



Pregnant women's use of the internet: a review of published and unpublished evidence

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Pregnant women's use of the internet: a review of published and unpublished evidence

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Abstract

Aim. To review evidence on the use of the internet by pregnant women.

Objective. To provide a critical summary on the extent and nature of published and unpublished evidence on the use of the internet by pregnant women.

Method. A structured literature review examining women's use of the internet during pregnancy and its effect on their decision-making in pregnancy. Searches were conducted for peer-reviewed local, national and international research papers as well as professional literature. The medical subject headings (MeSH) keywords 'pregnancy/pregnant' and 'woman/expectant mother' were combined to the search terms 'information/information need/information seeking/information searching', 'knowledge need(s)', 'access to information/information sources', and 'support/social support' and 'internet/world wide web' using Boolean connectors and applied to relevant electronic databases: the British Nursing Index, CINAHL, MEDLINE, PsycINFO, Science Direct, Web of Science, PubMed, Index of Thesis. The inclusion period was between 1 January 1995 and 31 July 2005. A search of the online *Journal of Medical Internet Research* was also carried out. Midwifery e-discussion groups in the UK and Republic of Ireland were contacted to identify any unpublished studies.

Analysis. Data were categorised using the classification of evidence framework from the Department of Health in the National Service Frameworks (DOHNSF) (cited in Anderson et al, 2004). Three independent reviewers, using a pro-forma, carried out the review and confirmed the findings of the data extraction.

Findings. A total of 16 published papers and two unpublished papers were retrieved that met the inclusion criteria. Pregnant women used the internet to seek social support from other pregnant women and to research specific problems, for advice on home remedies, to take part in discussion groups and for information on antenatal tests for birth anomalies.

Implications. Most of the papers included in the review were descriptive and few studies were of a size and quality to enable findings to be generalised. Well-designed studies instead of anecdotes and opinions are needed to determine the overall effect of internet use in pregnancy.

Key words: Pregnant women's use of the internet, information-seeking behaviour, published/unpublished evidence

Introduction

Pregnant women may get information about pregnancy and childbirth from a number of sources: health professionals, social services, family members and peers, books and other media. Midwives, obstetricians, GPs and pediatricians have traditionally been the main providers of information to women about their pregnancy, care and treatment options, but there is a growing body of literature that indicates this may be changing as women turn more and more to the internet for health information (Crandall et al, 2001). The internet is one of the fastest-growing sources of information on a wide range of health-related issues, including pregnancy and childbirth for many pregnant women (Sinclair et al, 2001; Brown et al, 2003; Bernhardt and Felter, 2004). As Pemberton and Goldblatt (1998: 594) state: 'It's time to embrace the concept of the informed patient and use their web-surfing skills.'

Many practitioners and researchers believe that people who are better informed are also better able to reduce their personal anxieties to understanding what is going to happen and to

participate in decisions about their own health care (Baker and Pettigrew, 1999). A great many health-seekers say that the resources they find on the internet have a direct effect on the decisions they make about their health care and on their interactions with health professionals (Bowen et al, 2003). It can only be assumed that use of modern communication, including the internet, has affected women's awareness of their health options and increased their demand for sharing the decision-making regarding pregnancy and delivery (Odlind et al, 2003).

Survey data confirms that health information is very popular with internet users yet relatively little qualitative social science research has been conducted about how people incorporate information from the internet into their everyday information practices (Wyatt, 2005). Midwives are expected to provide relevant, up-to-date information that meets the needs of women in their care. Health professionals who refrain from discussing with women information they have sourced from the internet may harm the relationship they have with their client (Nash, 2001; Murray et al, 2003).

Table 1. Total number of papers retrieved, number eligible and those included from each source

Source of search	Total no. papers retrieved from initial search	Papers identified as potentially eligible	Papers meeting all inclusion criteria and included in review
<i>Science Direct</i>	19	2	2
<i>PubMed</i>	121	13	9
<i>Proquest</i>	28	0	0
<i>MEDLINE</i>	156	12	6
<i>CINAHL</i>	78	5	4
<i>British Nursing Index</i>	3	2	1
<i>Index of thesis</i>	0	0	0
<i>Web of knowledge</i>	10	2	2
<i>Journal of Med Internet Research</i>	10	2	2 ¹
<i>E-list Midwifery Groups</i>	2	2	2 ²

¹ One excluded as full text unavailable ² Unpublished

Aim and objective

The aim of this review was to provide an overview of the evidence on the use of the internet by women in pregnancy and childbirth. The objective was to provide a critical summary on the extent and nature of published and unpublished evidence on the use of the internet by pregnant women.

Embarking on a literature review requires the structure, process and outcomes to be clearly articulated. Many researchers have published guidance on how to conduct the process including Parahoo (1997), Rees (2003) and Taylor (2005).

Search strategy

The authors identified a list of 'key words and synonyms', which were used to search relevant databases. The medical subject headings (MeSH) key words: 'pregnancy/pregnant' and 'woman/expectant mother' were combined to the search terms 'information/information need/information seeking/information searching knowledge need(s)', 'access to information/information sources' and 'support/social support' and 'internet/world wide web using Boolean connectors and applied to relevant electronic databases: the British Nursing Index, CINAHL, MEDLINE, PsycINFO, Science Direct, Web of Science, PubMed, Index of Thesis. The inclusion period was between 1 January 1995 and 31 July 2005. A search of the online *Journal of Medical Internet Research* was also carried out. Midwifery e-discussion groups in the UK and Republic of Ireland were contacted to identify any unpublished studies.

Inclusion and exclusion criteria

No restriction was applied in terms of method. Published reports and opinion pieces or commentaries were included that specifically described women's use of the internet during pregnancy. Restriction on date of publication was applied as

noted above. The search was limited to articles published in English and to those directly relating to the use of the internet by pregnant women.

To refine the literature search the following questions were asked for each citation (where there was insufficient information in the citation, the paper was located):

- Does the paper explore the use of the internet in pregnancy, in particular does it address reason(s) for pregnant women searching online?
- Is the paper a review containing data, a case study, a research study or guidelines with supporting data?

Papers were included when either or both of these questions were affirmed.

Titles and abstracts were examined and when abstracts met the inclusion criteria, the full text of the article was obtained. All relevant publications were retrieved and read. Papers were selected based on their content and relevance. An inherent problem with electronic databases is that if the paper has not been properly indexed, then it will not be identified during the search. Therefore to widen the scope of the review the reference list of every paper reviewed was scanned for any other relevant work. The numbers of papers identified through this process is presented in Table 1. There was some duplication between computer databases.

All three authors checked the papers that were excluded and included in the review to ensure that adequate judgment was applied to the review process. The 18 papers that were identified as relevant, selected and critically analysed by the primary author for the review were those that actually discussed internet use in the context of pregnancy and the pregnant woman. The small number of papers reviewed was due to the exclusion of those papers where the focus was clearly more on women generally searching the internet for health information or health professionals' use of the internet during pregnancy e.g. Zakaria (1998), Adler (2002) and

Stewart (2003). One paper by van der Slikke (1999) was excluded, as the reviewers were unable to access the full text of the article.

Of the 18 papers retrieved, eight were from the US (Rillstone et al, 2001; Teres, 2002; Viau et al, 2002; Eriksson-Backa, 2003; Bernhardt et al, 2004; Capitolo, 2004; Pettigrew et al, 2004; Spink et al, 2004) and two were Canadian (Challis et al, 1996; Westfall, 2003). Five were British (Lass and Brinsden, 2001; Sinclair et al, 2001; Ernst and Schmidt, 2002; Lavender et al, 2003; Soltani and Dickinson, 2005), one from Finland (Maijala et al, 2003) and two from Australia (Pemberton and Goldblatt, 1998; Jaques et al, 2004). Searching and retrieval was followed by a critical analysis of the literature.

Synthesising the evidence

To promote an evidence-type approach, a grading hierarchy was used to assess the level of evidence presented. More than 100 diverse grading scales are in use by various medical publications, which can be confusing for readers (Agency for Healthcare Research and Quality, 2002). Many use different systems to grade the quality of evidence and the strength of recommendations (Upshur, 2003). The same evidence and recommendation could be graded as II-2, B; C+, 1; or 'strong evidence, strongly recommended' depending on which system is used. Quality assessment frameworks for research are generally based on a hierarchy of evidence with the majority of hierarchies of evidence giving a higher ranking to quantitative research findings from randomised controlled trials (RCTs) and systematic reviews of RCTs (Upshur, 2003; Scott-Findlay and Pollock, 2004; Dobrow et al, 2004). Information derived from other methods is accordingly assigned lesser value (Rycroft-Malone et al, 2004).

The results of qualitative research (e.g. critical theory or interpretative analysis) are not regarded as producing high-quality evidence (Pearson, 2003). It has been suggested that such articles should not be scored for methodological rigour

as, it may be that it is the quality of the writing that is judged rather than the quality of the research itself (Hawker et al, 2002). The widespread use of hierarchies of evidence that grade research studies according to their quality has helped to raise awareness that some forms of evidence are more trustworthy than others (Glasziou et al, 2004). Citing RCTs as the gold standard may be interpreted as implying that other research designs are second rate, or lacking in rigour, rather than complimentary and appropriate for different research contexts, stages and interests. RCTs should not invariably be considered as a gold standard for health research, which should seek to incorporate a range of methods appropriate to the research questions (McCourt, 2005).

Where relevant and possible, the literature was graded according to the type and quality of research using the evidence categories employed by the Department of Health in the National Service Frameworks (DOHNSF, 2001) (cited in Anderson et al, 2004) (see Table 2). This framework was used because it has been piloted for use with both peer-reviewed and non peer-reviewed research (Anderson et al, 2004). Data were abstracted by one author (BL) and cross-checked by two further authors (MS/GK), who independently assessed each selected study for methodological quality and relevance, based on the DOHNSF validated grading hierarchy.

Findings

While the body of research on women and the internet is growing, most of the published research does not make specific reference to pregnant women and there is an underlying assumption that they are included in general surveys on women's use of the internet e.g. Tucker (2001), Murphy and Murphy (2003), Pandey et al (2003) and Pettigrew et al (2004). There has been considerable emphasis on research investigating the internet as a general source of health information in papers published within the past five years. Some of these are population-based (Christian et al, 2001; Tuffrey and Finlay, 2002), whereas others focus on specific diagnostic groups such as women with cancer (Pereira et al, 2000;

Table 2. Evidence categories used by the Department of Health in the National Service Frameworks (DOHNSF) (2001)

Typologies of supporting evidence	
A1	Systematic reviews, which include at least one randomised controlled trial (RCT), e.g. systematic reviews from Cochrane or NHS, centre for reviews and dissemination
A2	Other systematic and high-quality reviews, which synthesise references
B1	Individual RCTs
B2	Individual non-randomised, experimental/intervention studies
B3	Individual well-designed non-experimental studies, controlled statistically if appropriate. Includes studies using case control, longitudinal, cohort, matched pairs or cross-sectional random sample methodologies, and well-designed qualitative studies; well-designed analytical studies including secondary analysis
C1	Descriptive and other research or evaluation not in B (e.g. convenience samples)
C2	Case studies and examples of good practice
D	Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified

Peterson and Fretz, 2003; Fogel et al, 2004) or general internet users (Tucker, 2001).

The classifications of the papers retrieved using the DOHNSF categories are displayed in Table 3. Studies on women's use of the internet in pregnancy are sparse. Much of the literature on the use of the internet in pregnancy was found in professional health literature. No randomised trials and relatively few rigorous studies have been conducted either internationally or in the UK on the use of the internet in pregnancy. However, it was possible to identify four main classifications of literature: B3, C1, C2 and D (see Table 2 for description of classifications).

The internet as a choice for information

In a media review, Teres (2002) points out that pregnancy is a time when many women feel isolated and confused. With so many choices in childbirth, so many different voices offering advice, it is difficult to know where to turn for information and support. For many women, the internet provides a new kind of safe haven. Often anonymous, it offers a never-ending source of information and reassurance. In a combined quantitative and qualitative project conducted by Lavender et al (2001) 'looking at supplying women with evidence-based information', 71% of the 24 respondents who had internet access said they would use it as a source to access information. When Soltani and Dickinson (2005) explored the views of 329 postnatal mothers on the information they were provided with during pregnancy, 88% of the respondents stated they received most of their information from health professionals and 72% from family and friends, but 28% also obtained information from the internet. However, when Jaques et al (2004) asked 737 pregnant women about their preferred sources for information on prenatal testing for birth defects, only 6.8% of the women in the group who had prenatal testing and only 9.3% of women in the group who did not have any prenatal testing had used the internet as a source of information on the subject. In both groups, face-to-face counselling with a doctor or counsellor, followed by leaflets and then videos were the most popular choices of information sources. Jaques et al (2004) did not indicate what influence the information obtained from the internet had on the women.

In Westfall's interview-based research project, 3% of the 27 participants used the internet to seek advice and information on the use of home remedies to maintain their health during pregnancy (Westfall, 2003). In another small study carried out by Eriksson-Backa (2003), which compared three groups of people in different health situations (pregnant women, diabetics and 'healthy people'), 17% of the pregnant women stated that they would choose the internet as a first choice of health information. When Sinclair et al (2001) asked 169 pregnant women from two maternity units about using the internet to find information about birth, 18% of women who had internet access in the rural hospital used the internet to source information about birth compared to 31% of women in the urban maternity unit.

From the literature sourced, it is not possible to measure the true extent of the use of the internet by pregnant women, as

there are incidences where usage goes unreported e.g. Viau et al (2002) in their study on the health concerns and health promotion behaviours of pregnant women over the age of 35, reported women sought health information from the internet but give no actual figures. Maijala et al (2003) briefly mention in their grounded theory study, which looked at interaction between care-givers and families expecting a malformed child, how parents who had been informed about a fetal malformation often sought information independently about the malformation from the internet – again, no actual figures were quoted.

The internet as a source for information

In terms of the type of health information sought from the internet, the only literature found that discussed specific topics were those of Spink et al (2004) and Bernhardt and Felter (2004). Spink et al (2004) reported 'pregnancy/obstetrics' was one of the top five medical or health queries on the internet. Many queries related to health issues during pregnancy or the health of a baby. For example, 'When should I take a pregnancy test?' and 'Should pregnant women fly in an aeroplane?' Although Bernhardt and Felter (2004) mainly focused on mothers of young children seeking online paediatric health information, they asked mothers questions about their use of the internet for health information during pregnancy and reported websites of particular interest were those that offered information on fetal development dependant on gestational age. Of the 20 women in their focus group, many of the participants (number not stated) reported that they sought social support on the web from other pregnant women and used the internet to research specific problems they were having with their pregnancy. Unfortunately Bernhardt and Felter (2004) did not elaborate on what these 'specific problems' were.

In a prospective study using anonymous closed questionnaires conducted by Lass and Brinsden (2001), 5% of the 175 women used the internet as a decision-making tool in relation to helping them choose where they should have their private in-vitro fertilisation treatment. The internet was named by pregnant women as a trusted source for advice on the use of home remedies to maintain their health during pregnancy (Westfall, 2003); however, due to the small (n=27) non-random design, and geographic specificity of the study, no generalisations could be made.

Discussion fora, followed by web clinics, were the most popular form of internet source cited by pregnant women in the study conducted by Eriksson-Backa (2003), compared to the control group of healthy individuals who showed more interest in accessing online newspapers and magazines as a health information source. Bernhardt and Felter (2004) found commercial information websites to be the most frequently visited sites by their research participants, but these were the least popular internet source in Eriksson-Backa's study among pregnant women. The reasons given for women favoring these sites were because they could shop, socialise and research a wide range of topics all from the same website. Eriksson-Backa (2003), Bernhardt and Felter (2004) and Sinclair et al (2001) did express serious concern about trusting the reliability of information from commercial sites. More

Table 3. Papers on internet use in pregnancy retrieved and categorised using the Department of Health in the National Service Frameworks (DOHNSF) classification

Bibliographic reference	Evidence level	Study design/method	Sample	Outcomes
Bernhardt and Felter, 2004 (US)	B3	Qualitative, four focus groups	20 mothers of young children	Almost all women reported using the internet during their pregnancy especially true for first pregnancies; searching websites for information on fetal development, social support, to researching specific problems in pregnancy.
Capitulo, 2004 (US)	B3	Ethnography, participant observation and email review	82 to 87 mothers (including one grandmother)	An online perinatal loss group connected women who otherwise would not have met. The culture of online support can link individuals who are geographically distant but share common issues.
Challis, 1996 (Canada)	D	Letter	Three scenarios	There are instances where pregnant women obtain irrelevant/inappropriate information from the internet that can have a negative impact.
Eriksson-Backa, 2003 (US)	B3	Qualitative, one-to-one interviews	17 pregnant women, 18 diabetics, 15 in control group	Discussion forums were more popular among pregnant women compared to the diabetic and control group. Pregnant women as a group used and trusted internet sources the most.
Ernst and Schmidt, 2002 (UK)	D	Exploratory, email letter	One pregnant woman	Advice offered to a pregnant woman from the internet about herbal medicine is misleading at best and dangerous at worst.
Jaques, 2004 (Australia)	B3	Exploratory, questionnaire	737 pregnant women	Face-to-face counseling with a doctor or counsellor was the preferred source of information about prenatal testing. The internet was the sixth preferred information source.
Lass and Brinsden, 2001 (UK)	B3	Prospective using closed questionnaire	175 patients attending a private IVF clinic	Some 5% of new patients used the internet as their primary source for information in helping them choose private in vitro fertilisation treatment.
Lavender, 2003 (UK)	B3	Qualitative/quantitative questionnaire	24 consumers of maternity care	Almost 71% of respondents had access to the internet and would use it to access health information. One qualitative response viewed the internet as 'a dangerous and more confusing mode of accessing information especially if searched in a haphazard way'.
Maijala et al, 2003 (Finland)	B3	Grounded theory semi-structured interviews	29 mothers and fathers	Parents often sought information independently from the internet about the fetal malformation.
Pemberton and Goldblatt, 1998 (Australia)	C2	Case study	One scenario discussed	A pregnant woman accessing information from the internet following diagnosis of fetal abnormality 18 weeks showed that the internet can provide the basis for a new, fruitful partnership between health professional and patient.
Pettigrew et al, 2004 (US)	C1	Descriptive, questionnaire, convenience sample	250 women attending obs/gynae clinic	Internet cited as one of the least common information sources among pregnant women/women on hormone replacement therapy (HRT) seeking information on complementary therapy.
Rillstone et al, 2004 (US)	C1	Exploratory, descriptive using grounded theory	1 RN, 1 Dr, 22 parents (13 women and 9 partners)	Women who had or were considering termination of pregnancy (TOP) for fetal anomalies gained support from the internet.
Sinclair et al, 2001 (UK)	B3	Postal survey, questionnaire	169 postnatal women	18% of pregnant women in one maternity unit and 31% in another used the internet to access information about birth.
Soltani and Dickinson, 2005 ² (UK)	B3	Cross-sectional survey using questionnaire	329 postnatal women	The majority of women obtained most of their information during pregnancy from health professionals (88%) and family and friends (72%), 28% also obtained information from the internet.
Spink et al, 2004 (US)	B3	Qualitative/quantitative using web queries	10 000 web queries	Analysis of medical or health queries to different web search engines found 'pregnancy/obstetrics' was among one of the top five categories.
Teres, 2002 (US)	D	Media review	N/A	For many pregnant women, the internet provides a new kind of safe haven, offering a never ending source of information and reassurance.
Viau et al, 2004 (US)	B3	Content analysis, semi-structured interviews	50 women in third trimester of pregnancy	Pregnant women reported freely asking questions of their providers and seeking health information from multiple sources e.g. internet.
Westfall, 2003 (Canada)	B3	Exploratory and descriptive semi-structured interviews	27 pregnant women	The internet was cited as a trusted source among women seeking information on the use of home remedies in pregnancy and 3% used it to seek information on the use of home remedies during pregnancy.

¹ Unpublished

² In press

trust was given to websites that had little or nothing to gain financially. They praised organisational and academic websites as good for health information; however, there was criticism that these websites can be too scientific and difficult to understand. Many of the studies retrieved did not expand on the nature or quality of the information the pregnant women sourced from the internet or how the women used the information e.g. Viau et al (2002), Maijala et al (2003) and Jaques et al (2004).

Benefits to pregnant women using the internet

In the American study conducted by Bernhardt and Felter (2004: 4), they refer to how one woman found the information she sought from the internet during her pregnancy relieved her anxiety or fear of 'not knowing what to expect'. Teres (2002) comments on how women need to connect and bond with one another during pregnancy, and to rely on other women for support. DIPEX.org (2005) is an example of a website developed in the UK where women can listen to a number of different audio-visual interviews of women talking about their experience of antenatal screening, as well as accessing information on treatment choices and where to find support. Jaques et al (2004) suggests the internet could be used as a form of personal support or 'virtual support'. Capitolo's qualitative study using ethnography to describe and interpret the culture of an online perinatal loss group, found the essence of the culture was 'shared metamorphosis'. The culture of online support can link individuals who are geographically distant but share common issues. The internet linked women together who otherwise would not have met. Participants shared virtual identities, created a community and by joining the perinatal loss listserv ensured that they would never be alone (Capitolo, 2004). Rillstone et al (2001), in their exploratory descriptive study noted how some women who had a previous pregnancy with a fetal abnormality benefited from accessing the internet for support when faced with a subsequent pregnancy. Pemberton and Goldblatt (1998) give an example of a case study where a pregnant woman carrying a baby with a congenital abnormality sourced information from the internet. Although much of the information found was irrelevant, some was of value. Pemberton and Goldblatt (1998) enhanced their own learning about Proteus syndrome through access to information retrieved by parents on the internet. They were encouraged to search for further advice and information on this rare condition.

Risks to pregnant women using the internet

Much of the literature discussing the risks associated with pregnant women using the internet mentions how patients often lack the background to be able to interpret and put into context the information they obtain (Challis et al, 1996; Ernst and Schmidt, 2002). In a short letter to an editor, doctors warned of how inappropriately informed patients was leading to counselling difficulties in their prenatal diagnoses clinic. They present case studies depicting outcomes of how irrelevant or inappropriate information accessed from the internet can have a negative impact (Challis et al, 1996).

In an investigation into internet advice offered by medical herbalists to a pregnant woman regarding herbal treatment for morning sickness, Ernst and Schmidt (2002) found that advice about herbal medicine is readily available over the internet. They give good examples of how advice offered via the internet can be confusing, inaccurate, lacking in scientific rationale and does not always provide cautionary information, therefore putting women and their fetuses at risk (Ernst and Schmidt, 2002). Similar points were also echoed by a pregnant woman in the study conducted by Lavender et al (2003).

Discussion

The broad search strategy used in this review process was able to capture both published and unpublished literature on this topic. Little work has been published about women's use of the internet as a source for health information in pregnancy. The majority of literature relating to use of the internet in pregnancy is descriptive rather than trial based. Overall, data were of poor quality, and derived mainly from small-scale studies and many were too small for results to be generalised. The majority of the evidence was found within the text of papers, which were looking at other issues, and the internet was inadvertently mentioned. Outcomes were inconsistent and therefore it was not possible to make comparisons of results between studies. Because of the limited literature, it is not possible to say if the online-seeking behaviours of pregnant women are consistent with studies of other internet-using populations, which have found that internet users frequently seek online information on specific health conditions (Fox and Raine, 2002).

Teres (2002) has drawn attention to the possible negative effect on how the internet may cause anxiety in women pregnant for the first time. Perhaps we should consider an intervention similar to that of Brown et al (2002), who piloted a programme 'Women on the web', which taught pregnant women about using the internet as a source of information, how to perform internet searches, how to evaluate health information and discuss information with their providers. The women evaluated the programme as 'good' or 'excellent'; however, the uptake for programmes remained poor until they were incorporated into existing prenatal classes and other training programmes.

The strongest finding to emerge from this review is the lack of rigorous research regarding what pregnant women actually do with information they source from the internet. Given the widespread use of the internet and the claims that are made about its benefits as a tool for communicating health information and empowering consumers in healthcare decisions, this lack of research evidence is challenging. There is no rigorous evidence regarding the risk and benefits of pregnant women using the internet as a source for health information. Well-designed studies instead of anecdotes and opinions are needed to determine the overall effect of internet use in pregnancy. This review, which focused specifically on issues pertaining to women's use of the internet in pregnancy and childbirth found much of the literature to be mainly speculative or opinion based.

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