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The Internet in Problematic Pregnancy

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“Making it all Normal”: The Role of the Internet in Problematic Pregnancy

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Abstract

Women are actively encouraged to educate themselves about pregnancy from formal sources (e.g. information leaflets, ante-natal classes, books). In addition, informal stories of pregnancy and birth are routinely told between women. However, increased prenatal testing means that more fetuses are diagnosed with abnormalities, shifting the information requirements during pregnancy. Traditional sources of information cannot cover all possible outcomes, and the internet is beginning to fill this gap. This article draws from interviews¹ of experiences of ante-natal screening and pregnancy to explore how the internet provides a unique resource for problematic pregnancies. It allows access to information about rarer condition way beyond standard pregnancy texts as well as personal narratives about conditions. Learning how others have coped or are coping in similar situations can help alleviate feelings of isolation, and also places women back in a familiar territory of shared pregnancy narratives.

Keywords:

Internet; interviews; pregnancy; pregnancy, high-risk; reproduction

As far as we can tell women have always sought and been given advice about pregnancy although the sources of information have varied over time and between places (Hanson, 2006). In the United Kingdom today, women are encouraged to educate themselves through the provision of ‘formal’ advice. This ranges from official texts such as *The Pregnancy Book* (Department of Health, 2006) and *Emma’s Diary* (RCGP, 2005) to leaflets produced by primary care or hospital trusts. There is also a huge range of books and magazines offering advice and guidance. A search on a U.K. online bookshop returned over 1000 hits in the health section with pregnancy in the title (search carried out 01/04/08). Alongside printed sources of information, women have often gained support and advice through sharing of stories of pregnancies and births between women. These ‘informal’ sources of advice are often highly valued by women, and birth stories in particular can be understood to form part of the cultural praxis (Pollock, 1999). Consequently, seeking and receiving different forms of information could be considered a ‘normal’ part of pregnancy.

Miller (2005) has argued that understandings of pregnancy and childbirth are shaped by cultural accreditation of authoritative knowledge. Whilst the forms of authoritative knowledge might vary between times and places, it always shapes ‘acceptable’ practices and constructs ‘experts’. Miller argues that currently in the United Kingdom, authoritative knowledge resides in biomedical explanations and women are expected to regularly consult health and medical professionals for their expert opinions. To a large extent medicalised pregnancy can be seen to be dominant, and it is an important part of the transition to motherhood (Miller, 2005). Yet even within biomedical fields, the importance of peer support is recognized as potentially having a positive impact on pregnancy (Raymond, 2009).

The provision of pregnancy information on the internet can be seen to complement traditional patterns of pregnancy information. Indeed many printed sources also have a website (e.g. <http://www.emmasdiary.co.uk>, <http://www.motherandbabymagazine.com>), and some sites focus on building virtual communities (e.g. <http://www.ukparents.co.uk>) mirroring the ‘formal’ and ‘informal’ pattern of traditional sources. Hardey (1999) has argued that the internet has the potential to revolutionize the provision of health information. He points out that as internet users increasingly have the same access to expert knowledge as health professionals, in addition to a range of alternative sources of information,

the internet poses a greater challenge to medical hierarchy than any before and will inevitably reshape the doctor-patient relationship. Yet as Nettleton, Burrows and O'Malley (2005) have shown, consumer use of the internet supports the idea of media convergence, in which traditional trusted information-givers (such as NHS Direct) are valued highly online. Whilst the informants in their study did turn to the internet for health advice, this was not to challenge medical expertise, but to investigate whether or not they should seek medical advice for 'mundane' conditions or to enhance understanding in relation to healthcare consultations.

A number of concerns have been raised about internet use and health including the ability of lay people to choose appropriate sources and the development of web-based support groups for 'deviant' behaviors (e.g. pro-anorexia sites). Many studies have looked at the quality of health information on the internet often identifying significant amounts of poor quality information, yet much less is known about how people use the information (Powell, Lowe, Griffiths & Thorogood 2005). Eysenbach and Köhler (2002) study revealed that although people state that they consider the authorship of in judging credibility, but they do not always do this in practice. However, what is clear is that people are generally aware that internet may be inaccurate (Ziebland, Chapple, Dumelow, Evans, Prinjha, Rozmovits, 2004).

Internet support groups are often seen as beneficial or harmful depending on the health issue being discussed. So whilst groups supporting cancer patients are seen as positive (Van Uden-Kraan, Drossaert, Taal, Shaw, Seydel & Van de Laar, 2008), groups which are positive about anorexia are seen as problematic (Gavin, Rodham & Poyer 2008). However it is the process of validation within a like-minded community which is a major source of support (Gavin et al., 2008). Thus technology has allowed the development of online communities to become 'expert' patients but also to resist biomedical frameworks (Fox, Ward & O'Rourke, 2005). The global reach of the internet means that information and online communities are extensive so locating sources of both of interest and in line with an individual's viewpoint is probable (Lasker, Sogolow & Sharim 2005).

Alongside the growth of the internet there have been substantive technological developments in ultrasound scanning and prenatal screening. In the UK, the National Institute for Clinical Excellence

(NICE) which has responsibility for providing national guidance on healthcare recommends that routine care of pregnant women include a screening test for Down's syndrome and an ultrasound scan between 18-20 weeks to screen for structural anomalies (NICE, 2003). Some maternity care providers also offer additional scans and/or screening tests, as well as diagnostic tests for women considered to have a higher risk of a fetal anomaly.

One of the consequences of these developments in antenatal care is that increasing numbers of women are being made aware of possible fetal anomalies, which they might never have heard of before. A diagnosis of a rarer condition means that some women have to consider issues beyond the scope of traditional sources of pregnancy information. As Jones, Statham and Solomou have highlighted, living with a diagnosis of fetal abnormality leaves women in a state of 'ambivalence, uncertainty, and loss' (2005:204) that can isolate them from friends and family members. The wider changes in information provision outlined above sit alongside the issue of women having to face 'problems' and make decisions during pregnancy about issues beyond their knowledge circle. In this article we explore the relationship between these two developments.

In this article, we use the term 'problematic' to describe when the women themselves appear to understand their pregnancy as difficult in some biological way. This could be for variety of reasons, such as acute pregnancy sickness (hyperemesis gravidarum) or the detection of a fetal anomaly. In a similar way, the term 'normal' is used to mean a perceived normative experience rather than the biomedical definition of 'normal pregnancy'. This allows us to focus on women's lived experiences, rather than impose external definitions.

Methodology

This article is based on secondary analysis of interviews gathered for the DIPEX Health Experiences research project (www.healthtalkonline.org). The project undertakes qualitative interviews of patients' experiences of health and illness and publicizes them through a website in order to provide support for others in a similar situation. The interviews for this article were undertaken for two particular health issues: experiences of antenatal screening for fetal anomaly and experiences of pregnancy between 2003

and 2005. Informants were recruited through a range of different organizations including a GP research network, midwives and antenatal clinics, and national voluntary support groups such as the National Childbirth Trust, Antenatal Results and Choice (ARC), and support groups focused on specific conditions such as spina bifida or heart defects. The sample was chosen to encompass diversity in demographic factors (such as age, ethnicity, marital status, place of residence), and variation in experience. It included 66 women, 6 couples and 3 male partners. Ethical approval for the studies was given by a UK multi-centre research ethics committee. The studies gained written consent before the interview, and the full transcripts were returned to the participants for checking with the option to delete sections if they wish to. The projects were also overseen by expert advisory panels to ensure good practice paying particular attention to the need for sensitivity about the subject area. More detailed accounts of access, selection and interview processes can be found elsewhere (Locock, Alexander & Rozmovits 2008).

The transcripts were analyzed with the assistance of NVIVO software. Internet use was identified in 41 of the transcripts, and these formed the main sample for this project. The full transcripts were read by different members of the research team and an initial coding framework was agreed. As the thematic analysis progressed, additional coding categories were added.

Heaton (2004) has argued that there are three main issues that form the debates as to the reliability of secondary qualitative analysis. The first issue is whether or not the data collected for one purpose ‘fits’ the secondary research question. The second is to what extent researchers who were not immersed in the field can gain an in-depth understanding. The third issue is the way in which existing debates surrounding the verification of qualitative findings are intensified. These issues are used to outline the methodological issues which arose in this project. .

The DIPEX project utilizes narrative interviewing techniques in which the informants are invited to tell their own story, in their own words, before being asked about particular areas relating to the main experience under investigation (including issues around information and support). Not all the interviewees were asked specifically about internet use, and even in the 41 transcripts where use of the internet was mentioned it was not always explored in depth. However, there were detailed accounts of internet use in

18 transcripts, and the mentions in the other transcripts could be used to confirm the analysis of these. So whilst in this article we cannot generalize about internet use *per se*, we would argue that there is sufficient ‘data fit’ within the narrative area of the accounts for a meaningful exploration of internet use.

As Heaton (2004) points out, the second issue of remoteness from the field is not an issue confined to secondary qualitative analysis. In many qualitative projects, fieldwork, transcription and analysis are carried out by different people. The inclusion of a member of the primary research team in this project ensured that the interpretation of the data would remain grounded in the fieldwork and the findings verified against other analyses relating to this data set. Consequently, whilst the findings in this article, like qualitative research in general, cannot be generalized, it should not raise any additional concerns in relation to its findings.

This study is limited in a number of important ways. As a secondary analysis of qualitative data, it has relied on interview transcripts which were collected for another purpose. Although all informants were asked about what sources of support and more than half of the informants mentioned internet use, including 18 containing detailed descriptions, it is possible that more specific questioning about internet use might have yielded additional accounts. For example, whilst some of the accounts mentioned the need to assess the reliability of internet information carefully, there was only limited information about how they did this. However, many of the women in this research had been through traumatic experiences, including in some cases the death of their baby or termination of a much wanted pregnancy. Secondary analysis could be seen as particularly suitable in these cases, as it limits the extent to which informants are overburdened for the benefit of research (Heaton, 2004). Like all qualitative projects these findings cannot be generalizable, yet they do offer insights into the ways in which the internet is being used in this particular context.

This research sought to discover in what ways the internet was being used as a source of information when pregnancy became ‘problematic’. It begins by seeking to contextualize the values that women placed on different forms of information in general. It will then outline how the need for information changes when the pregnancy became ‘problematic’. Focusing on the balance between

'formal' and 'informal' internet sources, it will argue that each makes a different contribution to the women's information needs. It will also argue that although in many ways the use of the internet continues to follow traditional patterns of pregnancy information-seeking, it also provides a technological solution to the issues raised by expansion of diagnostic technologies.

Findings

Educating Themselves About Pregnancy

All of the pregnant women interviewed had sought information about pregnancy during their pregnancies, although the type and frequency of the information seeking varied. Print sources such as books, magazines and leaflets were the most frequent sources mentioned, and most of the women had found them to be very helpful and informative:

I think, I think I did find a good book, I looked at quite a lot of books and a lot of them were all kind of lots of soft focus pictures of parenthood, and [um] I found a nice book that just was all about answering your questions really. And that's been really good because it's, whenever I've felt anxious about something, you know, like when you get a pain somewhere then I've gone and looked it up and it says, normally says, "You get pain," or, you know, or sort of and explains what it might be. So that's been quite good [um] having that.

It seemed like the biggest thing that had ever happened to me but I didn't know what to do or where to go [laughing]. Emotionally I think it was hard. [um] And of course I went out and bought a bunch of pregnancy books and I really, that was the way that I learned about things. Or the [um], the way that I scared myself and made myself feel better because, of course, the[er], the pregnancy books all talk about high risk of miscarriage in the first trimester. [um] But they can also be reassuring. I mean they, it's nice to have information, I think.

I think, when I found out I was pregnant I was like, “Oh, this was just the best thing ever”. You know, I just wanted to read up on, I mean like, everyone knows the basics, I think everyone knows the basics, but then I wanted to know more and so I went out and bought, you know, Parent magazine and this magazine and I got some textbooks off the internet and, you know, sat down and, and merrily read them. And it was fine while you were reading all the good bits. But when it came to, you know, the not so good bits it was, “Oh, God, I didn’t know about that” or, “Oh, yes, that could happen”.

These extracts illustrate the ways in which women set out about educating themselves and the importance they attached to understanding the processes of pregnancy. As well as information from print sources, most of women discussed pregnancy with other women. These accounts were also valued, and could include both positive and negative aspects of pregnancy and childbirth:

It was mainly people giving me their, their horror stories of, of their birth, really. That was the only thing that was very unhelpful. [um] But apart from that, no, not really. In fact, [um] obviously, being a hairdresser I spoke to, speak to lots of women and [er] I had all very positive conversations most of the time so, about birth and pregnancy and got a lot of, you know, helpful information off some people and, and yeah, yeah it was, it was good.

The different sources of information were valued by the women in different ways. The ‘formal’ sources often seem to focus on the ‘biological’ narrative, giving details of fetal development, screening and diagnostic tests and bodily signs and symptoms which could be either worrying or ‘normal’. In contrast, the ‘informal’ sources of information were valued for their ‘emotional’ narratives as they concentrated more on the bodily experiences and feelings which helped the women deal with the everyday discomforts of pregnancy and prepare for childbirth and motherhood as the following illustrate:

One of my sisters-in-law, she was quite [um] helpful . . . You know, she, you know, told me about her pregnancies, and, and we hadn't really talked much about them before. I mean I, I think I remember asking how the birth went when she had her children, and I think it just meant that she had more of a connection with me now that I was pregnant I suppose. And, you know, her experiences were quite, [um] I think they were quite normal actually. And she just, I think it was more in the emotional level - she was talking about how she felt.

It's just listening to different people and, and trying to find where you fit best and what you want. [Um] I have a nice experience, because my sister-in-law, one of my sisters-in-law, is also pregnant at the same time. We are attending the same yoga class for pregnant women, and she's going eight weeks in front of me. So, and she knows everything about it, because this is her second baby and she really knows everything there is to know [laughs]. So whenever I am in doubt I call her and I ask.

Bodily experiences are considered a form of embodied knowledge, which can be valued above and beyond other forms of information (Lowe, 2005). The combination of formal and informal sources of information offered sufficient support during 'normal' pregnancies, but, as we show in the following, often could not meet either the factual or emotional needs of women during problematic pregnancies.

Challenging Issues

Moving into a 'problematic pregnancy' could begin either through the development of particular symptoms, or through the diagnosis of a possible problem during antenatal care. In both cases, the women and/or their partners' need for information went beyond that available in their normal sources of information. One of the women interviewed whose pregnancy ended in stillbirth following hyperemesis gravidarum said she had used the internet to look for advice as to how to cope with it.

There's nothing that I've found that can help. [um] I've tried buying, I bought a tape. I got it off the internet. I mean, I've looked into it extensively to see if there's anything that you can take [um]. I bought a tape off the internet - it cost me like forty pounds - for [um] a tape that you listen to and it's like, it's just music . . . it's supposed to help balance you out. It didn't work. [um] I've bought [um] Peggie Pops which are ginger and sour-tasting things that are supposed to help you. I've drunk ginger tea, ginger biscuits, ginger ale, [um] although there has been a study done very recently, I think, where they've said that [um] ginger - and there's another vitamin as well, I think it's a B vitamin - that [um] is supposed to make you feel, is supposed to ease the symptoms of morning sickness. [um] But I have to say that none of it's worked with me

In other cases, the internet is used to explore the parameters of the diagnosis that has just been given. One woman attended on a Friday for her anomaly scan and was told that her fetus did not seem to be developing normally and carried the markers of either Trisomy 13 or 18:

And we spent the weekend just crying and crying and crying, and searching on the internet for anything that we could find out about all these words that they'd said to us. [um] And probably by Sunday night we had contacted a number of organizations, or got details of a number of organizations that could help us. [um] And it was difficult to find the information. It's not easy, it's not easy to find. And we got details of [um] SOFT, which is an organization for people with trisomies. We got information from SANDS. We hadn't found ARC, we couldn't find, we didn't know they existed and we couldn't find ARC at the time. [um] And we'd read and we'd read and we'd read information.

In both these scenarios, the internet gave the women access to information beyond that of traditional sources. In the first case, the internet suggested solutions in the form of products not necessarily locally available. Although these were not successful, it is clear that the woman was selecting from a number of different alternatives, which included research studies. In the later case, the internet allowed immediate access to information about the rare conditions of Trisomy 13 or 18 and their prognosis, as well as the numbers of support organizations that could be turned to for help. The ability of the internet to locate helplines and support organizations was often of particular importance, and illustrates the ways in which web-based information usually compliments rather than replaces traditional sources of support.

Controlling the Information Flow

Many of the women were given tentative diagnoses and had to wait for either the results of diagnostic testing or appointments with specialists for confirmation. In some cases, they also had to make a decision as to whether or not they would terminate if the diagnosis was positive. Understandably many of them were dazed during the initial consultations, and some felt that they had not fully understood what they were being told about their fetus' prognosis:

I think we were in shock, to be honest with you, to be totally honest with you. We didn't, we, I just, we just sort of carried on. [um] I can't really remember talking about choices. I think we didn't want to talk about it because then that would seem as if there was something wrong. And I think we were just holding on to the hope that there was something wrong with the machine, or, [um] as I thought, that they'd be able to tell us how bad, if it w-, if there was something wrong, if it was Down's syndrome, how bad it was. I thought they'd be able to tell us that.

Whist all the women needed information following the initial diagnosis, this issue could be intensified if were given a diagnosis of a condition that they knew nothing or little about. They found that

the internet provided a variety of sources of information. This information could be accessed immediately it was wanted and it could be returned to several times if it was not understood or not the right time to be able to take in the complexity of the issues:

And, you know, we talked it over and we said, “We need to find out some more information on it”. And obviously [um] we looked up on the internet about different, you know, what anencephaly meant, [um] stumbled across a few medical papers, and I think there was a lot of American websites, because the Americans seem to be quite kind of clued up on letting other people know things. [um] Yeah, so stumbled a lot of, on their websites from the parents’ perspectives and got in contact with, [um] [pause] no, was it that? No, that was afterwards. [um] Yes, stumbled across on a few medical papers, read a few briefly, over a few medical papers, [um] didn’t quite underst-, still wasn’t really taking it in, quite emotional.)

That night I remember I looked on the internet to look up Diaphragmatic Hernia and some of it said that there’s an eighty percent mortality rate, [um] and I, I just couldn’t take it in, you know . . . I think, and especially [partner] got the impression, or my boyfriend got the impression, that it was just a little operation he’d have to have afterwards, and then be in hospital for a while and then come out. And once I saw that on the internet I didn’t look any further, I just didn’t want to know.

We didn't really, when we had the first scan we didn't understand that children with Down’s syndrome did tend to have heart defects. We didn't know that a large, a large percentage of children with Down’s syndrome also needed bowel surgery, or all the other health-related issues, chest infections. And I guess we're still learning even now. We were given at [specialist hospital], at the other hospital we were actually given

booklets, the Heart Child booklet and another Down's Syndrome Association booklet.

Then we went onto the internet, contacted the Down's Heart Group. Because we started doing lots and lots of research. So I guess by the second time we went back up for another cardiac scan, we were quite well armed with what we could expect next.

In these three extracts we can see the extent to which being in control of the information was valued in different ways by the women. In the first case, the diagnosis of anencephaly was given without really explaining it in any detail. The internet was used to confirm what the condition was as well as the prognosis. Although a range of sources was found, they could not initially take in the full meaning of the diagnosis. They also indicate how initial internet searches can be messy and uncertainty about the information can remain. Although in this case they 'stumbled' over medical papers, the initial process could be unfocused. The second couple also turned to the internet for information. This search revealed the full extent of the severity of the condition, and the woman chose to stop searching at that point. The final case presents a more productive narrative of internet use. They positively identified internet searches (and other forms of information seeking) as 'research' through which they could 'arm' themselves. They felt this allowed them to ensure they could understand any issues raised by the specialist hospital. This case also highlights the important of timing of information. The ability to access information at a time when it was wanted, rather than waiting for appointments with health professionals was mentioned by several of the informants as an important benefit of the internet:

And you know, I think about if my parents had gone through something like this, you know, where would they get the information from? You know, I mean we're talking about thirty plus years ago. Where would they get that information from? You know, they'd have to rely on the doctors. And we're very lucky now that, you know, all of that information is literally at your finger tips

The immediacy and timing of information is an important element where a termination is being considered. Although where there is evidence of severe fetal abnormality, there are no legal restrictions in England in terms of the timing of the termination, the form of abortion available is related to the number of weeks pregnant. Consequently, if a woman would prefer a surgical termination rather than having to go through a labor, she might need sufficient information early enough to be able to choose that option.

Deepening Understanding

As well as being able to control the flow of information, the internet was used by some of the informants to deepen their understanding of particular issues. Two of the respondents mentioned searching for pictures to prepare themselves or family members for the birth. One of the women described how she looked for pictures with her eldest son:

we went onto the internet and we found some photos of babies with cleft palates. [um]
If nothing else, you know, if you're going to have that shock value of seeing a baby with a facial problem, [um] do it now, don't do it when you're there in the delivery suite and it's very emotional [laugh]. So I mean, that gave us a chance to prepare a little bit, didn't it?

For others the ability to confirm treatment gave them reassurance that the medical advice they were receiving was the best course of action.

I felt, I felt that [um] everyone knew what the issue was and everyone seemed to be agreed on the treatment. I did actually also [um] consult a few websites on, on the internet. [um] And there was [um] actually a support group for people suffering from this condition with a lot of information about pregnancy, and it confirmed that this was the appropriate [um] treatment to be taking.

For many of the informants, the internet was used to help them prepare themselves for particular events. This could be medical consultations to confirm diagnosis or different courses of actions, or seeing their baby for the first time. The ability to access specialist information and/or visual images meant that they felt more in control of the situation.

Getting Support

As well as websites which provided information, the women also used the internet to gain an understanding of the experiences of others in similar positions. The forums and websites which portrayed the personal stories allowed them to go beyond biomedical information and to gain further advice and support based on lived experiences.

There are some websites that were obviously official. I mean what were reliable, reliable sources . . . then there are . . . the ones where mothers posted information on the web, then you knew that they weren't as reliable, but I liked reading them just to know that other people were, the way that they felt and that. Because the sensible websites would say things like, that you knew were right, and then the ones where mothers had written other things, I mean, it's like, people could be more sympathetic or they could empathize more.

It was mostly personal, it was, it's, it's more a sort of [um] exchange of information site between, between people with the condition. . . . here were various contributions from individuals there and as, as you sort of flicked in and out of them you got a picture of, of, [um] you know, how credible the stories were, and often the same person was coming back on and giving advice to others. And I felt there were a number of individuals there who were giving good advice and who'd obviously had quite, you know, interesting stories that were relevant.

These extracts both illustrate the difference ways in which the forums and stories were used to gain additional support. In the first case, the woman describes how the importance of the emotional aspects of the stories. It is clear that the woman believes that sympathy and empathy arose from the lived experiences. The second quotation also emphasizes the importance of relevant stories from people with the condition as a source of advice. Moreover, whilst both of these women valued the stories immensely, both recognize that personal stories could not automatically be considered reliable.

Whilst internet forums could be valued as a source of support within any pregnancy, the importance of these stories in the particular context of rarer conditions was also highlighted in the following quotation:

I think, none of the midwives looking after me told me what to expect, and the people doing my antenatal care here didn't really know, I don't think, what I was to expect. [um] So I'm really glad for the support I found on the internet from other women telling me what to expect.

In this case, the woman reports that the health professionals involved in her care did not seem able to give sufficient support, as they did not have adequate knowledge of the particular condition. In this case, the support gained from others who had been through the experience, seemed to replace rather than contribute to the more usual sources of support.

However, not all the women found the stories on the internet supportive. One of the women reported that they tended to be more negative than positive. She stated:

All weekend I was on the internet looking to see what I could find about these conditions . . . and of course what I discovered was that very often the very worse case scenarios appear on the internet, that people's personal stories of having lost children or

having had a really difficult time, and I suppose those that have had less difficult times are less inspired to write about their experiences. So I got a very grim picture

That the internet could be both a positive or negative source of support was recognized by many of the women. As one of the women put it, whilst the internet could be a “friend”, it could also be a “curse”. Yet whilst they recognized the need to assess the reliability of the information, and that not all the stories would be helpful, most of the women who had used the internet reported it as a constructive source of advice.

Discussion and Concluding Remarks

I was using [sniffs] using other people’s views to kind of (...) to reassure myself that, that it was normal, what I was going through

The importance of advice and support during pregnancy is not just widely recognized but institutionalized in both the organization of maternity services and wider cultural praxis. Yet whilst these often include discussion of ‘normal’ problems, rarer issues are unlikely to be covered. This gap means that when faced with ‘problematic’ pregnancies women’s usual sources of advice and information can be inadequate. Yet experiencing a ‘problematic pregnancy’ is likely to mean that women’s need for support and information increases, particularly if they are placed in a position of needing to make decisions about whether or not they wish to continue with the pregnancy. Whilst this level of complex decision- making is not necessarily a new issue *per se*, given the expansion of prenatal screening (Human Genetics Commission, 2006), it is likely that increasing numbers of women are going to be in this situation.

Similarly to other studies (such as Kouri, 2006) this study found that women used different sources of information for different areas of support during pregnancy. The ‘textbook style’ of formal sources of information in pregnancy books and leaflets was desired for its descriptions of the biomedical processes of pregnancy, it was not considered as being able to portray the experience of pregnancy. Instead these were gained through circulating stories of bodily experiences and emotions. Formal sources

were recognized as more reliable in terms of biomedical information, but personal stories of pregnancy and birth provide descriptions of the 'real' experience, and are particularly valued for their emotional understanding.

However the move into a problematic pregnancy often meant that traditional sources of information and support were insufficient. It is not possible for pregnancy books and leaflets written for a lay audience expecting a 'normal' pregnancy, to carry information about all the possible complications that could arise. Yet moving into a problematic pregnancy usually means that women's need for information increases. In a similar way, although women's need for support intensifies, traditional sources of support such as friends or family often become inadequate (Jones, 2005). It is in this situation that the internet might provide a solution.

One benefit of the internet is that it can provide health information on even the rarest of issues and, providing the user has easy access, the information is available all the time (Lasker et al., 2005). This means that not only are people no longer dependent on health professionals for information, but increasingly they have access to the same information (Hardey, 1999). The ability to choose the timing and depth of information to gather was of particular importance to these women. They were able to gain a better understanding of the issues, and prepare for appointments at which they might be asked to make particular decisions. They could locate contact details and helpline numbers for specialist organizations. They could also find images of particular conditions so as to prepare themselves and/or family members for the birth. Most of the women reported this as a positive outcome as they wanted to know as much as possible. However, not all the information found was felt to be constructive and negative outcomes could be over-emphasized.

As well as the providing information, the internet was also used as a source of support. As others have argued, finding information or support groups online can give people a sense of empowerment and provide a useful coping strategy (Van Uden-Kraan et al., 2008, Broom, 2005). Even with rare conditions it is highly likely that there will be online support groups. They might be particularly valuable for rarer conditions as traditional sources of support might not be available locally (Lasker et al., 2005). For the

women in this study, the stories of others who had been through the same experiences were particularly welcomed in terms of their emotional understanding. They enabled the women to compare their response to others to validate their feelings and to understand that they were not completely isolated as others had been through similar situations. The women felt they had learnt through others experiences what to expect, and how this might make them feel. For example, that a baby with a particular condition might be born blue and what it might feel like to have their baby whisked away. Yet this process did not mean that they accepted the stories as factually correct. Instead they took from the stories an emotional understanding of the experiences in order to help validate their own emotions. The valuing of vicarious learning via the internet has also been found in other health conditions, for example cancer (Ziebland, 2004) and mental health (Powell and Clarke, (2006). In this study, the authoritative knowledge of biomedical pregnancy (Miller, 2005) is not directly challenged, but women seek to increase their understanding through embodied knowledge gained through experience.

In many cases the need for information and support faced by these women arose from new technological developments. Many of them moved into a ‘problematic’ pregnancy because of prenatal diagnosis of a particular condition. Yet developments in technology are also providing some of the solutions. The internet gave access to information and support to the women which helped them to manage the situation they found themselves in. Moreover the use of the internet to access both formal and informal sources of information and support mirrored conventional uses of different sources of information. The women still looked both for formal sources of biomedical information from trusted sites (such as medical organizations and journals) and informal sources of personal stories to confirm the emotional journeys that they had found themselves on. Consequently their usage of internet could be seen to help to women to feel more ‘normal’ despite the problematic position they found themselves in.

Notes

1. The DIPEX Health experiences Research project publishes experiences of health and illness online as a resource for others in similar circumstances. See www.healthtalkonline.org. Our thanks go to them for access to this data set.

References

- Broom, A. (2005). Virtually he@lthy: The impact of internet use on disease experience and the doctor-patient relationship. *Qualitative Health Research*, 15(3), 325-345
- Drentea, P., & Moren-Cross, J. L. (2005). Social capital and social support on the web: The case of an internet mother site. *Sociology of Health and Illness*, 27(7), 920-943.
- Department of Health (2006). *The Pregnancy Book*. London: Central Office of Information.
- Eysenbach, G., Köhler, C. (2002) How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal* 324, 573-577.
- Fox, N., Ward, K., O'Rourke, A. (2005). Pro-anorexia, weight-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia. *Sociology of Health and Illness* 27(7), 944-971
- Gavin, J., Rodham, K., & Poyer, H. (2008). The Presentation of "Pro-Anorexia" in Online Group Interactions. *Qualitative Health Research* 18(3), 325-333.
- Hanson, C. (2004). *A Cultural History of Pregnancy: Pregnancy, Medicine and Culture 1750-2000*. Basingstoke: Palgrave.
- Hardey, M. (1999). Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health and Illness*, 21(6), 820-835.
- Heaton, J. (2004). *Reworking Qualitative Data*. London: Sage.
- Human Genetics Commission (2006). *Making Babies: reproductive decisions and genetic technologies*. Retrieved July 9 2008
<http://www.hgc.gov.uk/UploadDocs/Contents/Documents/Making%20Babies%20Report%20-%20final%20pdf.pdf>
- Jones, S., Statham, H., & Solomou, W. (2005). When expectant mothers know their baby has a fetal abnormality: exploring a crisis of motherhood through qualitative data mining. *Journal of Social Work Research and Evaluation*, 6(2), 195-206.

- Kouri, P., Turunen, H., Tossavainen, K., & Saarikoski, S. (2006). 'Pregnant Families' Discussions on the Net—From Virtual Connections Toward Real-Life Community. *Journal of Midwifery & Women's Health*, 51(4), 279-283.
- Lasker, J. N., Sogolow, E. D., & Sharim, R. R. (2005). The Role of an Online Community for People With a Rare Disease: Content Analysis of Messages Posted on a Primary Biliary Cirrhosis Mailinglist. *Journal of Medical Internet Research*, 7(1), e10.
- Locock, L., Alexander, J., Rozmovits, L. (2008) Women's responses to nausea and vomiting in pregnancy *Midwifery*, 24(2), 143-152
- Lowe, P. (2005). Embodied expertise: women's perceptions of contraception consultation. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 9, 361–78.
- Miller, T. (2005). *Making sense of Motherhood: A narrative Approach*. Cambridge: Cambridge University Press.
- Nettleton, S., Burrows, R., & O'Malley, L., (2005). The Mundane Realities of the Everyday. Lay Use of the Internet for Health and their Consequences for Media Convergence. *Sociology of Health and Illness*, 27(7), 972-992.
- NICE (2003). *Antenatal care: Routine care for the healthy pregnant woman*. National Institute for Clinical Excellence Clinical Guideline 6.
- Pollock, D. (1999). *Telling Bodies performing Birth*. New York: Columbia University Press.
- Powell, J., & Clarke, A., (2006). Information in mental health: qualitative study of mental health service users. *Health Expectations*, 9(4), 359–365.
- Raymond, J. E. (2009). Creating a safety net: Women's experiences of antenatal depression and their identification of helpful community support and services during pregnancy. *Midwifery*, 25(1), 39-49.
- Royal College General Practitioners (2006). *Emma's Diary*. Lifecycle Marketing.

- Van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, H., Shaw, B. R., Seydel, E. R., & Van de Laar, M. A. F. J. (2008) Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research* 18(3), 405-417.
- Ziebland, S. (2004). The importance of being expert: the quest for cancer information on the Internet. *Social Science and Medicine*, 59, 783–1793.
- Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., Rozmovits, L. (2004) How the internet affects patients' experience of cancer: a qualitative study. *British Medical Journal* 32, 564.