BIRTH ISSUES IN PERINATAL CARE

Exploring the use and quality of internet discussion forums in pregnancy: a qualitative analysis

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Abstract:	Background: The internet is widely used as a source of health information to assist decision making in pregnancy. Concerningly, the quality of information shared on online pregnancy forums is unclear. Our objectives were to explore online pregnancy forum health-related use and evaluate quality of information shared. Methods: This retrospective qualitative study had two phases of data collection and analysis. First, thematic analysis of a representative sample (n=480) of posts explored motivators for forum use. Second, a subgroup (n=153) of threads with clinical content were assessed for congruence with reputable sources. Results: Common motivators for forum engagement were a desire for lived experience, unlimited access and the opportunity to express emotions. Of 1098 responses sharing advice, information or experience, 601 (54.7%) were accurate, 230 (20.9%) were erroneous, incomplete or misleading and 267 (24.3%) lacked credible evidence. Of these, 60 (5.5%) were potentially harmful. Responses often directed women to a health care provider, but concerningly, failed to refer ten women in need of urgent medical assessment. Few discussions were self-regulating, with only 12 of 230 (5.2%) poor-quality messages subsequently rectified. Conclusions: Exchange of information and emotional support amongst peers are key functions of online pregnancy forums. There is a modest prevalence of poor-quality or potentially harmful information but more concerningly a lack of peer moderation. We suggest health care providers ensure pregnant women have a clear understanding of when clinical consultation is required. Clinicians may wish to discuss the supportive community aspects of online forums in cases where offline support is lacking.

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KEYWORDS

Pregnancy, Online forums, Qualitative research

1 | INTRODUCTION

The internet is widely used as a source of information to assist decision making in pregnancy. Time pressures and lack of a woman-centred approach are often stated as reasons why many pregnant women feel dissatisfied with the information provided by health care professionals and thus seek to fill this void by self-generated research.[1,2] Internet discussion forums provide a unique platform through which peer-to-peer information sharing gives women access to first-hand accounts of others with similar experiences. It has been reported that a majority of pregnant women consider health information on the internet to be reliable and useful,[3] with many finding reassurance from the normalisation of their experiences.[4] Although women acknowledge caution is needed when reading the stories of others,[4] this has been shown to provoke feelings of worry.[5] Given they rarely discuss this self-sourced material with health care providers,[3] it is concerning that there is little understanding of the quality of pregnancy-related information shared online.

The internet hosts a dual health information economy with recognised medical or allied formal sources of information alongside a rapidly growing peer-to-peer support structure existing in discussion forums. Historical concerns over the inconsistent quality of online health information have led to the development of quality evaluation tools such as HONcode (Health on the Net Foundation Code of Conduct). However, this method of certification focuses on editorial processes rather than verifying the quality of published content.[6] In comparison, discussion forums recruit moderators to manage day-to-day affairs but their role does not involve quality assessment. Previous research has reported

varying quality of online information across a range of health conditions.[7] A systematic review,[8] published in 2002, suggests that 55 of 79 (69.6%) studies meeting inclusion criteria reported quality of health information on web sites or pages as problematic with more recent findings specifically related to pregnancy describing content as inaccurate, incomplete or distorted.[9–11] Whilst it has been noted that "few examples of documented harm can be directly attributed to poor-quality information found online",[12] this conclusion cannot be generalised to all health conditions and could be due to the difficulty in assessing this parameter. It is clear existing literature lacks insight into the role of internet discussion forums, with pregnancy material particularly underrepresented. This study aimed to 1) explore health-driven reasons for online pregnancy forum engagement, 2) evaluate quality of health-related information shared among forum users.

2 | METHODS

This retrospective qualitative study had two distinct phases of data collection and analysis. Methodology was formulated in a flexible, iterative and emergent manner, without public involvement.

2.1 | Phase 1

The first phase aimed to explore health-driven reasons for internet discussion forum use in pregnancy using thematic coding of initial posts. Forums were identified by using the term "pregnancy forums" to search Google on 24th September 2018. The ten highest ranking results were assessed using the website analytics tool Alexa, run by a subsidiary of Amazon.com, to determine number of page views and visitors within the UK over the previous 30 days. Mumsnet[13] and Netmums[14] were selected as the most popular websites

providing an online network for parents, with well-established discussion platforms targeted at pregnancy.

On the user interface, both forums subcategorised pregnancy-related topics, with the broad themes of "pregnancy" and "net-mums-to-be" in Mumsnet and Netmums respectively containing over half of the pregnancy-related discussion threads. From these subthemes, a sample of discussion threads was generated by selecting the first 20 threads from each month between 1 September 2017 to 31 August 2018. Of these, 54 threads represented exclusively social discussions, notably of product brands and due date clubs, subsequently falling beyond the remit of this study and requiring exclusion, in these cases the next thread was selected. Initial posts from the 480 discussion threads were extracted to an Excel spreadsheet and thematic analysis was performed. An inductive approach following the six-phases outlined by Braun and Clarke[15] was used to develop coding categories by a single researcher (LE) and emerging themes were regularly discussed and refined with a second researcher (LR) who also had access to all data and used this to cross-validate and triangulate findings.

2.2 | Phase 2

The second phase aimed to evaluate quality of shared information. A subgroup (n=153) of cases where the original post presented a clearly defined clinical question or related to clinical circumstances where responses may have management implications were selected for quality assessment. Full discussion threads from this purposive sample were extracted and analysed using a framework derived from content analysis. After becoming familiar with the data, we identified coding units which were applied to all responses within the discussion threads, excluding those authored by the original poster. Responses

were recognised as conforming to four key response types: 1) advice to consult a health care professional, 2) action-centred advice, 3) verifiable information, or 4) personal experience. As a single response message could contain more than one of these response types, occurrences were recorded as independent data units (n=1355).

To assess the quality of the responses, an evidence-driven evaluation was performed, examples of which are shown in Table 1. Each data unit was validated against reputable sources with consideration of the context of the initial post in the corresponding discussion thread. A hierarchical approach was used to search for sources of evidence-based information. Most commonly, we referred to easily accessible standard health care information provided by the NHS[16] (878, 64.8%). At times, more formal guidelines were required, such as NICE[17] (16, 1.2%), RCOG[18] (13, 1.0%), BNF[19] (10, 0.7%) and patient information leaflets (8, 0.6%). More specialist information was validated against articles published in peer-reviewed journals (55, 4.1%). Responses consistent with information given by a reputable source were considered to be of good quality, whereas inconsistent, incomplete or misleading responses were considered to be of poor quality. To enhance reliability of findings, raw data and sources of reputable information were recorded in an audit trail by LE and reviewed by LR with any uncertainties further assessed until agreement was reached. Where congruence could not be determined with confidence (98, 7.2%), a senior midwife lecturer was contacted for expect input. If uncertainty remained (277, 20.4%), responses were labelled as lacking a reputable source or having insufficient information.

Responses were further assessed to determine whether they were potentially harmful. This was defined as a risk that physical harm to mother or fetus could result if the original poster were to act based on the response.

In an attempt to assess whether online forums are self-regulating, a light-touch discourse analysis approach was taken to record incidences where other authors of the discussion thread stated their disagreement with a previous response considered to be of poor quality.

2.3 | Details of ethics approval

The nature of informed consent required in internet-mediated research is widely debated.[20] This study did not seek explicit consent from online forum users as all data were sourced from the public domain, where it can be determined there is no reasonable expectation of privacy such that undisclosed observation presents a very low risk of potential harm. To determine whether research activities would require any additional permissions from the two forums included in this study the terms of use and privacy policies were scrutinised. Although no obvious conflicts occurred, for completeness and following informal institutional ethics committee advice, research permission requests were sent to and approved by the forum administration teams.

3 | RESULTS

3.1 | Forum demographics and usage

During the 12-month study period, 14 552 and 4673 threads were started on the Mumsnet and Netmums subforums respectively. Of the 480 initial posts selected for analysis, all appeared to be authored by women referring to their own pregnancy

experience. Usage occurred in first pregnancy as well as subsequent pregnancies. This included all stages from pre-conception to postpartum with some posting many years into parenthood.

Despite the non-specific nature of the selected subforums, certain topics were more frequently discussed with some topics co-occurring within the 480 initial messages analysed. These included 224 (46.7%) experiences of common pregnancy-related symptoms, 153 (31.9%) management of worrying symptoms present at the time of posting, 68 (14.2%) relationship or social concerns, 57 (11.9%) attitudes towards health care professionals, 52 (10.8%) analysis of test results, 43 (9.0%) labour and delivery uncertainties.

3.2 | Motivators for engagement with online forums

Three overarching themes emerged from analysis of initial posts, suggesting a desire for lived experience, unlimited access and the opportunity to express emotions are common motivators for discussion thread creation. It was not uncommon for multiple themes to coexist within an initial post.

A key theme was lived experience as many women invited others to share accounts of issues troubling them at the time of posting. This was largely in the context of a physical concern or circumstances related to their pregnancy management. The most common motivator appearing to underlie requests for lived experience was the original poster's desire to normalise their experiences and allay their worries.

I feel awful for moaning but I feel like I'm losing the plot and just need to know that there are other ladies out there that feel like this..or whether this is in fact not normal.

Has anyone experienced this? It's not at all what I was expecting and although I've been assured my baby is fine, I'm a little anxious going forward!

This was particularly evident in cases specifically soliciting positive outcomes.

Has anyone got a story like this with a positive outcome? I've suffered 4 miscarriage this year so this is just so difficult to fathom right now.

Requests were directed to encompass historical and contemporaneous narratives.

Has anyone else dealt with something like this?

So scary and be nice to talk to others in same situation

Each narrative possibly serving, in part, a different role with the first providing insight into potential outcomes and the second contributing a unique form of emotional support in mutual adversity.

The theme of unlimited access focuses on the implication that time and availability restraints associated with traditional health care interactions are motivators for online forum use. This is exemplified by two patterns of forum usage derived from analysis of

initial posts. Firstly, there were cases where the original poster was unable to access a service with reported reasons including a lack of available appointments and failure to meet eligibility criteria.

> *My gp has no appointments for today. Just wondered if anybody had a clue as to what could be up?*

> *There was nothing they could do as our hospital won't scan until 6 weeks - they just said go home and do as little as possible until the bleeding stopped.*

Secondly, other cases showed that online forums are sometimes used to bridge the waiting period between a prior clinical consultation and the next planned contact, in this instance forum users tended to seek emotional support through requests for lived experience.

> *I'm 10 weeks pregnant and last week was picked up to have a 3.5cm cyst on ovary and a fibroid in womb lining. I haven't been given much information. Don't meet a Midwife until 2 weeks time. Has anyone had an ovarian cyst/fibroid in pregnancy before? Did it impact on it?*

Findings also suggest the unlimited availability of online forums overcomes other more understated limitations, such as providing a platform for discussion of concerns that the original poster may consider too trivial to warrant consulting a health care professional. This often seemed driven by worries of wasting the health care provider's time, taking

away from those more in need of the services and fears of being perceived in a negative light if seen to be requesting numerous visits for possibly minor concerns.

Should I ring the midwife or should I just see if it gets any better? Hate feeling like I'm wasting their time!

The final theme of emotional motivators reflects the spectrum of emotional involvement noted throughout initial posts. In cases of emotion-driven engagement, online forum use was often preceded by unsuccessful self-management and symptom progression.

I've had mild thrush throughout my pregnancy and didnt treat it until now (I'm now 34 weeks). On Saturday it got worse sore, itchy, some discharge. I used a pessary on Saturday night and since then I've had loads of yellow creamy gunky discharge coming out. Is this normal? I'm worried.

Engagement sometimes occurred during a point of crisis such that symptoms or test results were threatening pregnancy viability.

I had a small bleed on Wednesday evening, had bloods taken early hours Thursday morning, 3am In a&e and went back Saturday for repeat bloods. HCG levels dropped by 100... Is there by any chance this isn't a miscarriage? I am worried sick.

In these circumstances, the forum provided an opportunity for venting of emotions such as worry and low mood. However, sometimes reasons for emotion-driven engagement

was different. If individuals felt support provided by real-life connections did not fulfil all emotional needs they deliberately reached out to unknown others.

Am too ashamed to turn to friends as I feel foolish for some reason.

I just feel so lonely and wanted to talk to people who understand.

Occasionally, where outcomes were suboptimal, forums were used as a platform to express anger. This was in some cases directed towards a health care professional, most commonly when users felt their expectations had not been met, citing their lack of confidence in the health care professional.

I suffered a 4th degree tear the first time - I suspect mostly due to the crappy doctor and mismanagement I had.

I'm 35 weeks and had a panick attack about 45 mins ago. Hubby rang ambulance and they got here within 5 mins. I had calmed down but they didnt ask me anything about my pregnancy or even ask if i was pregnant. And didnt even both checking baby. Should they have done that?

Expressions of positive emotions were less common suggesting these are less forceful motivators, however, use of incongruent emoticons and mild humour were at times noted as a mechanism of coping with unfavourable circumstances.

I've just found out at my 12 week scan I'm having twins. Shocked in an understatement. I am terrified. I feel so ill, made worse by this shock 😂 [face with tears of joy emoji commonly used to express humour or amusement][21]

I have also developed the dreaded pregnancy waddle haha! My hubby is always telling me "you're definitely walking like a pregnant woman now!"

3.3 | Quality of messages shared on online forums

Of 153 discussion threads selected for further analysis, 83 threads were hosted on Mumsnet and 70 threads on Netmums. Collectively, these discussion threads contained 1221 responses which generated 1355 response statements.

As shown in Table 2, the provision or absence of advice to consult a health care professional was deemed appropriate in most cases (106/153, 69.3%). Of particular concern was the failure to direct 17 (11.1%) women to a health care professional when considered advisable by reputable sources. This included ten (6.5%) women in need of urgent medical assessment; five abdominal pain with additional symptoms, two vaginal bleeding, one self-reported symptoms of ectopic pregnancy, one fall, one suffering from severe headaches.

The quality characteristics of all other responses within this dataset are outlined in Table 3. A total of 1098 response statements were categorised as action-centred advice, verifiable information or personal experience. When assessed for congruence with reputable sources, 601 (54.7%) were consistent, 230 (20.9%) were inconsistent,

incomplete or misleading and 267 (24.3%) lacked credible evidence or had insufficient information for assessment.

Sharing of personal experience was the most prevalent response type (477/1355, 35.2%) and the most likely (132/477, 27.7%) to be incomplete or misleading. Of these, 120 (25.2%) were viewed as providing presumptive reassurance by citing personal positive outcomes in response to an initial message whose author, according to guidance, required medical assessment to exclude possible undesirable outcomes. In contrast, 12 (2.5%) responses were thought to provoke undue worry by overstating potential for adverse outcomes. In comparison, fewer responses sharing action-centred advice (22/251, 8.8%) or verifiable information (76/370, 20.5%) were found to be of poor-quality. These typically related to messages discussing advisory self-management, safety of behaviours, symptom commonality and explanations of physiological processes or investigation results.

Some (60/1098, 5.5%) responses were considered to be potentially harmful, for example, through advocating unsafe behaviours, normalising concerning symptoms and devaluing recommended management. These had a similar prevalence across response types.

Few discussions were found to be self-regulating, with only 12 of 230 (5.2%) inconsistent, incomplete or misleading response statements subsequently directly rectified. However more reassuringly, these corrections often (5/12, 41.7%) targeted responses considered to be potentially harmful.

4 | DISCUSSION

Our findings suggest that online forums serve as an alternative information source and extended support network for pregnant women looking to complement their offline experience. This is consistent with existing literature across a broad range of health conditions.[22–26]

Common motivators for forum use appear to be underpinned by a perception that online forums provide a platform capable of overcoming deficiencies in the offline world. Internet forums are used to supplement traditional health care interactions. This study reflects existing literature in recognising forum use prior to or following professional contact as a method of managing expectations and validating understanding.[1,25] Additionally, online forums are used to bridge the waiting period between planned contact with health care professionals. Others have shown this in the context of supplementing information regarding proposed treatment,[25] however, in pregnancy it more often appears to be used as a source of guidance if circumstances change or a new problem arises.

Previous studies indicate that sharing of personal experience is multifunctional, often reported as being used to create a sense of community[27] and nurture an empathetic environment within online support groups.[28] Moreover, the ability to connect with others sharing a mutual understanding has been described as empowering.[29] This is particularly pertinent in less prevalent health conditions. Whilst these are likely to play a role in pregnancy forums, this study suggests sharing of experience also serves to provide insight into possible outcomes, whether they are reassuring or not, frequently in the context of new-onset symptoms. The trend towards seeking lived experience for common

symptoms potentially perceived as too trivial to qualify for professional consultation or more worrying symptoms following health care professional contact supports the notion that experiences of unknown others can provide emotional support.

Comparing studies assessing quality of health information shared on the internet is challenging due to differences in design and a lack of comparators in current literature. We found 20.9% of advice, information and personal experience to be inconsistent or misleading, notably higher than the equivalent of 0.2% reported in a breast cancer forum[30]. When exclusively considering provisions of advice, an error rate of 7.2% was found, comparable to 8.6% reported in a weight loss forum.[31] Additionally, our sample exhibited a lower proportion of self-regulating posts, but reassuringly these frequently targeted potentially harmful responses. Further study is needed to better understand the self-regulating power of online discussion forums.

4.1 | Strengths and limitations

This study used a systematic inductive approach to provide a detailed and contemporary analysis of online pregnancy forum usage and quality characteristics. When interpreting these findings there are several limitations to consider. Firstly, although data saturation was achieved, a sample generated from a wider group of forums would be needed to ensure findings about information quality can be applied more generally. Secondly, motivators for online forum use were inferred from initial posts within discussion threads with no consideration of reasons why individuals engage with online forums as a responder. Furthermore, given the lack of direct questioning, this may not represent the full range of reasons women choose to engage with an online community. Thirdly, due to the nature of retrospective analysis, information regarding the original poster was at

times limited such that cautious judgement was needed when applying guidelines. Attempts were made to enhance to reliability of this process, including the recording of a detailed audit trail and independent reviews. Lastly, real-world implications of poor-quality responses are unclear. Detrimental impact may be overemphasised in the absence of sufficient data indicating whether the original poster would act on the basis of responses.

4.2 | Conclusions

This study suggests that peer-to-peer exchanging of informational and emotional support represents a key function of online pregnancy forums. Common motivators for forum engagement seem to be underpinned by a perception that the platform is capable of overcoming deficiencies in the offline world. Overall, there appears to be a modest prevalence of poor-quality or potentially harmful information but more concerningly a notable lack of peer moderation. In the absence of evidence considering the likelihood of any detrimental impact resulting from poor-quality or potentially harmful information, we suggest health care providers ensure pregnant women have a clear understanding of when clinical consultation is required. Clinicians may also wish to discuss the supportive community aspects of online forums in cases where offline support is lacking. Future research should consider, through direct participant contact, other social and emotional factors which both encourage online forum engagement and are served by such engagement.

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TABLE 1 Examples of evidence-driven evaluation of response quality, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Response type	Congruence with reputable source	Initial post context	Response quote	Reputable source quote
Action-centred advice	Consistent	Severe itching	*When you get bloods done this week get them to add on bile acid and LFT's.*	*Intrahepatic cholestasis of pregnancy is diagnosed by excluding other causes of the itch. Your doctor will probably talk to you about your medical and family history and order a variety of blood tests. These will include tests to check your liver function [LFT] and measure your bile acid levels.*[32]
	Inconsistent	Inconsistent urine pregnancy test results in first trimester	*Just say you had a bleed if your that concerned no point waiting till your 12 weeks to find out.*	*Lies that go unrecognized can promote misinformation or lead to treatment that is inappropriate or harmful.*[33]
	Incomplete or misleading	Severe headache	*My saving grace was full fat coke so maybe try a can.*	*If you're pregnant, limit the amount of caffeine you have to 200 milligrams a day.*[34]
	No reputable source available or insufficient information	Inability to urinate	*try putting a few drops of peppermint essential oil in the toilet.*	*Postpartum Urinary Retention With Essential Oils (PURE), Randomised control trial, Estimated study completion date: July 1 2019, Results not yet published.*[35]
	Potentially harmful	Vaginal bleeding in first trimester	*If it's lots of red blood and lots of pain, I wouldn't go in.*	*Call your midwife or GP immediately if you have any bleeding from your vagina.*[36]
Verifiable information	Consistent	Vaginal bleeding and drop in serum hCG	*hcg is produced by a continuing pregnancy.*	*For a woman with an increase in serum hCG [human chorionic gonadotropin] levels greater than 63% after 48 hours inform her that she is likely to have a developing intrauterine pregnancy.*[37]
	Inconsistent	Abdominal cramps in first trimester	*worry about cramps and bleeding together but not separately.*	*Call your midwife or GP immediately if you have any bleeding from your vagina.*[36] *Call your midwife immediately if you have stomach pain and regular cramping or tightenings.*[38]

	Incomplete or misleading	Vaginal bleeding in first trimester	*epu* [early pregnancy unit] *won't deal with you.*	*All other women with pain and/or bleeding should be assessed by a health care professional (such as a GP [general practitioner], A&E [accident and emergency] doctor, midwife or nurse) before referral to an early pregnancy assessment service.*[37]
	No reputable source available or insufficient information	Antenatal thromboprophylaxis use if signs of possible labour at 35 weeks	*it would be worse to take Clexane when it's not required than skip it for one day.*	*Women receiving antenatal LMWH [low-molecular-weight heparin] should be advised that if they have any vaginal bleeding or once labour begins they should not inject any further LMWH. They should be reassessed on admission to hospital and further doses should be prescribed by medical staff.*[39]
	Potentially harmful	Foods to avoid in pregnancy	*New advice is that soft / runny eggs are all okay now, previously not.*	*Lion Code eggs are considered very low risk for salmonella, and safe for pregnant women to eat raw or partially cooked. If they are not Lion Code, make sure eggs are thoroughly cooked until the whites and yolks are solid to prevent the risk of salmonella food poisoning.*[40]
Personal experience	Consistent	Aspirin use to reduce risk of recurrent miscarriages	*I'm on it* [aspirin] *to reduce pre eclampsia risk.*	*If you're thought to be at a high risk of developing pre-eclampsia, you may be advised to take a daily dose of low-dose aspirin from the 12th week of pregnancy until your baby is delivered.*[41]
	Inconsistent	–	–	–
	Incomplete or misleading	Severe headache	*I took co-codamol for mine.*	*There are some painkillers you should avoid in pregnancy – such as those containing codeine – unless prescribed by your doctor.*[42]
	No reputable source available or insufficient information	Prenatal stress	*I was stressed all through my daughter's pregnancy and she's as chilled as they come.*	*There is little consistency in the literature regarding the most sensitive time in gestation for the influence of prenatal stress, and it is likely that there are different times of sensitivity dependent on the outcome studied, and the stage of development of the relevant brain or other structures.*[43]
	Potentially harmful	Fall in first trimester	*I fell all the way down the stairs on my bum at 20 weeks. I was panicking but when I rang the hospital they were totally unconcerned and said it was only a worry if I started cramping or bleeding.*	*The risk of sensitisation can be reduced by administering anti-D immunoglobulin to women following abdominal trauma.*[44]

TABLE 2 Analysis of response referral to a health care professional, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Discussion threads (N = 153)	**Reputable sources**			**Potentially harmful**
	Consultation advisory	Consultation unnecessary	No reputable source available or insufficient information	
At least one response advises consultation	56 (36.6)	26 (17.0)	3 (2.0)	–
Absence of advice to consult	17 (11.1)	50 (32.7)	1 (0.7)	10 (6.5)

Values are given as n (% of N). Percentages may not total 100% due to rounding. Assessment of congruence with reputable sources and harmfulness status are not mutually exclusive.

Advice to consult a health care professional was found in 257 response statements within 85 discussion threads.

TABLE 3 Analysis of response congruence with reputable sources and potential for harm, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Response type	Congruence with reputable sources				Potentially harmful
	Consistent	Inconsistent	Incomplete or misleading	No reputable source available or insufficient information	
Action-centred advice (N = 251)	146 (58.2)	18 (7.2)	4 (1.6)	83 (33.1)	11 (4.4)
Verifiable information (N = 370)	248 (67.0)	46 (12.4)	30 (8.1)	46 (12.4)	25 (6.8)
Personal experience (N = 477)	207 (43.4)	–	132 (27.7)	138 (28.9)	24 (5.0)

Values are given as n (% of N). Percentages may not total 100% due to rounding. Assessment of congruence with reputable sources and harmfulness status are not mutually exclusive.

Abstract

Background: The internet is widely used as a source of health information to assist decision making in pregnancy. Concerningly, the quality of information shared on online pregnancy forums is unclear. Our objectives were to explore online pregnancy forum health-related use and evaluate quality of information shared.

Methods: This retrospective qualitative study had two phases of data collection and analysis. First, thematic analysis of a representative sample (n=480) of posts explored motivators for forum use. Second, a subgroup (n=153) of threads with clinical content were assessed for congruence with reputable sources.

Results: Common motivators for forum engagement were ~~requirements~~ a desire for lived experience, unlimited access and the opportunity to express emotions. ~~Forums were often used as a triage system, concerningly, this failed to appropriately refer ten cases~~ women ~~where the original poster~~in ~~need~~ of~~ed urgent medical assessment.~~ Of 1098 responses sharing advice, information or experience, 601 (54.7~~4~~%) were accurate, 230 (20.9~~5~~%) were erroneous, incomplete or misleading and 267 (24.3~~2~~%) lacked credible evidence. Of these, 60 (5.5~~46~~%) were potentially harmful. Responses often directed women to a health care ~~professional~~provider, but concerningly, failed to ~~do so for~~~~appropriately~~ refer ten women in need of urgent medical assessment. Few discussions were self-regulating, with only 12 of 230 (5.2~~2~~%) poor-quality messages subsequently rectified.

Conclusions: Exchange of information and emotional support amongst peers are key functions of online pregnancy forums. There is a modest prevalence of poor-quality or potentially harmful information but more concerningly a lack of peer moderation. We suggest health care providers ensure ~~all~~ pregnant women have a clear understanding of

when clinical consultation is required. ~~They~~ Clinicians may wish to discuss the supportive community aspects of online forums in cases where offline support is lacking.

KEYWORDS

Pregnancy, Online forums, Qualitative research

1 | INTRODUCTION

The internet is widely used as a source of information to assist ~~in~~ decision making in pregnancy. Time pressures and lack of a woman-centred approach are often stated as reasons why many pregnant women feel dissatisfied with the information provided by health care professionals and thus seek to fill this void by self-generated research.[1,2] Internet discussion forums provide a unique platform through which peer-to-peer information sharing gives women access to first-hand accounts of others with similar experiences. It has been reported that a majority of pregnant women consider health information on the internet to be reliable and useful,[3] with many finding reassurance from the normalisation of their experiences.[4] Although women acknowledge caution is needed when reading the stories of others,[4] this has been shown to provoke feelings of worry.[5] Given they rarely discuss this self-sourced material with health care providers,[3] it is concerning that there is little understanding of the quality of pregnancy-related information shared online.

The internet hosts a dual health information economy with recognised medical or allied formal sources of information alongside a rapidly growing peer-to-peer support structure existing in discussion forums~~, each serving a different purpose~~. Historical concerns over the inconsistent quality of online health information have led to the

development of quality evaluation tools such as HONcode (Health on the Net Foundation Code of Conduct). However, this method of certification focuses on editorial processes rather than verifying the quality of published content.[6] In comparison, discussion forums recruit moderators to manage day-to-day affairs but their role does not involve quality assessment. Previous research has reported varying quality of online information across a range of health conditions.[7] A systematic review,[8] published in 2002, suggests that 55 of 79 (69.62%) studies meeting inclusion criteria reported quality of health information on web sites or pages as problematic with more recent findings specifically related to pregnancy describing content as inaccurate, incomplete or distorted.[9–11] Whilst it has been noted that "few examples of documented harm can be directly attributed to poor-quality information found online",[12] this conclusion cannot be generalised to all health conditions and could be due to the difficulty in assessing this parameter. It is clear existing literature lacks insight into the role of internet discussion forums, with pregnancy material particularly underrepresented. This study aimed to 1) explore health-driven reasons for online pregnancy forum engagement, 2) evaluate quality of health-related information shared among forum users.

2 | METHODS

This retrospective qualitative study had two distinct phases of data collection and analysis. Methodology was formulated in a flexible, iterative and emergent manner, without public involvement.

2.1 | Phase 1

The first phase aimed to explore health-driven reasons for internet discussion forum use in pregnancy using thematic coding of initial posts. Forums were identified by using the

term “pregnancy forums” to search Google on 24th September 2018. The ten highest ranking results were assessed using the website analytics tool Alexa, run by a subsidiary of Amazon.com, to determine number of page views and visitors within the UK over the previous 30 days. Mumsnet ~~(MN)~~[13] and Netmums ~~(NM)~~[14] were selected as the most popular websites providing an online network for parents, with well-established discussion platforms targeted at pregnancy.

On the user interface, both forums subcategorised pregnancy-related topics, with the broad themes of “pregnancy” and “net-mums-to-be” in Mumsnet and Netmums respectively containing over half of the pregnancy-related discussion threads. From these subthemes, a sample of discussion threads was generated by selecting the first 20 threads from each month between 1 September 2017 to 31 August 2018. Of these, 54 threads represented exclusively social discussions, notably of product brands and due date clubs, subsequently falling beyond the remit of this study and requiring exclusion, in these cases the next thread was selected. Initial posts from the 480 discussion threads were extracted to an Excel spreadsheet and thematic analysis was performed. An inductive approach following the six-phases outlined by Braun and Clarke[15] was used to develop coding categories by a single researcher (LE) and emerging themes were regularly discussed and refined with a second researcher (LR) who also had access to all data and used this to cross-validate and triangulate findings.

2.2 | Phase 2

The second phase aimed to evaluate quality of shared information. A subgroup (n=153) of cases where the original post presented a clearly defined clinical question or related to clinical circumstances where responses may have management implications were

selected for quality assessment. Full discussion threads from this purposive sample were extracted and analysed using a framework derived from content analysis. After becoming familiar with the data, we identified coding units which were applied to all responses within the discussion threads, excluding those authored by the original poster. Responses were recognised as conforming to four key response types: 1) advice to consult a health care professional, 2) action-centred advice, 3) verifiable information, or 4) personal experience. As a single response message could contain more than one of these response types, occurrences were recorded as independent data units (n=1355).

To assess the quality of the responses, an evidence-driven evaluation was performed, examples of which are shown in Table 1. Each data unit was validated against reputable sources[16–19] with consideration of the context of the initial post in the corresponding discussion thread. A hierarchical approach was used to search for sources of ~~gold standard~~evidence-based information. Most commonly, we referred to easily accessible standard health care information provided by the ~~, such as~~ NHS[16] ~~resources~~ (878, 64.8%)~~.~~ ~~or~~At times, ~~-~~more formal guidelines were required, such as NICE[17] (16, 1.2%), RCOG[18] (13, 1.0%), BNF[19] (10, 0.7%) and patient information leaflets (8, 0.6%). More specialist information was validated against articles published in peer-reviewed journals (55, 4.1%). Responses consistent with information given by a reputable source were considered to be of good quality, whereas inconsistent, incomplete or misleading responses were considered to be of poor quality. ~~More specialist information was validated against articles published in peer-reviewed journals. Responses consistent with information given by a reputable source were considered to be of good quality, whereas inconsistent, incomplete or misleading responses were considered to be of poor quality.~~ To enhance ~~credibility~~reliability of findings, raw data and sources of reputable

information were recorded in an audit trail by LE and reviewed by LR with any uncertainties further assessed until agreement was reached. Where congruence could not be determined with confidence (98, 7.2%), a senior midwife lecturer was contacted for expect input. If uncertainty remained (277, 20.4%), responses were labelled as lacking a reputable source or having insufficient information.

Responses ~~categorised as personal experience, poor quality or lacking a reputable source~~ were further assessed to determine whether they were potentially harmful. This was defined as a risk that physical harm to mother or fetus could result if the original poster were to act based on the response.

In an attempt to assess whether online forums are self-regulating, a light-touch discourse analysis approach was taken to record incidences where other authors of the discussion thread stated their disagreement with a previous response considered to be of poor quality.

2.3 | Details of ethics approval

The nature of informed consent required in internet-mediated research is widely debated.[20] This study did not seek explicit consent from online forum users as all data were sourced from the public domain, where it can be determined there is no reasonable expectation of privacy such that undisclosed observation presents a very low risk of potential harm. To determine whether research activities would require any additional permissions from the two forums included in this study the terms of use and privacy policies were scrutinised. Although no obvious conflicts occurred, for completeness and

following informal institutional ethics committee advice, research permission requests were sent to and approved by the forum administration teams.

3 | RESULTS

3.1 | ~~Overview of F~~forum demographics and usage ~~and demographics~~

During the 12-month study period, 14 552 and 4673 threads were started on the Mumsnet and Netmums subforums respectively. Of the 480 initial posts selected for analysis, all appeared to be authored by women referring to their own pregnancy experience. Usage occurred in first pregnancy as well as subsequent pregnancies. This included all stages from pre-conception to postpartum with some posting many years into parenthood.

~~3.2 | Purpose of online forum use~~

Despite the non-specific nature of the selected subforums, certain topics were more frequently discussed with some topics co-occurring within the 480 initial messages analysed. These included 224 (46.~~6~~7%) experiences of common pregnancy-related symptoms, 153 (31.9~~88~~%) management of worrying symptoms present at the time of posting, 68 (14.2~~17~~%) relationship or social concerns, 57 (11.9~~88~~%) attitudes towards health care professionals, 52 (10.8~~3~~%) analysis of test results, 43 (~~8.~~9.0~~6~~%) labour and delivery uncertainties.

~~Initial forum posts most commonly involved presentation of a concern with a request for experience sharing, this was consistent across most discussion topics (Table 1, Quotes 1 & 2).~~

Ive been itching that much ive bled a few times. I just cant get it to go away and its bloody worse at night. Anyone else had this?

When discussing symptoms of pregnancy experienced at the time of posting, women were also likely to seek advice, opinions or reassurance (Table 1, Quote 3). Occasionally, this was accompanied by a photograph to convey more information than possible with text alone. This was most common when symptoms involved vaginal bleeding or discharge.

I'm 27 weeks pregnant and have been woken up three times in the last week by a stabbing / stinging pain in my pubic bone area. Lasts for a few minutes, then goes. Haven't had anything at all whilst I'm awake / walking. Google suggests it's SPD, but I'm loathed to believe it. Anyone had anything similar? Does it tend to get worse? Anything that can be done? Help!

When considering more social concerns, requests for relationship advice and information regarding legal considerations, such as working regulations in pregnancy and child benefit entitlements, were common (Table 1, Quotes 4 & 5).

Any advice on how to approach him?

Are you still entitled to maternity pay if you will have only worked for your employer for 24 weeks? Getting really anxious about maternity pay

3.23 | Motivators for engagement with online forums

Three overarching themes emerged from analysis of initial posts, suggesting a desire for lived experience, unlimited access and the opportunity to express emotions are common motivators for discussion thread creation. It was not uncommon for multiple themes to coexist within an initial post.

A key theme was lived experience as ma~~*Theme 1: Lived experience*~~

ny ~~original posters~~women invited others to share accounts of issues troubling them at the time of posting. This was largely in the context of a physical concern or circumstances related to their pregnancy management. The most common motivator appearing to underlie requests for lived experience was the original poster's desire to normalise their experiences and allay their worries~~. (Table 1, Quotes 6 & 7),~~

> ~~*I'm a day off 36wks pregnant with baby no2. And I feel HORRENDOUS. I am starting to panic & feel very anxious that something is actually wrong with me or baby. I am exhausted, I can't sleep because I'm so uncomfortable, I have CONSTANT leg and pelvic pain where I feel like I've been punched downstairs - it feels bruised. EVERYTHING is an effort which exhausts me.. I feel awful for moaning but I feel like I'm losing the plot and just need to know that there are other ladies out there that feel like this..or whether this is in fact not normal.*~~
>
> ~~*My rheumy always told me that my RA won't affect my pregnancy and vice vers but having seen the women's health consultant, I'm high risk with a chance of blood clots, a pre term labour and a small birth weight. Has anyone*~~

experienced this? It's not at all what I was expecting and although I've been assured my baby is fine, I'm a little anxious going forward!

Tthis wais particularly evident in cases specifically soliciting positive outcomes ~~(Table 1, Quote 8)~~.

Has anyone got a story like this with a positive outcome? I've suffered 4 miscarriage this year ~~also~~ so this is just so difficult to fathom right now.

Requests were directed to encompass historical and contemporaneous narratives.

~~(Table 1, Quotes 9 & 10),~~

~~*My doctor guesses that I probably had an eptoptic pregnancy that resolved itself. My HCG is not down to 120. I guess I'm worried that this much bleeding indicates something worse, such as internal damage.*~~ *Has anyone else dealt with something like this?*

~~*Hi, has anyone been told they are high risk for Downs Syndrome in pregnancy? Just had harmony test done today and got to wait 1 -2 weeks for results. So scary and be nice to talk to others in same situation*~~

Eeach ~~of these~~narrative possibly serving, in part, ~~, in part,~~ a different role w~~-w~~ith the first providing insight into potential outcomes and the second contributing a unique form of emotional support in mutual adversity.

The theme of unlimited access focuses on the implication ~~Some individuals imply~~ that time and availability restraints associated with traditional health care interactions are motivators for online forum use. This is exemplified by two patterns of forum usage derived from analysis of initial posts. Firstly, there were cases where the original poster was unable to access a service with reported reasons including a lack of available appointments and failure to meet eligibility criteria ~~(Table 1, Quotes 11 & 12)~~.

My gp has no appointments for today. Just wondered if anybody had a clue as to what could be up?

There was nothing they could do as our hospital won't scan until 6 weeks - they just said go home and do as little as possible until the bleeding stopped.

Secondly, other cases showed that online forums are sometimes used to bridge the waiting period between a prior clinical consultation and the next planned contact, in this instance forum users tended to seek emotional support through requests for lived experience ~~(Table 1, Quote 13)~~.

I'm 10 weeks pregnant and last week was picked up to have a 3.5cm cyst on ovary and a fibroid in womb lining. I haven't been given much information. Don't meet a Midwife until 2 weeks time. Has anyone had an ovarian cyst/fibroid in pregnancy before? Did it impact on it?

Findings also suggest the unlimited availability of online forums overcomes other more understated limitations, such as providing a platform for discussion of concerns that the

original poster may consider too trivial to warrant consulting a health care professional. This often seemed driven by worries of wasting the health care provider's time, taking away from those more in need of the services and fears of being perceived in a negative light if seen to be requesting numerous visits for possibly minor concerns. ~~(Table 1, Quote 14).~~

Should I ring the midwife or should I just see if it gets any better? Hate feeling like I'm wasting their time!

~~*Theme 3: Emotional motivators*~~

The final theme of emotional motivators reflects the~~A~~ spectrum of emotional involvement ~~was~~ noted throughout initial posts. In cases of emotion-driven engagement, online forum use was often preceded by unsuccessful self-management and symptom progression. ~~(Table 1, Quote 15) with~~

I've had mild thrush throughout my pregnancy and didnt treat it until now (I'm now 34 weeks). On Saturday it got worse sore, itchy, some discharge. I used a pessary on Saturday night and since then I've had loads of yellow creamy gunky discharge coming out. Is this normal? I'm worried.

E~~e~~ngagement sometimes occurred~~ing~~ during a point of crisis such that symptoms or test results were threatening pregnancy viability ~~(Table 1, Quote 16)~~.

I had a small bleed on Wednesday evening, had bloods taken early hours Thursday morning, 3am In a&e and went back Saturday for repeat bloods.

HCG levels dropped by 100... Is there by any chance this isn't a miscarriage? I am worried sick.

In these circumstances, the forum provided an opportunity for venting of emotions such as worry and low mood. However, sometimes reasons for emotion-driven engagement was different. If individuals felt support provided by real-life connections did not fulfil all emotional needs they deliberately reached out to unknown others ~~(Table 1, Quotes 17 & 18)~~.

Am too ashamed to turn to friends as I feel foolish for some reason.

I just feel so lonely and wanted to talk to people who understand.

Occasionally, where outcomes were suboptimal, forums were used as a platform to express anger. This was in some cases directed towards a health care professional, most commonly when users felt their expectations had not been met, citing their lack of confidence in the health care professional ~~(Table 1, Quotes 19 & 20)~~.

I suffered a 4th degree tear the first time - I suspect mostly due to the crappy doctor and mismanagement I had.

I'm 35 weeks and had a panick attack about 45 mins ago. Hubby rang ambulance and they got here within 5 mins. I had calmed down but they didnt ask me anything about my pregnancy or even ask if i was pregnant. And didnt even both checking baby. Should they have done that?

Expressions of positive emotions were less common suggesting these are less forceful motivators, however, use of incongruent emoticons and mild humour were at times noted as a mechanism of coping with unfavourable circumstances~~s (Table 1, Quotes 21 & 22)~~.

> *I've just found out at my 12 week scan I'm having twins. Shocked in an understatement. ~~I don't even know where to start! I have a son who's 21 months and~~ I am terrified. I feel so ill, made worse by this shock* 😂 [face with tears of joy emoji commonly used to express humour or amusement][~~21~~21]
>
> *I have also developed the dreaded pregnancy waddle haha! My hubby is always telling me "you're definitely walking like a pregnant woman now!"*

3.~~3~~4 | Quality of messages shared on online forums

Of 153 discussion threads selected for further analysis, 83 threads were hosted on Mumsnet and 70 threads on Netmums. Collectively, these discussion threads contained 1221 responses which generated 1355 response statements.

As shown in Table 2, the provision or absence of advice to consult a health_care professional was deemed appropriate in most cases (106/153, 69.3~~28~~%). ~~Some (26/153, 17.06.99%) original posters received advice to consult a health_care professional when considered unnecessary, potentially encouraging suboptimal use of health_care resources.~~ O~~O~~f particular concern was the failure to ~~triage~~ direct 17 (11.1~~1~~%) ~~cases~~ women to a health care professional when considered ~~where consultation was~~ advisable by reputable sources. This~~,~~ included~~ing~~ ten (6.5~~4~~%) women in need of urgent medical

assessment; five abdominal pain with additional symptoms, two vaginal bleeding, one self-reported symptoms of ectopic pregnancy, one fall, one suffering from severe headaches.

The quality characteristics of all other responses within this dataset are outlined in Table 3~~2~~3. A total of 1098 response statements were categorised as ~~other~~ action-centred advice, verifiable information or personal experience. When assessed for congruence with reputable sources, 601 (54.74%) were consistent, 230 (20.9~~5~~%) were inconsistent, incomplete or misleading and 267 (24.3~~2~~%) lacked credible evidence or had insufficient information for assessment.

Sharing of personal experience was the most prevalent response type (477/1355, 35.2~~0~~%) and the most likely (132/477, 27.~~6~~7%) to be incomplete or misleading. Of these, 120 (25.2~~16~~%) were viewed as providing presumptive reassurance by citing personal positive outcomes in response to an initial message whose author, according to guidance, required medical assessment to exclude possible undesirable outcomes. In contrast, 12 (2.5~~2~~%) responses were thought to provoke undue worry by overstating potential for adverse outcomes. ~~In comparison, fewer responses sharing contextual advice (22/251, 8.8%) or verifiable information (76/370, 20.5%) were found to be of poor-quality.~~In comparison, fewer responses sharing action-centred advice (22/251, 8.8%) or verifiable information (76/370, 20.5%) were found to be of poor-quality. These typically related to messages discussing advisory self-management, safety of behaviours, symptom commonality and explanations of physiological processes or investigation results.

Some (60/1098, 5.546%) responses were considered to be potentially harmful, for example, through advocating unsafe behaviours, normalising concerning symptoms and devaluing recommended management. These had a similar prevalence across response types.

Few discussions were found to be self-regulating, with only 12 of 230 (5.22%) inconsistent, incomplete or misleading response statements subsequently directly rectified. However more reassuringly, these corrections often (5/12, 41.67%) targeted responses considered to be potentially harmful.

4 | DISCUSSION

Our findings suggest that online forums serve as an alternative information source and extended support network for pregnant women looking to complement their offline experience. This is consistent with existing literature across a broad range of health conditions.[22–26]

Common motivators for forum use appear to be underpinned by a perception that online forums provide a platform capable of overcoming deficiencies in the offline world. Internet forums are used to supplement traditional health care interactions. This study reflects existing literature in recognising forum use prior to or following professional contact as a method of managing expectations and validating understanding.[1,25] Additionally, online forums are used to bridge the waiting period between planned contact with health care professionals. Others have shown this in the context of supplementing information regarding proposed treatment,[25] however, in pregnancy it

more often appears to be used as a source of guidance ~~triage system~~ if circumstances change or a new problem arises.

Previous studies indicate that sharing of personal experience is multifunctional, often reported as being used to create a sense of ~~community[28]~~ community[27] and nurture an empathetic environment within online support groups.[28] Moreover, the ability to connect with others sharing a mutual understanding has been described as empowering.[29] This is particularly pertinent in less prevalent health conditions. Whilst these are likely to play a role in pregnancy forums, this study suggests sharing of experience also serves to provide insight into possible outcomes, whether they are reassuring or not, frequently in the context of new-onset symptoms. The trend towards seeking lived experience for common symptoms potentially perceived as too trivial to qualify for professional consultation or more worrying symptoms following health care professional contact supports the notion that experiences of unknown others can provide emotional support.

~~Findings from this study suggest that when pregnant women have low-risk concerns they tend to use online forums to engage with a generic contemporary cohort of direct peers, primarily for the benefits associated with a sense of community. In comparison, when pregnancy concerns are perceived to be of higher-risk, forum users are more likely to make explicit requests for shared experience in hope of attracting a seemingly more relatable source of support. These patterns of temporal-driven and experience-driven relatability suggest a multi-dimensional approach to support seeking. Thus, perhaps, some support requirements in pregnancy are more readily attainable through engagement with the online community rather than through one's traditional offline support network.[312]~~

Comparing studies assessing quality of health information shared on the internet is challenging due to differences in design and a lack of comparators in current literature. ~~Previous studies report 0.22% of postings were false or misleading in a breast cancer forum[32] forum[33] and 8.6% of advice was erroneous in a weight loss forum.[33,34] Most direct comparisons with our data indicate a notably higher 20.95% of advice, information and personal experience were erroneous, incomplete or misleading although a similar error rate of 7.217% is found when exclusively considering provisions of general advice.~~We found 20.9% of advice, information and personal experience to be inconsistent or misleading, notably higher than the equivalent of 0.2% reported in a breast cancer forum[30]. When exclusively considering provisions of advice, an error rate of 7.2% was found, comparable to 8.6% reported in a weight loss forum.[31] Additionally, our sample exhibited a lower proportion of self-regulating posts, but reassuringly these frequently targeted potentially harmful responses. Further study is needed to better understand the self-regulating power of online discussion forums.

4.1 | Strengths and limitations

This study used a systematic inductive approach to provide a detailed and contemporary analysis of online pregnancy forum usage and quality characteristics. ~~The enabled naturalistic exploration of pregnancy experiences, at times highlighting attitudes beyond which are commonly shared with clinicians or researchers. Importantly, this analysis contributes to an underrepresented area of research.~~

When interpreting these findings there are several limitations to consider. Firstly, although data saturation was achieved, a sample generated from a wider group of forums

would be needed to ensure findings about information quality can be applied more generally. Secondly, motivators for online forum use were inferred from initial posts within discussion threads with no consideration of reasons why individuals engage with online forums as a responder. Furthermore, given the lack of direct questioning, this may not represent the full range of reasons women choose to engage with an online community. Thirdly, due to the nature of retrospective analysis, information regarding the original poster was ~~often~~ at times limited s~~.~~uch that cautious judgement was needed when applying guidelines. Attempts were made to enhance to reliability of this process, including the recording of a detailed audit trail and~~,~~ independent reviews ~~and further analysis of uncertainties.~~ ~~degree of subjectivity was needed when applying guidelines. Attempts were made to enhance the reliability of this process, including temporally spaced reviews and the recording of a detailed audit trail.~~ Lastly, real-world implications of poor-quality responses are unclear. Detrimental impact may be overemphasised in the absence of sufficient data indicating whether the original poster would act on the basis of responses. ~~Whereas, total adversity may be underestimated by the inability to measure negative emotional impact.~~

4.2 | Conclusions

This study suggests that peer-to-peer exchanging of informational and emotional support represents a key function of online pregnancy forums. Common motivators for forum engagement seem to be underpinned by a perception that the platform is capable of overcoming deficiencies in the offline world. Overall, there appears to be a modest prevalence of poor-quality or potentially harmful information but more concerningly a notable lack of peer moderation. In the absence of evidence considering the likelihood of any detrimental impact resulting from poor-quality or potentially harmful information,

we suggest health care providers ensure pregnant women have a clear understanding of when clinical consultation is required. ~~They~~ Clinicians may also wish to discuss the supportive community aspects of online forums in cases where offline support is lacking. Future research should consider, through direct participant contact, other social and emotional factors which both encourage online forum engagement and are served by such engagement.

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TABLE 1 Examples of evidence-driven evaluation of response quality, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Response type	Congruence with reputable source	Initial post context	Response quote	Reputable source quote
Action-centred advice	Consistent	Severe itching	*When you get bloods done this week get them to add on bile acid and LFT's.*	*Intrahepatic cholestasis of pregnancy is diagnosed by excluding other causes of the itch. Your doctor will probably talk to you about your medical and family history and order a variety of blood tests. These will include tests to check your liver function [LFT] and measure your bile acid levels.*[32]
	Inconsistent	Inconsistent urine pregnancy test results in first trimester	*Just say you had a bleed if your that concerned no point waiting till your 12 weeks to find out.*	*Lies that go unrecognized can promote misinformation or lead to treatment that is inappropriate or harmful.*[33]
	Incomplete or misleading	Severe headache	*My saving grace was full fat coke so maybe try a can.*	*If you're pregnant, limit the amount of caffeine you have to 200 milligrams a day.*[34]
	No reputable source available or insufficient information	Inability to urinate	*try putting a few drops of peppermint essential oil in the toilet.*	*Postpartum Urinary Retention With Essential Oils (PURE), Randomised control trial, Estimated study completion date: July 1 2019, Results not yet published.*[35]
	Potentially harmful	Vaginal bleeding in first trimester	*If it's lots of red blood and lots of pain, I wouldn't go in.*	*Call your midwife or GP immediately if you have any bleeding from your vagina.*[36]
Verifiable information	Consistent	Vaginal bleeding and drop in serum hCG	*hcg is produced by a continuing pregnancy.*	*For a woman with an increase in serum hCG [human chorionic gonadotropin] levels greater than 63% after 48 hours inform her that she is likely to have a developing intrauterine pregnancy.*[37]
	Inconsistent	Abdominal cramps in first trimester	*worry about cramps and bleeding together but not separately.*	*Call your midwife or GP immediately if you have any bleeding from your vagina.*[36] *Call your midwife immediately if you have stomach pain and regular cramping or tightenings.*[38]

	Incomplete or misleading	Vaginal bleeding in first trimester	*epu* [early pregnancy unit] *won't deal with you.*	*All other women with pain and/or bleeding should be assessed by a health care professional (such as a GP [general practitioner], A&E [accident and emergency] doctor, midwife or nurse) before referral to an early pregnancy assessment service.*[37]
	No reputable source available or insufficient information	Antenatal thromboprophylaxis use if signs of possible labour at 35 weeks	*it would be worse to take Clexane when it's not required than skip it for one day.*	*Women receiving antenatal LMWH [low-molecular-weight heparin] should be advised that if they have any vaginal bleeding or once labour begins they should not inject any further LMWH. They should be reassessed on admission to hospital and further doses should be prescribed by medical staff.*[39]
	Potentially harmful	Foods to avoid in pregnancy	*New advice is that soft / runny eggs are all okay now, previously not.*	*Lion Code eggs are considered very low risk for salmonella, and safe for pregnant women to eat raw or partially cooked. If they are not Lion Code, make sure eggs are thoroughly cooked until the whites and yolks are solid to prevent the risk of salmonella food poisoning.*[40]
Personal experience	Consistent	Aspirin use to reduce risk of recurrent miscarriages	*I'm on it* [aspirin] *to reduce pre eclampsia risk.*	*If you're thought to be at a high risk of developing pre-eclampsia, you may be advised to take a daily dose of low-dose aspirin from the 12th week of pregnancy until your baby is delivered.*[41]
	Inconsistent	–	–	–
	Incomplete or misleading	Severe headache	*I took co-codamol for mine.*	*There are some painkillers you should avoid in pregnancy – such as those containing codeine – unless prescribed by your doctor.*[42]
	No reputable source available or insufficient information	Prenatal stress	*I was stressed all through my daughter's pregnancy and she's as chilled as they come.*	*There is little consistency in the literature regarding the most sensitive time in gestation for the influence of prenatal stress, and it is likely that there are different times of sensitivity dependent on the outcome studied, and the stage of development of the relevant brain or other structures.*[43]
	Potentially harmful	Fall in first trimester	*I fell all the way down the stairs on my bum at 20 weeks. I was panicking but when I rang the hospital they were totally unconcerned and said it was only a worry if I started cramping or bleeding.*	*The risk of sensitisation can be reduced by administering anti-D immunoglobulin to women following abdominal trauma.*[44]

TABLE 2 Analysis of response referral to a health care professional, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Discussion threads (N = 153)	**Reputable sources**			**Potentially harmful**
	Consultation advisory	Consultation unnecessary	No reputable source available or insufficient information	
At least one response advises consultation	56 (36.6)	26 (17.0)	3 (2.0)	–
Absence of advice to consult	17 (11.1)	50 (32.7)	1 (0.7)	10 (6.5)

Values are given as n (% of N). Percentages may not total 100% due to rounding. Assessment of congruence with reputable sources and harmfulness status are not mutually exclusive.

Advice to consult a health care professional was found in 257 response statements within 85 discussion threads.

TABLE 3 Analysis of response congruence with reputable sources and potential for harm, Qualitative analysis of online pregnancy forums, UK, 2017-2018

Response type	Congruence with reputable sources				Potentially harmful
	Consistent	Inconsistent	Incomplete or misleading	No reputable source available or insufficient information	
Action-centred advice (N = 251)	146 (58.2)	18 (7.2)	4 (1.6)	83 (33.1)	11 (4.4)
Verifiable information (N = 370)	248 (67.0)	46 (12.4)	30 (8.1)	46 (12.4)	25 (6.8)
Personal experience (N = 477)	207 (43.4)	–	132 (27.7)	138 (28.9)	24 (5.0)

Values are given as n (% of N). Percentages may not total 100% due to rounding. Assessment of congruence with reputable sources and harmfulness status are not mutually exclusive.

Dr. Marian MacDorman
Editor-in-Chief
Birth

5th September 2019

Dear Dr. Marian MacDorman,

Thank you for giving us the opportunity to submit a revised draft of our manuscript, ID Birth-19-06-27 entitled 'Exploring the use and quality of internet discussion forums in pregnancy: a qualitative analysis'. We are grateful for the insightful feedback and have incorporated all suggested changes. Please find below details of these revisions and a point-by-point response to each comment.

Editor-in-Chief Comments to Author:

1. ***Comment:*** *Abstract, Results - Change to "Common motivators for forum engagement were a desire for lived experience and unlimited. . . ". A bit further down, change "cases" to "women".*
   Response: We have made these changes as requested.

2. ***Comment:*** *All percentages should be shown to 1 decimal place, not 2 throughout the paper.*
   Response: We apologise for not noting this requirement and confirm that all values have been corrected to 1 decimal place.

3. ***Comment:*** *Abstract, conclusions, last sentence - not sure who "they" is*
   Response: We agree that this is ambiguous and have reworded "they" to "clinicians".

4. ***Comment:*** *Also Birth journal style is for health care to be two words - please correct throughout.*
   Response: We apologise for not initially noting this and confirm that "healthcare" has been corrected to "health care" throughout the manuscript.

5. ***Comment:*** *line 101 and elsewhere: I have no idea what "falsifiable information" is - please explain. Also, what is "other advice". please explain.*
   Response: We have attempted to clarify this terminology in a number of ways. Firstly, we have reworded these categories to the slightly more explanatory terms "action-centred advice" and "verifiable information". With "action-centred advice" referring to responses which suggest a specific action to be taken in response to the initial posting, excluding those suggesting health care professional consultation as this was coded separately. Whereas, "verifiable information" refers to response statements that do not suggest an action and which could often be verified with minimal reference to the context of the initial post. Secondly, we have added the following examples for these categories to Table 1 as suggested in comment 7.

Action-centred advice	Verifiable information
• *When you get bloods done this week get them to add on bile acid and LFT's.* • *Just say you had a bleed if your that concerned no point waiting till your 12 weeks to find out.* • *My saving grace was full fat coke so maybe try a can.* • *try putting a few drops of peppermint essential oil in the toilet.* • *If it's lots of red blood and lots of pain, I wouldn't go in.*	• *hcg is produced by a continuing pregnancy.* • *worry about cramps and bleeding together but not separately.* • *epu won't deal with you.* • *it would be worse to take Clexane when it's not required than skip it for one day.* • *New advice is that soft / runny eggs are all okay now, previously not.*

6. ***Comment:*** *I agree with the reviewer that the greatest weakness of the study is having only 1 person review the posts for scientific correctness. As the reviewer points out, there are differences of opinion within obstetrics and midwifery, and what might seem dangerous or*

inadvisable to one person (for example, home birth) might be felt to be the best choice for another person. I don't understand how you could remove subjectivity from this process and accurately reflect the diversity of opinion in this field. Suggest getting a second reviewer to go back through this materials to validate or change the choices made.

Response: We agree that the determination of whether a post is medically sound by an individual would be problematic and appreciate that this has highlighted a lack of clarity in the explanation of our methodology. To determine quality of responses in Phase 2 of the study we identified robust sources of information against which each response was audited against. The initial identification of resources was undertaken by one researcher and validated by the second. We followed a process of initially searching well-recognised and easily accessible sources of evidence-based health care information, if this yielded no clear standard for a response, formal evidence-based guidelines or peer-reviewed research was referred to. From this, a reputable source was found for 1078 of 1355 response statements. The distribution of sources was as follows; 878 (64.8%) NHS, 55 (4.1%) peer-reviewed research, 16 (1.2%) NICE, 13 (1.0%) RCOG, 10 (0.7%) BNF and 8 (0.6%) patient information leaflets from recognised authorities. Where there was any uncertainty regarding the congruity of a response statement to the information given by a reputable source, congruity was only recorded if both researchers agreed on the outcome following further assessment. Congruence could not be determined with confidence for a further 98 (7.2%) response statements which were assessed by a third individual, a senior midwife lecturer. If uncertainty still remained, responses were labelled as lacking a reputable source or having insufficient information.

We accept that this methodology may not represent the view of every practitioner but is perhaps a more robust approach to confirming the scientific correctness of responses rather than determining this from the opinions of a sample of clinicians.

We have sought to make this clearer in the manuscript to avoid any concern that this process reflects single researcher determination and have also provided the number of responses validated by each source to optimise transparency.

7. ***Comment:*** *Suggest also supplying an appendix or table that gives examples of recommendations which were thought to be against medical advice, etc.*

Response: We strongly appreciate this suggestion and in response have created Table 1 to provide examples of each response type (action-centred advice, verifiable information, personal experience), each status of congruence (consistent, inconsistent, incomplete or misleading, no reputable source available or insufficient information) and an example of a potentially harmful response for each response type. We have also included referenced sources of evidence-based information for each response.

8. ***Comment:*** *Results section - I disagree with the quotes being put into a table. In studies of this type, quotes are generally shown in the text. Please move all quotes to the text of the paper and delete Table 1. Quotes should be indented and in italics. Also, please remove subject numbers, i.e. (MN154).*

Response: We agree that the quotes are better suited in text, as such we have relocated all quotes, formatted with indentation and italics, removed subject numbers and deleted the original Table 1.

9. ***Comment:*** *Birth does not publish third-order subtitles - please remove them and reword as needed.*

Response: We apologise for not noting this requirement and confirm that all third order subtitles have been removed.

10. ***Comment:*** *lines 180-1 "substitute deficient offline factors" - unclear, please reword.*

Response: Thank you for highlighting this lack of clarity, this sentence has been removed from the manuscript as we felt this point is better covered in the discussion by the sentence

'Common motivators for forum use appear to be underpinned by a perception that online forums provide a platform capable of overcoming deficiencies in the offline world'.

11. ***Comment:*** *lines 141-3, 228-33, 299-301 - split into 2 sentences.*
Response: In accordance with this suggestion we have split lines 141-3 into 2 sentences, removed lines 228-33 following concerns highlighted by reviewer 1 and removed the paragraph containing lines 299-301 in the interest of reducing the total word count.

12. ***Comment:*** *lines 223-5 - Unclear. Why would you think that online advice is a form of medical triage????? Perhaps another word would better.*
Response: We have reworded this sentence to *'In pregnancy it more often appears to be used as a source of guidance if circumstances change or a new problem arises'* and removed all other mentions of medical triage.

13. ***Comment:*** *lines 301-3 - sentence unclear - please improve.*
Response: We have removed the paragraph containing lines 301-3 in the interest of reducing the total word count.

14. ***Comment:*** *line 311- please add a reference for this sentence.*
Response: As highlighted by Reviewer 2, we previously failed to clearly state the relationship between our findings and previous research. As such, we have reworded this sentence to ensure a more direct comparison between equivalent statistics. It now reads *'We found 20.9% of advice, information and personal experience to be inconsistent or misleading, notably higher than the equivalent of 0.2% reported in a breast cancer forum[30]. When exclusively considering provisions of advice, an error rate of 7.2% was found, comparable to 8.6% reported in a weight loss forum[31]'*. We hope this clarifies that the statistics of 20.9% and 7.2% represent findings from this study and have been compared to similar studies within a breast cancer and weight loss forum, which have been referenced.

15. ***Comment:*** *lines 317-21 - This sounds jargony and not objective. "originality". "naturalistic", "underrepresented area of research". Suggest shortening and writing in more objective language.*
Response: We agree that this paragraph is unnecessarily jargonistic and following your suggestions have condensed it to the following sentence to remove any ambiguity and ensure objectivity. *'This study used a systematic inductive approach to provide a detailed and contemporary analysis of online pregnancy forum usage and quality characteristics'.*

16. ***Comment:*** *line 331 - "a degree of subjectivity". what you do mean by this?*
Response: Thank you for highlighting this lack of clarity, this has now been reworded to *'Thirdly, due to the nature of retrospective analysis, information regarding the original poster was at times limited such that cautious judgement was needed when applying guidelines'.*

17. ***Comment:*** *line 336 - "Whereas, total adversity may be underestimated by the inability to measure negative emotional impact". Unclear and jargony - please improve.*
Response: On review of this statement, we feel that it is unnecessary and as such have removed it from the manuscript.

18. ***Comment:*** *All table titles should say something about the nature of the study, the study location, and year(s) of data collection. See tables published in Birth for examples.*
Response: We apologise for not noting this requirement and confirm that all tables have been updated to include this information.

Reviewer 1 Comments to Author:

19. ***Comment:*** *An interesting topic. Nice work. I commend you for highlighting why people go online! My concerns are mostly about methodology and clarifying language.*
Response: Thank you for your kind comments. We hope this revised version of our manuscript addresses your concerns satisfactorily.

20. ***Comment:*** *The results section of the Abstract is poorly worded--please review for clarity/language.*
Response: We agree that, within the abstract, clarity has been lost in an attempt to limit the word count. We have made the following changes in hope of improving the quality of the writing:
    - "and opportunity" changed to "and the opportunity"
    - "requirements for" changed to "desires for"
    - "cases" changed to "women"
    - *'Forums were often used as a triage system, concerningly, this failed to appropriately refer ten cases where the original poster needed urgent medical assessment'* changed to *'Responses often directed women to a health care provider, but concerningly, failed to refer ten women in need of urgent medical assessment'*

21. ***Comment:*** *p. 2, line 45, "each serving a different purpose..." not clear what "each" is.*
Response: On review of this statement, we feel that it is unnecessary and as such have removed it from the manuscript.

22. ***Comment:*** *Self-regulating. Does this mean the posters correct misconception, or merely anytime they post something in a different direction than a previous poster? A bit unclear how this is coded.*
Response: Thank you for highlighting this lack of clarity, we have reworded the methodology as follows to better explain the criteria used to determine whether posts were self-regulating. *'In an attempt to assess whether online forums are self-regulating, a light-touch discourse analysis approach was taken to record incidences where other authors of the discussion thread stated their disagreement with a previous response considered to be of poor quality'*.

23. ***Comment:*** *p. 10, line 228: first of all, not sure the implication belongs here. Second, if a person is concerned, shouldn't they consult their healthcare provider?*
Response: Thank you for raising this concern. On review, we agree that this implication is not well justified and as such have removed it from the manuscript.

24. ***Comment:*** *The "other advice" category confused me because you sometimes grouped it with falsifiable (see p. 10, line 249). Maybe define this category better.*
Response: We agree that this grouping is an unnecessary source of confusion and as such have now reported the statistics for these categories separately as *'fewer responses sharing action-centred advice (22/251, 8.8%) or verifiable information (76/370, 20.5%) were found to be of poor-quality'*. However, given that the discussion topics within these categories overlap extensively we have continued to report these together as *'These typically related to messages discussing advisory self-management, safety of behaviours, symptom commonality and explanations of physiological processes or investigation results'.* In addition, we have attempted to clarify the terminology and provide examples of these categories as described in response to comment 5.

25. ***Comment:*** *I would like a better understanding of how personal experience can be "incomplete or misleading". Do they tell their story and then offer advice and then the advice is incomplete? If so, it's not the story.*

Response: Where responses sharing personal experiences reported a behaviour, event or view that was deemed to not be in line with evidence-based information or guidance they were recorded as incomplete or misleading. For example, one response stated *'For those suffering migraines, you absolutely can take pain relief in pregnancy for them. I took co-codamol for mine*' in response to an original posting concerning a severe headache. Yet the NHS guidance on headaches in pregnancy reports that '*There are some painkillers you should avoid in pregnancy – such as those containing codeine – unless prescribed by your doctor'*. Whilst this woman's experience is not inconsistent with the NHS guidance it could be misleading as it suggests that co-codamol – a preparation of codeine and paracetamol available over the counter, can be taken for migraines in pregnancy without reference to only taking this if recommended by a doctor.

In the manuscript we further describe the nature of incomplete or misleading responses by reporting *'Of these, 120 (25.2%) were viewed as providing presumptive reassurance by citing personal positive outcomes in response to an initial message whose author, according to guidance, required medical assessment to exclude possible undesirable outcomes. In contrast, 12 (2.5%) responses were thought to provoke undue worry by overstating potential for adverse outcomes'.* The example discussed above was coded as providing presumptive reassurance in that the responder suggests co-codamol provides pain relief if suffering from migraines in pregnancy, however, the aetiology of the original poster's headache is not yet clear. We appreciate that this interpretation is limited by the need to define such variable data and whilst there is likely to be variability at case level, the key finding we are reporting is that responses tend to share more reassuring personal experience, before knowing whether it is directly applicable to the original poster.

26. ***Comment:*** *I think overall, it is a bit problematic you are only using one person to determine what is medically sound or not. Especially in the field of childbirth where opinions differ. I'd recommend multiple coders (maybe even an OB/nurse/midwife)*
Response: We are grateful that this concern has highlighted a lack of clarity in the explanation of our methodology. We hope the explanation provided in our response to comment 6 addresses any concern that this process reflects single researcher determination.

Reviewer 2 Comments to Author:

27. ***Comment:*** *Well put together study and well written paper. Useful insights for health services to be aware of.*
Response: Thank you, we really appreciate your encouraging comments.

28. ***Comment:*** *Thematic analysis of threads in online forums has now been undertaken in a number of studies - so the claim re originality of methodology (lines 319 - 320) requires further clarification - eg need to specify if this claim is being made in relation to the subject matter or the approach used to determine quality of responses or some other aspect of the methodology?*
Response: Thank you for bringing this lack of clarity to our attention. In response to a number of concerns regarding this paragraph we have condensed it to one sentence to remove any ambiguity and ensure objectivity.

29. ***Comment:*** *Further clarification would be useful on the difference in the stats referred to in lines 308 - 311: 'Most direct comparisons with our data indicate a notably higher 20.95% of advice, information and personal experience were erroneous, incomplete or misleading although a similar error rate of 7.17% is found when exclusively considering provisions of general advice.'*

Response: We agree that the relationship between our statistics and those of previous research has not been expressed clearly in this paragraph. As such we have reworded this to *'We found 20.9% of advice, information and personal experience to be inconsistent or misleading, notably higher than the equivalent of 0.2% reported in a breast cancer forum[30]. When exclusively considering provisions of advice, an error rate of 7.2% was found, comparable to 8.6% reported in a weight loss forum[31]'*. We hope that by directly comparing equivalent statistics, our finding can be more easily interpreted in relation to existing literature.

We look forward to hearing from you in due time regarding our submission and to respond to any further questions and comments you may have.

Yours sincerely,

Authors of manuscript ID Birth-19-06-27