without membership restrictions. All of these forums had over 100 users, and more than 1000 contraceptive-specific threads. We completed a preliminary descriptive analysis of the initial seven forums and selected five

Table 1 Description of the five forums investigated in more detail

| Overview | Mumsnet | The Student Room | Woman's Health | SH:24 | Reddit |
|--|---|--|--|---|---|
| Forum size (posts) | 1000+ | 1000+ | 1000+ | 1000+ | 1000+ |
| Methods discussed (n) | Coil (IUD or IUS)=19 Pill(s)=17 Injection=3 Patch=0 EC=0 Implant=3 General=5 Ring=0 Condom=0 Sterilisation=2 Natural planning=3 Withdrawal=0 | Coil (IUD or IUS)=0 Pill(s)=32 Injection=1 Patch=0 EC=4 Implant=5 General=6 Ring=0 Condom=2 Sterilisation=0 Natural planning=0 Withdrawal=0 | Coil (IUD or IUS)=8 Pill(s)=22 Injection=2 Patch=0 EC=3 Implant=2 General=6 Ring=3 Condom=3 Sterilisation=1 Natural planning=0 Withdrawal=0 | Coil (IUD or IUS)=11 Pill(s)=13 Injection=4 Patch=2 EC=4 Implant=4 General=2 Ring=1 Condom=3 Sterilisation=4 Natural planning=1 Withdrawal=1 | Coil (IUD or IUS)=22 Pill(s)=17 Injection=2 Patch=1 EC=0 Implant=1 General=3 Ring=1 Condom=2 Sterilisation=0 Natural planning=0 Withdrawal=1 |
| Average response rate (responses per question) (n) | 12 | 14 | 8 | 10 | 15 |
| Moderator presence | No | No | Yes | Yes | No |
| Expertise level of moderator | N/A | N/A | Non-expert | Expert | N/A |
| Estimated age group of users | 25+ years (mention of families) | ≤24 years (users in education) | Older 30+ years users frequently referenced their children, their long-term relationships | Mixture of all ages | Mixture of all ages |
| Characteristics of the conversations | Welcoming, friendly, positive, open, supportive | Vibrant, youthful, supportive, open, LGBT+ friendly | Appears to be a community in its own right with well-established norms and preferences. | Inclusive, professional, highly personal | Vibrant, supportive, open, LGBT+ friendly, inclusive Evidence of a mix of religious and cultural expectations |

EC, emergency contraception; IUD, intrauterine device; IUS, intrauterine system; LGBT+, lesbian, gay, bisexual, trans and plus; N/A, not available.

forums/subforums to provide a sample with variability in age of user, the presence of a moderator, and level of moderator knowledge (table 1).

We created a manageable dataset for analysis by selecting the 50 most recent threads across each of the five forums (n=250). The selection criteria for these threads was a minimum of six responder replies, and a focus on a contraceptive concern raised by an original poster (OP). We selected a randomised stratified sample by assigning the 250 threads a number and using a random number generator to select 10 threads from each forum providing a total of 50 threads for thematic analysis. We completed a formal qualitative analysis of this dataset supplemented by simple counting to quantify some elements of our findings.

Analysis

Following the random selection of 50 threads, which included 591 individual posts, both authors followed an established data familiarisation process¹⁴ through repeated reading of the 50 discussion threads to identify emergent themes. We then completed a full thematic analysis¹⁴ using Nvivo 12 to explore what was being talked about, what was the motivation for engaging with a forum and what behaviours could be observed from forum conversations. We coded the original posts into these emerging themes and the discussion that responded to them separately. Throughout the analysis process we met frequently to ensure themes accurately represented the data. Our coding strategy is given in online supplemental appendix 1.

Following this thematic analysis, we conducted a simple 'count' analysis^{15 16} to provide an overview of the size of the dataset, and to quantify some aspects of our findings including the quantity of factually inaccurate data presented on the forum, and the contraceptive methods discussed. This enabled us to describe the whole of our dataset in terms of the type of information presented, and the nature of enquiries and responses.

RESULTS

Description of the forums

All forums had some similar characteristics, including response rate and contraceptive methods discussed (table 1). Users across all forums showed high levels of trust and openness, evidenced by detailed discussion of highly personal material. We observed differences between forums in user profiles, conversation tone and the moderator role. One forum (SH:24) had an identified medically trained moderator (PB) who provided technical advice, whereas Woman's Health had users who assumed a moderator role because of their apparent knowledge and the frequency of their posts. SH:24 and Woman's Health both had forum users who would refer questions directly to these moderators instead of the whole forum. The approaches within Reddit and The Student Room seemed cautious with

a low threshold for offering medical advice, whereas Mumsnet users frequently offered self-management advice based on personal long-term experience.

User age could be estimated from the questions posed and the responses received within each forum. Forums used by an older user group (eg, Mumsnet) included concerns such as post-pregnancy contraception, contraception suitable for women of different ages and age-related fertility concerns. Users of this forum appeared more knowledgeable than other forum users regarding contraceptive use and technical knowledge. Younger users (eg, those using The Student Room) raised concerns about first-time contraceptive use, access to contraception away from home and discussions of first-time sexual encounters.

Content of forum discussions

Most contraceptive methods were discussed in all of the forums, with the 'coil' (either the intrauterine device/system) and 'pills' being the most popular topics for discussion in all except The Student Room, where the 'coil' was not discussed at all, possibly due to the younger age of the participants.

Why are people using forums for contraceptive advice, do they receive the type of information they request, and do they act upon the information received?

People used forums to meet an urgent need for help when other services were inaccessible, to contextualise their own experience with reference to the experience of others, to help manage a face-to-face consultation, to gain emotional support, and to access non-biomedical approaches to the management of side effects. The key advantage of a forum in this context is the rapid response from a large audience including detailed personal accounts and overt expressions of support. Users were often clear about their intentions and what type of response they preferred. Both the questions and the responses included detailed, specific and personal descriptions that engaged the reader and conveyed or responded to a particular type of need. Table 2 illustrates the range of reasons for posting and the responses they generated.

Many posts referenced a clinical interaction, for example, asking for information about a planned procedure or for clarification or questioning of the clinical advice obtained, or for the experience of others post-procedure. Forums were also used to obtain advice on how best to use the available face-to-face resource, for example, when to consult, who to consult or how to obtain a particular outcome from a consultation. Some posters used the forum when they were worried about another person and could not seek a consultation on their behalf, or where face-to-face care was difficult to access. We categorised these information needs in relation to face-to-face care as those arising when clinical consultations are inappropriate, inconvenient or insufficient (table 3).

Table 2 Reasons for posting and responses offered on forums

| Reason for posting | Example quotes of reasons for posting | Categories of responses given to OP post and their frequency | Example quotes of responses |
|--|--|---|--|
| Urgently seeking help, and unsure of what to do | "...So I had a Mirena fitted yesterday... my God I was not prepared for the pain and had awful awful craps... I can't help being completely paranoid that it's moved... I just want some reassurance it's normal?..." | Sharing practical advice (occurred in 33 threads, with 73 mentions) Questioning the OPs interpretation of symptoms (occurred in 10 threads, with 22 mentions) | Sharing practical advice: "...Had mine in yesterday. 1/2 day of cramping totally manageable with some ibuprofen..." Questioning interpretation of symptoms: "...You're definitely normal OP! It won't have moved, I had the same and once it passed I was so happy I'd had it fitted..." |
| Seeking to learn from the experience of others | "...I'm new here but really wanted second opinions on the issue I'm having. Partner and I had a burst condom incident the day after my last period ended. The next day I went and got Levonelle (it was within 24 hours from the incident)... Has anyone had a Levonelle failure?... Ah, I'm going crazy with worry. Any advice would be much appreciated!..." | Sharing of similar experience (occurred in 29 threads, with 98 mentions) Acknowledgement of variation in personal experience (occurred in 12 threads, with 23 mentions) Sharing of negative experiences (occurred in 18 threads, with 28 mentions) | Sharing of similar experience: "...Yes, it failed for me and I ended up with an ectopic pregnancy..." Acknowledgement of variation: "...I think if you're this late... you're not pregnant. Obviously, some people might experience it differently, but I doubt you are as FRERs are so sensitive..." Sharing of negative experiences: "...Levonelle messed with my cycle for a good 6 weeks..." |
| Seeking non-conventional, technical information | "...I've been trying edible cannabis products ever since my state made them legal. I've been wondering if anyone smokes or eats edibles while using birth control. Has it conflicted with your birth control?..." | Reference own clinical consultation (occurred in 18 threads, with 33 mentions) Demonstrate a high level of knowledge (occurred in 30 threads, with 93 mentions) Linking to external knowledge sources. (occurred in 2 threads with 6 mentions) | Reference own consultation: "...I was on the pill for years and often smoked weed... Never got pregnant or had an issue with it. All my doctors were aware and told me it was fine..." High level of knowledge AND linking to external sources: "...Personally, I haven't noticed an interaction nor would condone combining the two... but research has shown cannabis to influence female hormones, have a look at these scientific studies..." |
| Specifically requesting emotional support | "...Please help me. I am feeling overwhelmed, grief-stricken, and alone. Any kind words would help..." | Offer sympathy or empathy (occurred in 6 threads, with 12 mentions) | Sympathy/empathy: "...I have had the same experiences you have! I can't offer any advice but I thought it might help you to know you are NOT alone!..." |
| Seeking an approach to contraceptive side effects slightly outside a biomedical approach | "...I eat a 1200 calorie high protein, fibre diet. I also drink tons of water... I've worked so hard I haven't had a soda in a year if the pill reverses... I would have suffered for nothing lol...what do I do?..." | Offering alternative approaches to symptom management (occurred in 3 threads, with 29 mentions) | Alternative approach: "...Some people are 'volume eaters', other people respond more to the satisfaction that fat and protein stimulate... if you know which you are it will really help with the symptoms..." |

FRER, First Response Early Result (pregnancy test); OP, original poster.

How are users consulting forums for contraceptive advice?

Users frequently requested a specific type of help, for example, technical information, emotional support or the experience of others. To indicate their need users provided detailed information about their circumstances and the extent of their distress in order to facilitate the type of response they required. Having asked a specific question, or specified a type of response, users then actively managed their thread, posting and engaging with some responses more than others to obtain specific information. Typically, a user would post numerous questions within a thread, asking for more detail and clarification; once a significant number of responses had been received they would then effectively end the thread by expressing their gratitude.

"...Thanks @Gxxxxxl @axxxxxs @oxxxx @dxxxxe. I hated it from day 1 and these are more reasons I'll never have it again... I'll get it taken out now..."

How do responders influence the direction of conversations?

Just as the OPs worked to manage their threads, the responders were also active in influencing the outcome of a conversation. Responders frequently balanced the information within forum threads, for example, countering a thread that was largely positive by sharing their own negative encounters, or encouraging others to think critically about the advice they received within a thread and the signposting given. Responders were sometimes sympathetic, sometimes didactic and

Table 3 Forum discussions as an adjunct to clinical consultations

| Adjunct themes | Adjunct subthemes | Example quotes of adjunct motives |
|-------------------------------------|--|--|
| Clinical consultation inappropriate | Posting on behalf of someone else | "...My daughter has been put on the pill Rigevidon... Having read about it, it's scaring me... Will she get blood clots, a stroke or even die... she seems fine... Has anyone been on this pill or have any advice?..." |
| Clinical consultation inconvenient | Posting because cannot easily access clinical services | "...My doctor had told me to get the coil but not recommended which one as they don't provide the service I will need to go to a clinic. I need some information, I wanted the copper coil but with the heavy periods I don't want to become anaemic. What about Mirena? Has anyone any experience of either? Advice would be very much appreciated." |
| Clinical consultation insufficient | Posting on forums for clarification of information provided in clinical care Posting on forums, following a procedure to determine normality Posting on forums before a procedure, seeking insight Posting on forums to question medical experience | "...I've just started taking the combined pill... never taken any pills before. The person at the clinic recommended I take a 5-day break instead of 7. What is the reason for this and should I really take the 5-day break or go for the 7?..." "...I got my implant 3 days ago. I was told I "wouldn't feel a thing". The insertion was agony and bled lots. It continued to bleed, and bruise until my entire arm went numb and it was a constant source of pain. Three days later and the bleeding has gone. It's still bandaged. Is this normal? Did anyone else get this or did it go wrong?..." "...I guess I am frightened. I'm more frightened of the operation [female sterilisation] than the actual decision, what is the operation like and what follows? Thanks in advance..." "... I am desperate, I really wanted the coil to be OK and I don't know if I have an underlying problem that my doctor hasn't recognised?..." |

sometimes critical, but where this occurred unhelpful posts would often be countered.

"...Don't listen to those people who are complaining about sex before marriage, they're just ignorant and trying to make you feel bad, idiots. Of course you made a mistake, it happens. I hope you had a go at the guy for being a liar... he's definitely in the wrong if he flat out denied any chance of having an STD [sexually transmitted disease]..."

Is the information provided accurate?

Out of the total number of posts (n=591), 13% (n=80) contained clinical, technical information including contraceptive effectiveness, the likelihood of side effects, contraindications to use, and explanations of how contraceptives work. A fact check of these references showed that 76% (n=61) were consistent with current clinical advice. Most of the posts with inaccurate information (n=19) concerned the effectiveness of individual methods, the likelihood of side effects, or confusion about the active ingredients of hormonal methods. Across all posts (n=591) we discovered 1% of posts (n=6) had the potential to harm users; all of these posts recommended inappropriate doses of analgesics or alternative therapies to manage adverse symptoms.

Outcomes of consulting a forum

Thirty-five of the 50 OPs mentioned their intended actions after receiving advice from the forum. Three of the 35 reported significantly changing their course of action, for example, seeking medical advice or stopping their contraceptive method. Two OPs intended to discuss the new information gained through the forum conversations during their next clinical consultation. In 17 threads no clear advice was offered and

in 13 threads forum users expressed that forum advice supported their original intentions.

"...I would like to thank everybody who responded to my query. I have taken on board all of your comments and I guess I'll have to go to the appointment with the gynaecologist... so will decide after that..."

DISCUSSION

Online forums provide rapid responses to urgent problems, detailed accounts of the experiences of 'others like me', emotional support and advice in response to personal questions. The level of activity on contraceptive forums suggests that these spaces are highly valued. All the forums we studied had thousands of active threads on all methods of contraception, and contrary to recent suggestions that forums are becoming less popular,¹⁷ we found no evidence that this is an outdated form of communication.

Forum users are looking for emotional support and the experience of others that are often unavailable within clinical consultations and at a scale that is not usually available from friends and family. However, the conversations were consistently framed in relation to healthcare, and seemed important in preparing for and responding to consultations. We found no evidence to support the literature suggesting that forum conversations challenge clinical care, or result in decreased use of offline medical advice.^{18 19} Instead forums were used to understand and interpret the clinical approach, and advice was sought to learn how to use clinical care more effectively. Contrary to concerns about inaccurate information shared on forums²⁰⁻²² we found very little inaccurate information, and where this information did occur it was usually corrected.

Using forums involves significant work. Whether this is framing a question or managing a response,

both OPs and responders direct threads, engage with specific users, counteract critical or unsupportive messages and sift through responses. Despite this work, there is little evidence that forum users altered their actions in response to the advice they received; rather they sought to contextualise their experience with reference to that of others and obtain support within a broader process of making contraceptive decisions. Definitive solutions to the problems posted were neither offered or expected.

CONCLUSIONS AND IMPLICATIONS FOR FUTURE SERVICES

Our analysis of forum conversations has implications for healthcare organisations that offer or signpost to online contraceptive information. The process of engaging with forums requires significant work; however, forums are highly valued for the depth of user experience and the emotional support they offer, particularly to prepare for, understand and respond to clinical consultations. We think that improvements in the ‘wrap around’ information provided online to help decide when to consult, prepare for the consultation, understand the information given, and manage post-consultation questions may need more attention on contraceptive information sites. Users also want increased access to detailed information based on the experience of ‘others like me’, more emotional support and greater reassurance. These findings are another reminder of the emotional work of contraceptive decision-making and the importance of the context. More thinking is required on whether and how this information could or should be offered within health information websites or whether this remains outside the remit of the support provided by healthcare organisations.

Limitations

We could only analyse the contributions of those who were actively engaging with the forum, namely posting questions and writing responses. It was not possible to present data from the majority of forum users who only read forum information to inform their decision-making process, and do not contribute to online discussion.²³

Contributors TC and PB contributed equally to this article.

Funding This research was self-funded by SH:24.

Competing interests PB is Clinical Director of SH:24 and is the moderator on the SH:24 contraceptive forum.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. All applicable data are included in the article.

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