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EVIDENCE BASED MIDWIFERY



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CONTENTS

- Editorial: Past, present and future reflections on health technologies: male dominance, electronic research and sensor technologies. 3
Marlene Sinclair
- A public health intervention to change knowledge, attitudes and behaviour regarding alcohol consumption in pregnancy. 4
Fiona Crawford-Williams, Andrea Fielder, Antonina Mikocka-Walus, Adrian Esterman and Mary Steen
- Informing the midwife on rare genetic disorders and their effects on mothers breastfeeding – a mixed methods study. 11
Tom Laws, Lemuel Pelentsov, Mary Steen and Adrian Esterman
- Parents' experience of the care they received following a stillbirth: a literature review. 16
Hayley Coffey
- A critical literature review of epidural analgesia. 22
Elizabeth Newnham, Lois McKellar and Jan Pincombe
- Sensitivity and specificity of electronic databases: the example of searching for evidence on child protection issues related to pregnant women. 29
Helena Mc Elhinney, Brian Taylor, Marlene Sinclair and Mary Rose Holman
- Information for authors, news and resources. 35

Past, present and future reflections on health technologies: male dominance, electronic research and sensor technologies

Key words: Technology, research, sensor technology, maternity, data, information, data capture, knowledge transfer, evidence-based midwifery

In 1990, I was shown the computer room and, believe me, it was a sight to be forever remembered – a dark room filled with awe and mystery into which every now and then a very senior person would take my little hard square computer disk and emerge with it magically ‘formatted’.

Curious Marlene was determined to master the special skill and disseminate the knowledge of ‘how to’, but I met considerable resistance, as this was definitely the man field and it was a little like GOLF (‘Gentlemen Only, Ladies Forbidden’).

The ritual of obtaining a disk and taking it to the master for his magical formatting continued for months, until I learned by stealth, observation and reading a technical instruction manual how simple this was. It made me determined to share every piece of simple knowledge I had about computers with my colleagues and, in particular, my female colleagues. This led to me developing a BSc module ‘Surfing the internet’ in 1996.

After discovering that electronic databases for literature searching were being developed at a phenomenal rate and I would not have to sit in the library with flimsy microfiche slides and large index volumes, I started a module on evidence-based midwifery, exposing midwives to the world of electronic searching for evidence. Then, I lived in a small bubble where the local world and its context were keeping me living happily but in ‘splendid isolation’.

The internet has changed this for me, and for all of us, and now we can live in the world of social media with virtual reality and electronic touching at micro, meso and macro level. Talking to people almost anywhere in the world at any time of the day or night is so routine for the millennials, yet I can remember how difficult it was to make a long distance telephone call and how expensive it was.

Today, we Skype without a fee. However, there are risks for us to be wary about and unregulated and unmonitored online purchasing is an area ripe for conflict, harm and international legislation.

We can purchase medical devices including: sonicaids, blood pressure monitors, SPO2 monitors, infusion pumps, medications and abortion kits, among others, and all we need is the money. The CE marking or FDA approval is not something the majority of the general public consider, as many trust the internet for purchasing in the same way as they trust Facebook, YouTube or Netmums.

The user, lurker or contributor to social media accepts and signs up to shared information with a level of naivety and disclaimers and ‘I agree’ tick boxes are just completed as quickly as possible to get to the desired goal.

The new sensor technology is the major shaper of our future lives in maternity care and this is mainly because of its data-capturing power. Data can be collected from

implants within us, sensors touching us on the outside and a full range of electromagnetic devices surveilling, testing, impacting; affecting all of our lives without us ever being conscious of its presence.

The recent outbreak of the Zika virus demonstrates the power of technology to connect, inform, share, support and enable knowledge transfer and dissemination rapidly at a global level.

Resources, such as Healthcare Information For All, are powerful testimonies to the invaluable impact of an open access route to knowledge transfer (Healthcare Information For All, 2016).

Technology is becoming more and more invisible as it develops at a phenomenal rate. The modern micro computer chip would not have been imagined in 1990 when I stood outside the room in which the single computer was housed. The future is indeed sensor data capture, but it will evolve much more rapidly than we can fully comprehend.

I look at the technology available today and its mega potential for use by the generation of young people known as the ‘post-millennials’, or the ‘z generation’, in particular. Every day, smarter technology is developed and the market can be flooded with a range of tested and untested medical devices, making internet purchasing a risky business (Gibson, 2015).

These young people are currently 18 to 20 years old and they live online. They are experts in the use of ‘emojis’ and we now have a full dictionary of emojis (World Translation Foundation, 2016) that is based on the concept of crowdsourcing. This is a live dictionary resource where people come to find meaningful symbols and also share these with the online community. The online world of our teenagers should not be alien to us – it is an open resource and we are free to access it at the touch of a button. Our role is to be aware of it, be critical of it and know what is being used by the women in our care and be able to advise them of the recommended quality assurance and safety standards.

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A public health intervention to change knowledge, attitudes and behaviour regarding alcohol consumption in pregnancy

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Accompanying tables can be found at rcm.org.uk/ebm

Abstract

Aim. To evaluate the effectiveness of a public health intervention aimed at changing knowledge, attitudes and behaviour.

Methods. A non-blinded parallel group randomised controlled trial of pregnant women over 18 years of age. Women were recruited in the second trimester and assigned to one of two treatment groups. Both groups completed an initial questionnaire assessing knowledge, attitudes, and practices relating to alcohol consumption during pregnancy. The intervention group then received a mocktail recipe booklet and participants were asked to share the information with their partner. The control group received standard antenatal care. A follow-up questionnaire was conducted four weeks post birth. Primary outcome measures were a knowledge score of the health risks associated with alcohol consumption during pregnancy and an attitude score toward drinking during pregnancy. Secondary outcome measures included whether or not the woman and her partner abstained from drinking. Ethical approval was granted by the Women's and Children's Health Network and the University of South Australia.

Results. A total of 161 participants were recruited at baseline (intervention = 82, control = 79) and 96 participants completed the trial (intervention = 49, control = 47). The findings suggest that the mocktail booklet was effective at improving knowledge ($p < 0.001$; effect size 0.80) and improving attitudes towards drinking during pregnancy ($p = 0.017$; effect size 0.43) in the intervention group compared to the control group. Although women in the intervention group were 30% more likely to abstain from drinking than in the control group (RR=1.3, 95% CI 0.97 – 1.75), this result was not statistically significant ($p = 0.077$).

Conclusions. Knowledge regarding the effects of alcohol consumption as well as attitudes towards drinking significantly improved as a result of a mocktail recipe booklet. Improving knowledge and changing attitudes has the potential to change health behaviour. Therefore, this intervention may reduce the percentage of women who continue to drink alcohol while they are pregnant and improve outcomes for infants and children.

Key words: Alcohol, FASD, pregnancy, health promotion, evidence-based midwifery

Introduction

Alcohol is a teratogen that can cross the placenta and pass from mother to baby. Consuming alcohol during pregnancy can cause miscarriage, stillbirth and a range of lifelong physical, behavioural, and intellectual disabilities known as fetal alcohol spectrum disorders (FASD) (Centers for Disease Control and Prevention, 2014; Sokol et al, 2003; O'Leary, 2002). Despite this, significant percentages of women around the world continue to consume alcohol. Worldwide estimates suggest that between 40% and 80% of pregnant women consume alcohol at some stage of their pregnancy (O'Keeffe et al, 2015; Centers for Disease Control and Prevention, 2014; Malet et al, 2006). In Australia, almost half of pregnant women were found to have consumed alcohol before knowing of their pregnancy, with 19.5% continuing to consume alcohol after learning of conception (Callinan and Room, 2012). A major barrier to preventing FASD may be a lack of awareness of the risks associated with alcohol consumption in pregnancy. Additionally, conflicting advice

from different sources can lead to confusion about what are safe drinking limits during pregnancy.

Previous evidence has suggested that public health interventions may be an effective way of improving knowledge about specific health behaviours (Wakefield et al, 2010; Noar, 2006). Public health interventions may include practices such as: introducing warning labels on alcohol containers and advertising campaigns involving posters, leaflets, media advertisements and more. With regards to alcohol consumption during pregnancy, studies from the US have suggested that brief clinical interventions have the potential to reduce the risk of harm (Gilinsky et al, 2011; Stade et al, 2009). However, studies examining the effectiveness of public health interventions to reduce alcohol consumption during pregnancy have been inconclusive (Crawford-Williams et al, 2015a). Studies in South Africa, the US and Canada have used a variety of public awareness and health education campaigns to inform women about the harmful effects of consuming alcohol in pregnancy,

including: social marketing campaigns; warning labels on alcohol containers; television commercials; pamphlets; posters; and text messaging interventions (Chersich et al, 2012; Evans et al, 2012; Hanson et al, 2012; Lowe et al, 2010; Glik et al, 2001; Casiro et al, 1994; Kaskutas and Graves, 1994). These studies suggest that public health interventions may be effective at improving knowledge, yet there is much variability in the findings and a paucity of literature in this area, particularly outside of North America.

Printed materials are a commonly used public health intervention utilised to improve knowledge, attitudes and patient outcomes (Farmer et al, 2008; Paul et al, 1998). These have been found to be effective in health behaviour change, particularly in the areas of smoking cessation, physical activity and alcohol consumption (Redman and Paul, 1997; Ley, 1988). Unfortunately, many health education materials targeted towards pregnant women have not been evaluated for their effectiveness. In Australia, a plethora of print materials relating to alcohol consumption during pregnancy exist yet the majority have been found to be of low to moderate quality, based on the DISCERN quality assessment instrument for assessing the quality of written health information (Crawford-Williams et al, 2015b; Charnock et al, 1999). The low to moderate quality of many of these health education materials has the potential to undermine the evidence, and may be contributing to the high percentages of women continuing to consume alcohol in pregnancy. Given that printed materials are inexpensive, accessible, and convenient to use, they could be an effective intervention within health settings (Farmer et al, 2008).

Public health interventions are often heavily theory-driven and based on the knowledge, attitudes and practice (KAP) model, which recognises the important connection between knowledge, attitudes, and behaviour (Médicins du Monde, 2011). Knowledge is an important aspect of health behaviour as it is necessary for individuals to be properly informed of risks and benefits.

However, having knowledge of a particular health behaviour does not necessarily mean this behaviour will be adhered to. Attitudes can be described as tendencies towards certain behaviour, often based on peer influence and social context. These also play a key role in an individual's decision to perform certain health behaviours or not. Therefore improving health education and providing the public with greater health knowledge and changing public attitudes towards health behaviours may have the best result in changing health behaviour. The KAP model was taken into consideration during the development of this study, as it is recognised that targeting pregnant women's knowledge about alcohol consumption may then lead to a change in attitudes and influence behaviour change.

Aim

This study aimed to assess the effectiveness of a printed health education document to improve knowledge about alcohol consumption among pregnant women, change attitudes to drinking during pregnancy and reduce alcohol consumption among pregnant women.

Method

Trial design

A two-armed randomised controlled trial (RCT) was conducted to evaluate the effectiveness of a public health intervention to change knowledge, attitudes and behaviour concerning the effects of alcohol consumption among pregnant women. The CONSORT guidelines (Schulz et al, 2010) are used to report the trial outcomes in this paper. The trial was registered with the Australian New Zealand Clinical Trials Registry (trial ID: ACTRN12614001182684) and was a multicentre, non-blinded, parallel group RCT comparing a public health intervention with standard antenatal care. Baseline data collection began in November 2014 to July 2015. Follow-up data collection concluded in January 2016.

Inclusion criteria

Pregnant women aged 18 years and over, resident in South Australia, in the second trimester of pregnancy and who had agreed to be followed up post delivery were eligible to complete a questionnaire.

Exclusion criteria

Those unable to comprehend English, or with a current substance misuse problem, severe, uncontrolled mental illness or cognitive impairment that could interfere with the ability to consent were excluded. The exclusion criteria were assessed with a brief screening survey before participants were invited to participate in the trial.

Setting

The trial was conducted at the women's outpatients clinic in the Women's and Children's Hospital (WCH), South Australia, and the Birthing and Assessment Unit at the Lyell McEwin Hospital (LMH), South Australia. WCH is the largest maternity and obstetric service in South Australia with approximately 5000 births annually. LMH is a leading teaching hospital in the northern suburbs of Adelaide. Inclusion of two main sites allowed for a larger and more diverse sample population. Recruitment occurred at the sites concurrently so women at each site had an equivalent chance of being allocated to the control or intervention group.

Development of the intervention

The intervention was a recipe booklet of non-alcoholic beverages known as 'mocktails'. The development occurred in two stages. Firstly, it was informed by a document analysis of existing printed health education materials in order to ensure the newly developed booklet was of high quality (Crawford-Williams et al, 2015b). Particular consideration was given to the language and reading grade level as well as text structure, style, layout, colour and images of the booklet. The booklet also included a publication date, links to further information, and facts based on evidence; all aspects found to increase the quality of health education documents (Crawford-Williams et al, 2015b). The second stage involved focus groups held with women and their partners (Crawford-Williams et al, 2015c). Focus group participants were shown copies of existing documents relating to alcohol consumption during

pregnancy and asked what was effective and what design elements worked best. It was determined that the booklet needed to: be easy to read; stand out; provide information on why to avoid alcohol; contain general facts about healthy nutrition in pregnancy; provide alternatives to alcohol; and include positive messages (Crawford-Williams et al, 2015b; France et al, 2014). The final intervention took the form of a 10-page booklet containing five mocktail recipes; four pages providing information on the reasons to avoid alcohol during pregnancy, how the baby may be affected, and general nutritional facts for a healthy pregnancy as well as a page targeted at partners.

Procedure

An information sheet explaining trial details, how to contact the researcher and the right to withdraw was given to women by the principal researcher (FCW) at an antenatal appointment during their second trimester. Women were recruited during the second trimester as pregnant women are provided with an overwhelming amount of information in the first trimester and it was thought that the intervention may prove more effective if provided at a time when less information is received by women. Eligible participants were asked to complete a baseline questionnaire upon enrolment. This took approximately 15 minutes to complete and all of the participants were given the same baseline. Following allocation to the intervention group, participants were given a copy of the booklet and asked to read it thoroughly, share the information with their partner and family and make use of the recipes throughout their pregnancy. Participants in the control group received standard antenatal care which may or may not include advice on alcohol. Participants were followed up four weeks post delivery. At this time, participants were phoned to remind them of the trial and reminded about the follow up questionnaire.

Measures

The questionnaire contained information on participant knowledge of the effects of alcohol consumption during pregnancy; attitudes towards pregnant women drinking alcohol; personal alcohol consumption before and during pregnancy; partner's alcohol consumption before and during the pregnancy; partner's influence on the woman's drinking; and basic demographic information. Sections of the questionnaire were based on a previously used alcohol and pregnancy questionnaire (Peadon et al, 2011; Environics Research Group, 2006); however, questions were added on the influence of the partner and partner's alcohol consumption. The final modified questionnaire totalled 52 questions and took approximately 15 to 20 minutes to complete.

The questionnaire was assessed for content validity by a panel of five experts from a range of background including: substance use in pregnancy; midwifery; psychology; biostatistics; and questionnaire development. Based on this assessment, changes were made to the section on alcohol consumption to align with standard questions from the *National drug strategy household survey* (Australian Institute of Health and Welfare, 2011). Additionally,

the questionnaire underwent assessment of test-retest reliability with 10 pregnant women who were administered an identical questionnaire on two separate occasions one week apart. The reliability of the items, as measured by the Intraclass Correlation Coefficient (ICC), average measure for agreement was 0.88 ($p < 0.05$, range $r = 0.55 - 0.92$). This was considered to be a moderate to high level of agreement and the items were unchanged. Finally, the questionnaire was pilot tested by four pregnant women. Minor changes to the wording of attitude questions were made based on this assessment. The follow-up questionnaire was identical to the baseline questionnaire; however, participants in the intervention group were asked their opinion of the mocktail recipe booklet design and the information it contained. The purpose of the follow-up questionnaire was to identify a difference in main outcome measures between the intervention and control groups due to exposure to the developed public health intervention.

Randomisation

A computer-generated list of random numbers was used for participant allocation. This allowed each woman an equal chance of being allocated to either the intervention or control group. Participants were randomly assigned to one of the two treatment groups on a 1:1 allocation ratio.

Allocation

The allocation sequence was concealed from the researcher enrolling participants (FCW) by using sequentially numbered, opaque, sealed envelopes. Corresponding envelopes were opened only after the enrolled participants completed the baseline questionnaire and it was time to allocate the intervention. The researcher generating the allocation sequence was not involved in participant recruitment.

Participants were informed of the purpose of the trial at recruitment; however, were only allocated a treatment group after they had provided consent and completed the baseline questionnaire. Given the nature of the intervention participants, researchers, and data analysts were aware of the group allocation.

Outcome measures

The primary outcome measures were knowledge regarding the effects of alcohol consumption during pregnancy and attitudes towards alcohol consumption in pregnancy. Secondary outcomes were women's and partner's alcohol consumption. Knowledge was measured as a continuous variable using percentage of correct answers to 13 true/false/unknown statements. Attitudes were measured on a five-point Likert scale with statements such as 'I would have positive feelings towards a pregnant woman who was drinking alcohol' and responses from strongly agree to strongly disagree. These were summed to create an attitudes score ranging from eight to 40 with higher overall attitude scores indicating negative attitudes towards alcohol consumption during pregnancy.

Consumption was measured using standard questions from the *National drug strategy household survey*

(Australian Institute of Health and Welfare, 2011). For this analysis, only women who drank alcohol pre-pregnancy were included (n=112), and the percentage abstaining during pregnancy compared between the two groups. Data were also collected on variables thought to be associated with increased risk of alcohol consumption during pregnancy such as gestation, maternal age; socio-economic status; education level; past drinking habits; as well as partner's drinking habits. In order to assess the acceptability of the booklet, women in the intervention group were asked at follow-up if they had read the booklet, found it useful, if it motivated them to cut down their alcohol consumption, and any improvements they would suggest. Further free text comments were invited.

Sample size estimation

The study was powered to detect a medium effect size for change in knowledge and attitude scores between study groups. Given that recruitment was fairly late in pregnancy (16 to 26 weeks' gestation), the authors felt that there would not be sufficient time between recruitment and birth to see a change in drinking behaviour that would allow them to power on this outcome measure. However due to the association between knowledge, attitudes and behaviour the authors included drinking behaviour as an outcome measure (Médicins du Monde, 2011). In order to detect a medium effect size (Cohen's $d=0.5$) in change scores between the intervention and control groups, a sample size of 64 women in each group was required, based on a two-sided t-test with type 1 error set at 0.05 and power at 80%. In fact, the trial aimed to recruit a total sample of 154 women to allow for an attrition rate of 20%.

Statistical methods

Descriptive statistics of baseline characteristics are presented by treatment group. Due to randomisation, any imbalance at baseline can only occur by chance. As such, no formal testing of baseline differences was undertaken. Linear mixed effects models (LMM) were used to examine intervention effects on the primary outcome measures. In these models, the outcome measure was the dependent variable, with group, time and a group-time interaction term as fixed effects. The trial participant was the random effect. The formal test of an intervention effect was the level of significance of the interaction term, which represents a group comparison of change scores. Our approach to missing values for the primary outcomes included two further analyses. Firstly, the authors imputed missing data using a last observation carried forward (LOCF) approach. Secondly, the authors imputed the missing data using multiple imputation with 10 datasets. Regression models were then undertaken with the post-intervention outcome measure as the dependent variable, with group and baseline value of the outcome measure as independent variables. Further, adjusted models were run which included gestation, and 'trying to conceive' as covariates, since these variables were somewhat imbalanced between groups at baseline. Secondary outcome measures, namely drinking behaviour in the women and

their partners, were analysed by calculating the rate ratios with 95% confidence intervals. Analyses were undertaken using the statistical packages SPSS Statistics 21 (IBM Corp, 2012) and Stata 14 (StataCorp, 2011).

Ethical considerations

The trial protocol was approved by the human research ethics committees of the Women's and Children's Health Network, Adelaide, South Australia (protocol no: HREC/13/WCHN/121), and the University of South Australia (protocol no: 0000031358).

Results

Flow of participants

The majority (452) of individuals screened were ineligible, including women who did not meet the inclusion criteria for gestation (301), and acceptable level of English (151). A further 78 refused to participate after being informed about the trial. Therefore, 161 eligible, consenting women participated in the trial. Of these 161 women, 82 were randomised to the intervention group and 79 to the control group. Overall, 96 women (59.6%) completed the follow-up questionnaire: 47 in the control, and 49 in the intervention group.

Demographics

Overall, participants had a mean age of 29.2 years, were predominately Caucasian (80.7%), lived with their partner or partner and children (93.8%), and were employed as professionals (54.7%). Half of participants had a university degree, with 91.9% having grade 12 education or higher. The majority of participants' average household income was over \$50,000 per year (79.5%). Additionally, 46.0% were first-time mothers, and 62.7% of the pregnancies had been planned. The intervention group appeared to be at somewhat longer gestation and less likely to be trying to conceive.

Knowledge and attitudes

Baseline results indicated that several knowledge statements were incorrectly answered by more than half of all participants. These included: 'small amounts of alcohol during pregnancy will not cause harm to a baby'; 'the risk of harm to a baby from drinking alcohol during pregnancy is the same for all women'; 'drinking spirits will cause more harm to a baby than wine'; and 'alcohol causes the most harm to the baby when consumed in the second or third trimester'.

The majority of respondents believed that pregnant women should not drink alcohol and no participant believed that it is ok for pregnant women to consume four or more drinks on one occasion. The majority of participants felt that information should be readily available to pregnant women about the effect that drinking alcohol during pregnancy may have on the unborn baby and that health professionals should ask pregnant women how much and how often they drink at their first antenatal visit and at each additional antenatal visit. Nevertheless, only 40.4% of participants thought that all women were aware of the effects that drinking alcohol during pregnancy can have on a baby.

Alcohol consumption

More than half of the sample had consumed alcohol in the 12 months previous to the pregnancy. Of those women, 83.0% consumed an average of seven drinks or less per week. The mean number of drinks for women who consumed alcohol was 4.65 standard drinks per week. Wine was the most commonly named beverage (68.7%), followed by beer and then spirits. In total, 23% of drinkers had never consumed more than four drinks on a single occasion (binge drinking), while 14.3% reported binge drinking once or twice a week before pregnancy. Of the women who reported drinking before pregnancy, 15% reported drinking in a previous pregnancy and 84% had stopped drinking since learning that they were pregnant.

A total of 123 (76.4%) of the women had partners who consumed alcohol on a regular basis. The mean number of standard drinks per week for partners was 6.64. For the partners, the most commonly consumed beverage was beer (85.4%), followed by wine. A similar number of partners reported binge drinking at least once or twice a week as the women (14.9%); however, a smaller percentage reported never binge drinking (10.6%). Since learning of the current pregnancy, the majority of partners had made no changes to their drinking behaviour (57.1%), while others had reduced the amount of alcohol they consumed (8.7%) or reduced the number of times a week they consumed alcohol (29.8%).

Partner's influence on alcohol consumption in pregnancy

The majority of women reported that their partners' behaviour would not influence their alcohol consumption in pregnancy, even if their partner continued to drink (62.1%), or if their partner stopped drinking (56.5%). However, over one-quarter said they would be less likely to drink alcohol in pregnancy if their partner encouraged them to stop or cut back (28.6%) and one in 10 said they would be more likely to drink if their partner offered them alcohol (11.2%).

Knowledge and attitude

For knowledge score, the intervention group improved by an average of 9% in correct answers, compared to the control group. This was a highly statistically significant difference ($p < 0.001$) and represents a large effect size; imputing missing values and adjusting the models by gestation and intention to conceive made little difference to this result. Similarly, the intervention group improved in mean attitude score compared to the control group, with the difference of 1.4 points being statistically significant ($p = 0.023$). The effect size of 0.43 reflects a medium difference. Again, the other models provided similar results.

Women and partners' drinking

Of women who consumed alcohol before pregnancy 80.6% ($n = 25/31$) of the intervention group stopped drinking during pregnancy compared to 61.9% ($n = 26/42$) of the control group, a rate ratio (95% CI) of 1.30 (0.97–1.75), $p = 0.077$. This percentage represents all women who stopped drinking, including those who stopped drinking prior to the intervention. For partners who consumed alcohol before

the pregnancy, 8.1% ($n = 3/37$) of the intervention group stopped drinking during the pregnancy compared to 11.6% (5/43) of the control group, a rate ratio (95% CI) of 0.70 (0.18–2.72), $p = 0.604$.

Appraisal of intervention

Responses to questions soliciting comments on the practicality, effectiveness and design of the mocktail booklet revealed adequate acceptance of the intervention: 96% of women in the intervention group read the booklet and 92% found the booklet helpful. However, only 12% of women in the intervention group had shared the information with their partner. Over 73% of participants reported that the booklet did not motivate them to cut down their alcohol consumption as they had already chosen not to drink during pregnancy. All participants reported that it was an interesting and useful information package that was a great size and enticing style. Other comments included: the booklet reaffirmed the need to stop drinking; it provided good recipes and creative ideas for non-alcoholic drinks; women did not feel left out when everyone else was drinking; the booklet stimulated discussions about drinking during pregnancy; however, some women tended to drink wine so were not interested in cocktail alternatives.

Discussion

This RCT is the first study assessing a public health intervention in Australia in the area of alcohol consumption during pregnancy. A trial of this kind was deemed important as, despite a number of public health campaigns and government warnings about the risk associated with drinking during pregnancy, many of these interventions are not evaluated for their effectiveness. This trial examined the effects of a public health intervention on knowledge, attitudes, and alcohol consumption among pregnant women. The findings of this trial suggest that a printed booklet is effective at improving knowledge on the topic of alcohol consumption during pregnancy as well as changing attitudes of pregnant women. The authors found that the mocktail recipe booklet significantly increased knowledge among the intervention group, compared to women in the control group. It also significantly changed attitudes of the women in the intervention group. The intervention did not have a statistically significant effect on changing alcohol consumption behaviour; however, a higher percentage of women in the intervention group compared to the control group abstained from alcohol throughout the pregnancy.

Despite overall knowledge scores improving in the intervention group, baseline data showed that several knowledge statements were incorrectly answered by the majority of participants. This suggests that future interventions may need to focus on specific details that are not as widely known or understood regarding alcohol consumption during pregnancy. It has been previously reported that although pregnant women are aware that alcohol has the potential to cause harm to unborn babies, they lack knowledge of the specific details of the effects. Furthermore, women

have reported that the information received from various sources regarding safe levels of drinking in pregnancy is often confusing and contradictory (Crawford-Williams et al, 2015c; Elek et al, 2013; Raymond et al, 2009).

Attitudes towards pregnant women consuming alcohol were generally negative, which is consistent with past research (Peadon et al, 2010; Raymond et al, 2009). A moderate but statistically significant increase in negative attitudes was seen in the intervention group which suggests that a printed health education booklet is appropriate to change attitudes about alcohol consumption during pregnancy. The findings of this trial also demonstrated that the majority of pregnant women already have negative attitudes towards excessive alcohol consumption in pregnancy, and this may be the reason that many women had already chosen to stop drinking alcohol before participation in this trial.

Pregnancy is a key time to promote change in health behaviours, such as smoking and drinking in mothers and their partners (Waterson et al, 1990). Recent studies have suggested that between 20% and 40% of pregnant women in Australia continue to consume alcohol even after learning that they are pregnant (O’Keeffe et al, 2015; Callinan and Room, 2012). The majority of women consuming alcohol during pregnancy in Australia do so in the first trimester, which is a time that has the potential to have the most severe consequences for the fetus (O’Keeffe et al, 2015). This suggests that early in the pregnancy is the time when most women need to alter their drinking behaviour. In the current trial, it was decided to recruit pregnant women during the second trimester as pregnant women, particularly first-time mothers, are provided with an often overwhelming amount of information in the first trimester (Crawford-Williams et al, 2015c). It was proposed that the effectiveness of the current intervention may be more evident at a time when less information is received by the participating women; however, many women in the current trial made the decision to stop drinking early in pregnancy and therefore the intervention was less effective in changing drinking behaviour. Future trials in this area would be enhanced by recruiting pregnant women as early as possible in pregnancy in order to have more success in reducing alcohol consumption.

The intervention did not have a significant impact on reducing alcohol consumption for partners. The findings of the trial indicated that the majority of pregnant women in the intervention group did not share the mocktail recipe booklet with their partner, which may have contributed to the lack of change in the partners’ alcohol consumption. Modifications may need to be made to the intervention in a future trial, in order to make the printed document effective

at changing alcohol consumption behaviour and to further target the information to partners.

Additionally, future research may like to include partners as well as pregnant women in the trial, rather than relying on the women’s perception of their partner’s alcohol consumption. The findings from this trial suggest that a public health intervention is an acceptable method of providing information to pregnant women. It is easy to implement and received positive feedback from all women in the intervention group. In order to improve certain aspects of the mocktail booklet for use in a larger trial it is recommended that printed materials are targeted towards women who consume wine in particular as this was the most commonly consumed beverage by women in the current sample. Additionally, it would be beneficial to include information about attitudes towards alcohol consumption in pregnancy in the intervention group in order to see a larger effect in the change in attitudes between the groups.

Strengths and limitations

The larger than expected number of non-returned follow-up questionnaires reduced the amount of data available for statistical analysis. However, imputation of missing data produced very similar results. The sample consisted of predominantly Caucasian, well-educated, high-income women making generalisation problematic. It was difficult to demonstrate a change in drinking behaviour with such small numbers of drinkers in our sample. Clearly, in future research, it is necessary to replicate this study with a much larger sample size and to exclude women who never consume alcohol.

Conclusion

This trial shows that printed health education material can achieve significant improvements in overall knowledge of the effects of alcohol consumption in pregnancy, and can change attitudes towards pregnant women who consume alcohol, although these findings need to be considered in light of the relatively small numbers who completed the follow-up study. The success of this small-scale trial provides incentive for a larger trial to be conducted in the future.

Furthermore, future research should be conducted with populations of women who are continuing to consume alcohol during pregnancy in order to determine the effectiveness of a public health intervention on changing drinking behaviour. Given that printed health education documents are common, inexpensive and convenient to use, the findings presented here demonstrate substantial support for these interventions to be used within health settings.

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Informing the midwife on rare genetic disorders and their effects on mothers breastfeeding – a mixed methods study

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Abstract

Background. An inability to breastfeed is a common source of maternal distress. Genetic disorders can prevent lactation and impair mothers and infants ability to express breastmilk.

Aim. The purpose of this paper is to report on the experiences of some mothers attempting to breastfeed when they or their infant have the rare genetic disorder ectodermal dysplasia.

Methods. A mixed methods approach identified supportive care needs of parents caring for a child with ectodermal dysplasia. A secondary analysis determined that most mothers responding to an online survey and participating in a focus group held unresolved psychological issues related to their inability to breastfeed. The study received ethical clearance from the University of South Australia human research ethics committee prior to proceeding with data collection.

Findings. Mothers in this study expressed frustration with the lack of understanding held by healthcare professionals and the lack of practical support when attempting to establish breastfeeding. Emotional comorbidity was linked to perceived failure to breastfeed. Mothers requested an awareness-raising approach to assist midwives and health professionals identify feeding problems earlier. The importance of active listening to mothers' concerns and refraining from cursory judgement was identified.

Implications. While genetic screening is offered to pregnant women who have a known family history of a genetic disorder, many genetic orders are rare and go undetected. Newly birthed mothers with a genetic disorder may encounter difficulties when attempting to establish breastfeeding. More genetic education is needed to assist midwives in gaining a better understanding of how physiological problems, associated with a genetic disorder, may be a root cause of breastfeeding difficulties.

Key words: Ectodermal dysplasia, rare genetic disorder, lactation, breastfeeding support, midwives, evidence-based midwifery

Background

The benefits of breastfeeding for mother and infant are well established (Stuebe, 2009). However, many mothers experience difficulties in initiating breastfeeding in the early postpartum period because of issues such as nipple pain, breast engorgement and mastalgia (Wagner et al, 2013). The most frequently reported maternal problem resulting in cessation of exclusive breastfeeding (EBF) is the mother's perception of insufficient milk production (Hargreaves and Crozier, 2013; Kent et al, 2013; Nielsen et al, 2011).

These factors contribute significantly to making attainment of the WHO recommendations for EBF (up to six months) a rare occurrence in developed countries, including the US, UK and Australia (McDonald et al, 2012a). Mothers' emotional wellbeing is often affected when they do not meet clinical recommendations, many of which underpin societal expectations of being a good mother (Williamson et al, 2013).

Infants may also have problems establishing a breastfeeding routine because of prematurity at birth and an abnormal physiology (Genna, 2013). Common and rare genetic disorders have the potential to affect breastfeeding for mothers and infants. There are more than 8000 rare diseases and the characteristics of some disorders are so diverse that they are not able to be categorised by diagnosis (MacLeod et al, 2015; Spagnolo and du Bois, 2015). Rare diseases occur in 6% to 10% of the population and affect some 350 million people worldwide (Feltmate et al, 2015).

Genetic disorders have been linked to cleft palates and lips;

these infant abnormalities make attachment and sucking difficult (Donovan, 2012). Most research is focused on exploring corrective treatments for ankyloglossia (tongue-tie) and orofacial clefts – the most common congenital malformations in humans (Finigan et al, 2013; Klockars and Pitkäranta, 2009). However, according to Edmunds et al (2013) and Owens (2008), there are few studies recording the difficulties experienced by mothers when breastfeeding an infant with ankyloglossia or a cleft palate.

This study focuses on a rare genetic disorder termed ectodermal dysplasia (ED) and its effects on breastfeeding. The topic is unique in that both mother and child can be affected by ED, but not receive a formal diagnosis until many months or years following birth. This situation differs markedly from mothers with an infant born with ankyloglossia or cleft palate, where the anatomical abnormality is commonly detected at routine examination in the postpartum period.

This means that the literature on breastfeeding difficulties and support needs for mothers with a child with ankyloglossia and orofacial clefts cannot be applied to ED mothers.

The authors know of no study that explores the experiences of mothers who are breastfeeding a child with ED.

Ectodermal dysplasia

ED is used to identify a group of congenital anomalies that are associated with an abnormal development of one or more structures derived from the ectoderm (teeth, hair, nails, skin and sweat glands) and breast tissue development (Wright et

al, 2014). This rare genetic disorder, in its most common form, has an incidence of one per 100,000 live births and often affects mothers' and infants' capacity to breastfeed (Voutilainen et al, 2012; Kaercher, 2004).

Physiology

Mothers with ED face substantial problems in initiating and maintaining breastfeeding because of their altered physiology. Mothers with ED often suffer from mammary hypoplasia and, therefore, may not have the breast development normally linked to pregnancy and they are often unable to lactate in the postpartum period, despite having normal hormone levels and nerve innervation (Arbour and Kessler, 2013). Research into breast malformation associated with ED has been undertaken for many years (Clouston, 1939), yet few studies have recognised the significance of limited or complete lack of breastmilk in these mothers and the potential impacts this may have on both mother and newborn. Mothers can also present with obvious breast asymmetry, absence of nipples, inverted nipples, or accessory nipples – these abnormalities make infant attachment to the breast more difficult (Asai and Irvine, 2011; de Alvis and Weerasinghe, 2004).

Infants with ED often experience substantial difficulties in establishing and continuing with breastfeeding. A reduction of sweat gland function results in an inability to sweat and control core temperature; putting the infant at risk of a life-threatening sequelae – hyperthermia, febrile seizures, intellectual disability and, eventually, death (Blüschke et al, 2010). Skin contact with their mother during breastfeeding may raise an infant's body temperature, causing them to become agitated and withdraw from the breast.

In addition, a characteristic of ED that is not well understood is an abnormal amount of nasal secretions that serve to impede breathing and prevent continuous sucking. Cleft palate is also a common feature associated with ED that, when combined with other difficulties, can make breastfeeding impracticable from birth (Lu and Schaffer, 2008).

Here the authors present a secondary analysis that aims to examine the prevalence and type of breastfeeding problems experienced by these mothers and infants. An understanding of these difficulties is needed to assist in developing strategies to minimise the psychological co-morbidities experienced by these mothers (Dowling and Brown, 2013).

Method

The initial study aimed to provide an in-depth account of the experiences and supportive care needs of parents caring for a child diagnosed with ectodermal dysplasia. A mixed methods approach was used. Focus group interviews were conducted with both parents and an internet survey was used to recruit English-speaking participants. Full details can be accessed in Pelentsov et al (2015).

Study design

Parents attending the Australian National Ectodermal Dysplasia Annual Conference in Sydney (2011) were invited to disclose their experiences and support needs in focus groups.

A total of four focus groups were facilitated with 23 parents of children with a rare disease (17 mothers and six fathers). Focus group size ranged from three to 10 participants. Questions were purposefully broad to aid discussion; participants were encouraged to direct the conversation between themselves and other parents in areas that they considered significant to their personal and partner's experience. Focus group discussions were digitally recorded and this data were augmented by written notes taken by the researchers.

A content analysis of the verbatim transcripts was used to create themes in accordance with the process identified by Elo and Kyngäs (2008). A review of the literature on parental support needs by Pelentsov et al (2014), in conjunction with the themes developed from focus group data, were used to validate the design of a survey. The questionnaire was pilot tested for reliability; the final version contained less than 50 Likert questions and several open-ended questions for both mothers' and fathers' comments. The study received ethical clearance from the University of South Australia human research ethics committee prior to proceeding with data collection (protocol: 0000031772). Rare Voices Australia and allied international support groups circulated the survey web address with an invitation to participate to members. The survey was broadcast internationally using the Survey Monkey software. The survey elicited 126 responses from a widerange of countries. The thematic analysis of the qualitative data and survey are presented in Pelentsov et al (2015).

Secondary analysis

A secondary analysis of data is a useful means of finding answers to research questions that emerge from the initial research question, particularly where a population may have been elusive to the researcher's initial attempts to understand a phenomenon (Hinds et al, 1997). Having completed the analysis phase of the study, there were ongoing reflexive discussions among the researchers that resulted in the identification of a deeper meaning to comments made in the focus groups and survey relating to breastfeeding issues experienced by the mothers. There were no direct questions relating to the topic in the primary data collection. This occurrence prompted a formal secondary analysis of the data. Here the authors present a detailed analysis of this phase of the study; the aim of which is to report on the experiences of mothers attempting to breastfeed when they or their infant have ED. The authors followed the process of analysis described by Long-Sutehall et al (2011).

The research question for secondary analysis was close to the primary research question. The primary data (transcripts and audio recordings) had sufficient quality and detail to support a coherent secondary analysis. These data were sorted for inclusion/exclusion and subsequently analysed using a constant comparative method (Charmaz, 2006).

Literature review

There is a plethora of literature identifying the emotional burden carried by mothers failing to breastfeed, but there is a dearth of literature on the support needs of parents caring for a child with ED and, in particular, an understanding of

breastfeeding-related issues (Burns et al, 2010). A systematic search of the literature in Google Scholar, MEDLINE, Embase and Scopus was undertaken using the key words 'lactation', 'breastfeeding', 'rare genetic disorder' and 'ectodermal dysplasia'; the search was augmented by a manual exploration of the relevant literature.

The search resulted in only one paper specific to the research aim: a case report by de Alvis and Weerasinghe (2004) identified a 19-year-old mother diagnosed with ED following being unable to breastfeed her newborn child. Upon examination, the mother was found to have, among a number of characteristic features of ED, hypoplastic breast tissue and a complete absence of breastmilk secretion.

Findings

Both the focus group and survey responses are used to report on mothers' experiences of initiating breastfeeding and decisions to use alternative methods of providing infant nutrition. Four out of the six mothers in the focus group reported problems initiating breastfeeding:

"I couldn't breastfeed. After two months there was hardly anything" (K, mother, aged 39).

"I did not know until the geneticist in WM hospital told me" (L, mother, aged 37).

Of the 126 parents who responded to the survey, 116 (92%) were mothers. Notably, 32 (25%) of the respondents had themselves been diagnosed with ED. Breastfeeding difficulties were reported by 51 (41%) of mothers. Open-ended comments from maternal carriers of ED included:

"I was not able to produce breastmilk" (Australia, mother).

"I have had five children and I breastfed the first for three months and tried with all the others but ended up reverting to bottle feeding" (UK, mother).

Many mothers described feeding problems linked to ED:

"Unable to latch due to his nose being full of ED gunk" (Pakistan, mother).

"Blocked nasal passages" (Australia, mother).

"My baby was unable to coordinate sucking and breathing" (Canada, mother).

"...she also had extreme reflux to the point of being hospitalised. So she was only breastfed for about a week" (US, mother).

"Both our boys silently aspirated, and are now peg fed. It is believed that this was due to ED affecting the swallowing nerve" (anon).

When respondents were asked whether these breastfeeding difficulties were experienced with all infants or just infants with ED, the majority experiencing breastfeeding difficulties 34/48 (67%) said that it was only for their infants with ED.

All of the mothers experiencing difficulties reported problems communicating with midwives and expressing their concerns that they were unable to breastfeed their newborn. A common theme emerged that these mothers felt they were not being actively listened to. These mothers reported that midwives appeared not to consider or acknowledge that there might be an underlying physiological problem preventing them from establishing breastfeeding. Midwives giving care to these mothers would continue to encourage

them to establish breastfeeding:

"...But midwives don't accept that. It's like 'no you can do it'. You know, 'there's no such thing as lack of supply'. And, 'you know, just feed more regularly and it will just increase', and all this sort of stuff, and that's an issue too because they're not understanding of those issues" (J, mother, aged 35, from Australia).

"One of them pulled me aside and she goes: 'I know your husband is forcing you not to do this...'" (A).

"But... even lactation consultants have no idea" (J, mother, aged 35).

Both mothers and fathers within the focus group openly shared how the negative breastfeeding experience had impacted on them psychologically:

"And I stepped back and I thought if this was my first situation again that would have just crushed me... I was devastated" (L, mother, aged 37).

"Because there's so much guilt that comes with that (unable to breastfeed)" (J, mother, aged 35).

Several of the participants voiced concerns that the midwives and doctors involved in their care appeared to lack knowledge and acceptance that a physiological problem relating to a genetic condition could be a possible underlying cause of why they were unable to breastfeed:

"...they're so unaware of medical conditions [...doctors and midwives] that might give rise to your inability to do it. That because they're first port-of-call is always everyone can do it and that there is no such thing as can't" (D).

"It was phenomenal ...when I couldn't and ah they were arguing with me I had to see so many different midwives and lactation consultants this is all within like one day of A being born. And um... this midwife, I said: 'Look I have to put my daughter on formula. I'm not going to starve her.' And this midwife said: 'Um... we're a child-friendly hospital, we don't carry formula'"(L).

Some mothers stressed the need to raise awareness among midwives and lactation consultants:

"Better awareness to all these nurses and doctors and they can definitely run some programmes" (R, mother, Sri Lanka).

Discussion

Mothers and potential mothers have long been exposed to public health messages that imply that breastfeeding is a core maternal activity that is natural and trouble-free (Leeming et al, 2012; Williamson et al, 2012). It has been reported that most publications, aimed at increasing the prevalence of breastfeeding, carry a sub-text suggesting to mothers that they have a moral duty to breastfeed and those that do not are depriving their infant of a maternal bond and optimal nutrition (Williams et al, 2013).

As a consequence of these social messages, descriptive studies identify that mothers interpret being unable to breastfeed as a personal shortcoming in a manner which disempowers them (Dowling and Brown, 2013). An understanding of such moral difficulties is needed to assist in developing strategies to minimise the psychological comorbidities encountered by these mothers (Schmied et al, 2011; Cooke et al, 2007). From a clinical perspective,

it is assumed that a routine and formal prenatal lactation assessment is sufficient to identify women who may struggle to establish breastfeeding. 'During the prenatal period, physicians have an opportunity to screen women for certain biological, psychological and social risk factors that might interfere with mammogenesis, successful lactation or breastfeeding' (Jatoi and Kaufmann, 2010: 79). However, there is a lack of evidence to show: a relationship between mothers predicted to have breastfeeding issues and their actual experience of breastfeeding; a link between mothers identified as at risk of not being able to breastfeed and outcomes of any support (McDonald et al, 2012b).

This secondary analysis of data provided by this mixed methods study has highlighted maternal and also paternal dissatisfaction with midwives' and doctors' lack of understanding and acceptance that rare genetic disorders may affect lactation and infant-feeding techniques.

Other mothers have also written about the lack of understanding and acceptance and how this has psychologically affected them (Kelly, 2010). Not being listened to was a core theme identified in this study; this finding is directly relevant to maternity services advocating a woman-focused approach to care and personalised care (Midwifery 2020 Programme, 2010).

To date, maternal antenatal assessment practices have lacked evidence-based information to assist the midwife in detecting rare genetic disorders (Godino and Skirton, 2012) and poor knowledge of the impact of the disorder on human physiology has made it difficult for midwives to plan appropriate care. Godino and Skirton (2012) contend that, while genetic content is lacking in educational programmes, midwives are amenable to genetics education, and this should then be clinically translated to the application of genetic principles in their everyday practices. Skirton et al (2012) suggest midwives should have embedded into their curriculum essential knowledge and skills in genetics with the aim of improving their genomic literacy.

Traditionally, neonatal examination has been carried out by junior paediatricians and general practitioners (Baston and Durward, 2010; Hayes, 2003). Among the UK midwives qualified to perform a physical examination, one-third carried out no formal examinations of infants (Green and Oddie, 2008). However, it has been recently recommended that examination of the newborn should be

undertaken as a compulsory skill within the pre-registration midwifery programme, including detailed knowledge of genetics (Blake, 2012). At present, registered midwives must undertake a special qualification in the examination of the newborn (McDonald et al, 2012a).

Current assessment practices for mother and infant are not structured to detect rare genetic problems and lack of evidence-based information indicates that midwives appear to be disadvantaged in their opportunity and ability to detect genetic abnormalities in the antenatal period, at birth and during the establishment of breastfeeding. There have been recent recommendations to include genetics into midwifery curricula; fulfilling these recommendations would assist in filling the knowledge gap identified in this study (Godino and Skirton, 2012; Skirton et al, 2012). Notably, a systematic search of the literature found no published articles linking midwives' knowledge of difficulties in breastfeeding to physiological problems associated with a genetic condition.

A limitation of this study was that healthcare professionals were not invited to comment on their understanding of links between genetic disorders and implications for breastfeeding. The authors acknowledge that some midwives and doctors may have considered that breastfeeding problems could be associated with genetic abnormalities (ankyloglossia and orofacial clefts), however, the literature suggests that this was not common practice.

Conclusion

Studies continue to identify that mothers with breastfeeding problems have unmet psychological needs requiring more informed support from health professionals. This study describes a rare genetic disorder strongly associated with an inability of the mother and/or infant to establish breastfeeding. Mothers with ED may have substantial difficulties with milk production and infant attachment, yet there has been little reporting on the special needs of this group. Many of the mothers in this study reported a sense of personal regret and guilt for not providing their offspring with a good nutritional start in life. The importance of listening to mothers' concerns and not being judgemental is paramount when giving care and meeting the needs of this specific cohort of mothers. Early recognition of this group of disadvantaged mothers would enable alternative nutritional intake to be negotiated with mothers and potentially reduce disappointment.

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Parents' experience of the care they received following a stillbirth: a literature review

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Abstract

Background. Stillbirth can be considered by both midwives and families as a highly emotive yet almost invisible topic that is often not fully explored or discussed.

Aim. This paper focuses mainly on primary, qualitative research that demonstrates the lived experience of parents who have endured a stillbirth. The intention was to gain an understanding of what parents perceived as good practice, in order to inform future recommendations for clinical practice.

Method. Platform host Ebscohost was used to search electronically across the following databases: Embase, Global Health, Journals from Ovid, Maternity and Infant Care, MEDLINE, CINAHL Plus with text, Science Direct, British Nursing Index, The Cochrane Central Register of Controlled Trials, e-journals; PsycINFO, Psychology and Behavioral Sciences. Key words included 'stillbirth experience & parents', 'stillbirth & memories', 'stillbirth & care', 'stillbirth & midwives', 'stillbirth & fathers'. A total of 45 papers were found and screened for relevance and appropriateness, 20 were selected based on the emerging themes and eight papers met the criteria and were included for review.

Findings. Most women reported a dearth of information during their first encounter with the health service. Fathers felt they were often excluded during communication and information-giving. A woman's psychological health was negatively affected when induction was delayed for more than 24 hours after the diagnosis of fetal death. Parents valued the obtaining of mementos and being offered choice and informative support about meeting their stillborn baby.

Recommendations. Optimal timing of induction and appropriate preparation for vaginal birth and meeting the baby are also important, as is ensuring the provision of high-quality mementos.

Conclusion. Effective sensitive communication, individualised care and guidance from health professionals in making informed choices about meeting and remembering the child were vital in reducing parents' trauma associated with stillbirth.

Key words: Stillbirth, parents' experience, memories, care, bereavement, evidence-based midwifery

Introduction

The definition of a stillbirth, according to the RCOG, is: 'Any child expelled or issued forth from its mother after the 24th week of pregnancy that did not breathe or show any other signs of life' (RCOG, 2010: 20).

Unfortunately, stillbirth is not a rare occurrence. In the UK around 10 babies are stillborn every day (Sands, 2016). A series of reports in *The Lancet* (Lawn et al, 2011) pertaining to stillbirth, recorded that there are twice as many stillbirths globally as there are deaths due to HIV and AIDS. Yet, in contrast, stillbirths are almost invisible, resulting in a lack of support for families, and an unclear standard for care (Scott, 2011). It has even been suggested that discussing stillbirth is considered to be one of the last taboos (Frøen et al, 2011).

Women experiencing a stillbirth are generally cared for by midwives (Fenwick et al, 2007; Schott et al, 2007). However, the care required may differ from that of a normal birth. Midwives are potentially required to consider the family's psychological wellbeing to a greater extent. This may be daunting for midwives who lack skills in providing this valuable support. Fenwick et al (2007: 154) concur that care provision in such situations can be stressful while also being 'personally and professionally challenging for the midwife'.

Background

Stillbirth rates in the UK remained largely unchanged from the late 1990s to 2011. More recent statistics show a decline,

and the rate is now at its lowest level since 1992. However, there is still much more that needs to be done (Sands, 2016). Stillbirth rates that were included in the 2013 infant mortality figures showed that they accounted for more than half of infant deaths in children under one year old in the UK (Office for National Statistics, 2013) with three in 10 stillbirths occurring at 37 weeks' gestation and beyond (Manktelow et al, 2015; CMACE, 2011). See Table 1 for a breakdown of the primary causes of stillbirth.

Sands was formed in 1978 by Bel Mooney, a journalist, and Hazelanne Lewis, a psychiatric social worker, both of whom gave birth to stillborn babies. At that time in the UK, most parents were not allowed to see, hold or bury their babies. No photographs were taken, and they could not put their baby's name on the stillbirth certificate. Bel wrote an article in *the Guardian* describing her experience, and Hazelanne then wrote to national newspapers asking bereaved parents to contact her to share their stories. An incredible amount of replies from all over the UK revealed a vast unrecognised need for support and information for parents and families (Schott and Henley, 2009).

In the 1980s, Sands suggested it might be beneficial for parents to see, hold and collect mementos of their stillborn baby and included this recommendation in their first edition of *Miscarriage, stillbirth and neonatal death: guidelines for professionals* (Kohner and Henley, 1991). The guidelines were highly commended, and recommended as a basis for staff training by the House of Commons Health Committee.

The *Second report on maternity services* (House of Commons Health Committee, 1992) recognised the need for sensitivity in care and support of bereaved families and stated that all units should facilitate training in line with the Sands guidelines.

In contrast, guidelines published by NICE (2007a) were seen to 'jeopardise' the hard work previously done by Sands (Lynch, 2010). NICE (2007a; 2007b) indicated to both parents and health professionals that it was considered unhelpful for parents to see their dead baby and advised that it should not be encouraged. Sands extensively campaigned to have the wording of the NICE guidelines changed. NICE then issued a 'clarifying statement' (O'Malley, 2010) conveying that the guidelines were intended to promote free choice, and suggested seeing and holding the stillborn baby may not benefit everyone. Dimery (2010) and Henley and Schott (2008a) are of the opinion that conflicting findings from research have led to uncertainty among health professionals and has seen practice swing from one extreme to the other: neither of which are helpful for parents or health professionals.

Scott and Bevan (2012) highlight their concerns regarding current 'on-the-job' training of students and qualified midwives. Specific training on caring for parents whose baby has died is only included in regular training for midwives in about half of all units in the UK (Henley and Schott, 2010).

Method

Platform host Ebscohost was used to search electronically across the following databases: Embase, Global Health, Journals from Ovid, Maternity and Infant Care, MEDLINE, CINAHL Plus with text, Science Direct, British Nursing Index, The Cochrane Central Register of Controlled Trials, e-journals; PsycINFO, Psychology and Behavioral Sciences. Key words included 'stillbirth experience & parents', 'stillbirth & memories', 'stillbirth & care', 'stillbirth & midwives', 'stillbirth & fathers'. The key words were searched for in the abstract and title key word fields.

Inclusion criteria

Peer-reviewed original research pertaining to the parents' experience following a stillbirth; qualitative full-text articles; quantitative full-text articles; English language; published between 2000 and 2015; research undertaken in high-income countries with maternity services comparable to the UK.

Exclusion criteria

Meta-analyses; literature reviews or secondary analyses; published prior to 2000; not English; research undertaken in low-income countries; peer-reviewed original research relating to miscarriage; neonatal death; midwives' perceptions.

A total of 45 papers were found and screened for relevance and appropriateness. Papers from countries without a comparable maternity service were excluded because of the sensitive nature of the research, and the complexities around ethical consideration when analysing the data, would require a sound understanding of models of maternity care

in those countries (Crisp, 2015). Of the 45 papers, 20 were selected based on the emerging themes and were assessed more thoroughly. It was notable during the search that the majority of in-depth studies were conducted in Sweden and studies from the UK were lacking. Eight papers met the criteria and were included for review, based on the richness, impact and quality of the data.

Table 1. Primary causes of stillbirth, using the maternal and fetal classifications (CMACE, 2011)

Cause	%
No antecedent or associated obstetric risk factors	27.8
Specific placental conditions n=389	
Other specific placental conditions	7.1
Placenta infarction	3.7
Massive perivillous fibrin deposition	0.5
Velamentous insertion	0.2
Vasa praevia	0.1
Antepartum or intrapartum haemorrhage	11.4
Mechanical n=273	
Cord around the neck	4.2
Other cord entanglement or knot	2.4
Cord prolapse	0.5
Breech presentation	0.3
Other mal-presentation	0.3
Uterine rupture before labour	0.3
Compound presentation	0.03
Face presentation	0.03
Uterine rupture during labour	0.03
Including associated obstetric factors: n=134	
Other associated obstetric factor	1.2
Premature rupture of membranes	0.8
Spontaneous premature labour	0.8
Intrapartum asphyxia	0.7
Polyhydramnios	0.2
Oligohydramnios	0.1
Other birth trauma	0.1
Hypertensive disorders of pregnancy	6.9
Intrauterine growth restriction	6.6
Infection	5.1
Maternal disorder	5.0
Associated obstetric factors	4.0
Specific fetal conditions	3.8

Findings

A CASP tool for both quantitative and qualitative data was used to analyse the papers. Six themes emerged and were highlighted during the critiquing process. However, this paper will focus on three themes considered to be of significant relevance to the care of the family following a stillbirth:

- Communication and information-giving
- The timing of the induction of labour
- Meeting and remembering the 'silent child'.

Communication and information giving

Communication is a vital aspect of all midwifery care provision (Johnson and Taylor, 2010). Stillbirth is no exception; practitioners need to utilise their communication skills effectively. When told bad news, parents remember the words used and the actions and attitudes of the professionals involved. This can place a heavy burden on the professional who has the responsibility of telling parents their child has died (Thomas, 2011).

Trulsson and Rådestad (2004) reported on the experiences of 12 women following a stillbirth. The majority of the women reported 'knowing' that something was wrong before their initial contact with health professionals and indicated that this initial contact was their main cause of trauma. The women reported feeling that their fears were disregarded, with some being told that their symptoms were normal.

Many of the women reported that they were left to pick up on cues from the healthcare professional's body language and overheard them discussing their care without involving them or their family. This lack of communication may lead to higher levels of anxiety and could place a strain on the midwife-woman relationship, which is built on trust.

Trulsson and Rådestad's (2004) findings suggest that communication skills were inadequate – that the women felt they were not listened to; their concerns were disregarded and there was a dearth of information-giving during the diagnostic ultrasound examination. Säflund et al (2004) reinforced the importance of communication in their phenomenological study. The authors were of the opinion that, if parents were assisted during this time, their attachment to the baby would be strengthened, thus aiding the grieving process, and reducing their level of trauma.

Trulsson and Rådestad (2004) and Säflund et al (2004) warned that a lack of communication may have contributed to an increased level of trauma from the stillbirth experience, and may add to the anxiety felt by the health professionals. The authors recommended better preparation of healthcare professionals in bereavement care. At present, most NHS trusts do not have a structured bereavement training package; also time constraints and staff shortages have a detrimental impact on the ability to release midwives for training (Schott and Henley, 2010).

Samuelsson et al's (2001) phenomenological study focused on fathers' experiences of stillbirth. The authors suggest that in a society of gender conditioning men are not perceived to grieve the loss of a stillborn child. Badenhorst et al (2006) corroborated this view, finding that the father's perceived lack of social support intensified their grief.

The fathers said they felt sidelined during stillbirth care and that their partner was seen as being the chief mourner. They felt it was important that they were recognised as a mourner and acknowledged as a parent also grieving the loss of their baby. While the fathers are often the main source of support for the mother, it is important to recognise the need to assist the father in this role, while providing him with emotional bereavement support. It is clear from the research that fathers need to be involved in information-giving and decision-making. This could help to reduce the father's anxiety levels and provide them with a purpose by reinforcing their role and helping to recall information for the mother. The vulnerability of fathers to psychological distress after stillbirth needs to be recognised (Dean, 2006; Turton et al, 2006; Samuelsson et al, 2001). Bennett et al (2005) highlighted the array of emotions a bereaved father may experience and stated that many felt helpless, frightened and angry at the mother's pain and distress. This could be further intensified if the father was treated as a bystander. The aforementioned studies further corroborated Conway and Russell's (2000) previous study, which described couples' experiences following a pregnancy loss and found that many fathers received sub-optimal support from staff, and recommended that when the father is present he should be asked how he is and listened to in his own right.

It is often difficult for distressed parents to absorb and understand all the information. The guidelines recommend that healthcare professionals clarify the understanding of the information communicated to parents by asking them to explain what they have understood. The guidelines also highlighted that parents may want more information about their baby's condition, or the reason for their death. The midwife's assistance in obtaining this information and their involvement in a later debriefing are also part of the recommendations. Scott and Bevan (2012) and Einaudi et al (2010) noted the importance placed on a debriefing with the midwife; this is considered to provide the parents with a sense of closure and to aid the grieving process. Despite these recommendations, the experiences highlighted in the studies reviewed (Downe et al, 2013; Säflund et al, 2004; Trulsson and Rådestad, 2004; Samuelsson et al, 2001) suggest that communication and information-giving is substandard, despite being a vital aspect of care.

The timing of induction

When a fetal death is confirmed prior to labour, women are faced with a time lapse to dwell on the prospect of giving birth to their stillborn child. Samuelsson et al (2001) and Badenhorst et al (2006) found that many fathers felt they immediately wanted the baby removed via CS. The RCOG green-top guideline (2010) pertaining to stillbirth strongly recommends vaginal birth and suggests that the future delivery implications of a CS should be carefully discussed and a joint decision made. The practice of inducing the labour of bereaved mothers is varied and there is no standard practice for the timing of induction after the diagnosis of a stillbirth (Malm et al, 2011). Trulsson and Rådestad (2004) and Peters et al (2015) suggested that the timing of

induction could have detrimental effects on the mother's psychological health, with some mothers experiencing post-traumatic stress disorder (PTSD).

Säflund et al (2004) highlighted the importance of communication during the diagnosis and birth interval. The authors noted the significance of ensuring parents receive structured information about the process of induction, birth and meeting the baby, particularly if they choose to go home in the interim period. It was also regarded as imperative that parents have a source to refer to, such as written information, and a contact number should they need further support.

Rädestad's (2001) quantitative study involving 759 women (380 of who gave birth to a stillborn), showed a clear correlation between the timing of induction and an increased prevalence of anxiety symptoms such as increased stress and lowered self-esteem.

Anxiety and depression symptoms were measured using the validated Trait Anxiety Inventory (Spielberger et al, 1983). The inventory is a self-reported assessment that differentiates between the temporary condition of state anxiety and the long-standing quality of trait anxiety. The tool incorporates two scales containing 20 statements, with a score for each statement chosen by the participants. The total score detects the correlation between anxieties related to bereavement and anxiety as a general trait. Anxiety symptoms were present in women whose induction of labour began more than 24 hours post-diagnosis of the fetal demise. The author recommended immediate induction following the diagnosis, in an attempt to reduce psychological distress.

Trulsson and Rädestad (2004) conducted a relatively small qualitative study, which consisted of interviews with 12 women following a stillbirth and re-affirmed Rädestad's original findings. There was a reported five-fold increase in long-term anxiety in women whose labour was induced more than 24 hours after diagnosis of fetal death. However, the authors changed their previous recommendations and advised that the timing of induction should be assessed to meet the individual needs of the parents.

The Sands guidelines (Schott et al, 2007) reflect Trulsson and Rädestad's (2004) recommendation that tailoring the time between diagnosis and induction according to individual needs would be in the best interests of the family. Samuelsson et al (2001) held the view that parents need time to prepare themselves psychologically and physically for the birth. The author stated this time-lapse allows the parents to adjust, communicate and support each other. They also recommended that healthcare professionals use this time to prepare the parents for labour and meeting their stillborn child.

Meeting and remembering the 'silent child'

Robinson et al (1999) proposed that attachment to a child does not begin at birth, but a long time before; in some cases, before conception. Therefore, when a stillbirth occurs, it would be incorrect to assume that the parents have not already formulated an attachment to the child. Early writing on the psychology of maternal attachment by Winnicott (1975: 300) described the phenomenon of formulated hopes, dreams and wishes as 'primary maternal preoccupation'.

Säflund et al (2004) state that it is important to help the parents to meet, and later separate from, the stillborn baby, in order to aid an important phase of grief known as 'giving up'. Parkes (1971: 95) described this as 'an individual's awareness of his ability to cope with an actual or fantasised loss'.

In contrast, Turton (2001) and Hughes et al (2002) found a 'suggestive' relationship between seeing the stillborn baby and PTSD. However, they go on to state this link was not statistically significant.

The authors recommended that women should not be encouraged to hold their dead baby. These recommendations were based on evidence from a very small sample of 65 women, who, at the time of the study, were in a subsequent pregnancy. It could, therefore, be argued that during that time anxiety levels would naturally be higher and so the results could be challenged. Schott and Henley (2009) noted that Hughes et al (2002) stated in their report of the study that some participants did see their baby, and did not have any symptoms associated with PTSD. NICE (2007a) published guidelines based on the findings of Hughes et al (2002) and recommended that healthcare professionals do not encourage parents to see and hold their stillborn child, unless they expressively wished to do so. The RCOG (2010) also stated that 'carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed'.

Such recommendations are contrary to the findings of Samuelsson et al (2001), Rädestad et al (2007), Henley and Schott (2008a) and Downe et al (2013). Samuelsson et al (2001) reported that the majority of fathers in their study found it natural to pick up and hold their stillborn child. They were curious to explore the baby's general appearance, taking note of fingers, toes and hair; however, they commented that, if left to make decisions regarding meeting and remembering the baby alone, they may not have done so, as they did not feel able to think logically at the time.

Downe et al (2013) further corroborated this contrast in findings, reporting that the mothers in their study had a natural desire to hold their baby. They also reported a need for healthcare professionals to be more assertive suggesting that for some parents persuasion may be appropriate (Downe et al, 2013). Schott and Henley (2007) believed that this debate has led to the pendulum being swung so far in the opposite direction that choice is being taken away from parents, with health professionals' perceptions of best practice being imposed upon them instead.

Rädestad et al (2009) found the amount of staff support influenced the mother's decision whether or not to hold the baby, as did the mother's level of education. The authors also found an overall beneficial effect of holding a stillborn baby born at term (after 37 weeks' gestation). Statistics showed an increased prevalence of headaches and sleep disorders among mothers who did not hold their term stillborn baby. However, the author noted that results failed to determine any possible beneficial or adverse effects of holding a stillborn baby born at 28 to 37 weeks' gestation.

It may be interesting to apply Bowlby's (1969) attachment theory to pregnancy and consider the possibility that a later

gestation may indicate a higher level of attachment. Taking Robinson et al's (1999) theory of attachment and Parkes' (1971) theory of 'giving up' into account, it is not evident from the studies whether the women were assisted by the healthcare professionals in achieving and later giving up their bond with the baby.

It is clear from the literature that sensitive preparation is vital in ensuring that the parents are not traumatised by the visualisation of the stillbirth (Rädestad and Christoffersen, 2008). Also, in order to make decisions regarding meeting and separating from the baby, parents need support and guidance. Some parents found it useful to know what other parents had done when making these decisions.

Rädestad (2001) and Downe et al (2013) demonstrated the importance of preserving concrete tokens of remembrance. Women that had mementos – such as photos, footprints and casts – reported fewer symptoms relating to anxiety than those without tokens. In Rädestad's (2001) study, more than a third of the 314 women wished that they had more reminders of their child. This indicates the importance for staff to be proactive in obtaining good quality tokens of remembrance. A total of 94% of women had a photo of their stillborn baby. However, 16% of these were not satisfied with it. The timing of the photo was the main source of dissatisfaction, as it affected the appearance of the baby; when preparing the parents for the birth; the collection and timing of mementos could also be discussed. Downe et al (2013) stressed the importance of guidance and encouragement from staff when parents consider collecting mementos.

The authors found that ensuring good quality mementos was the anchor point for a good or bad experience. Säflund et al (2004) noted that all of the fathers in their study had tokens of remembrance and considered these items highly valuable. Data from Downe et al (2013), Säflund et al (2004) and Rädestad (2001) emphasised that information regarding parents options for spending time with their baby should be clear and given both verbally and in writing. Parents should be supported and made aware of the opportunity to take their baby home. Schott et al (2007) encouraged healthcare professionals to provide informed choice regarding meeting and remembering the baby, but to remain mindful of cultural beliefs that may influence decisions to see or collect mementos of their stillborn baby.

Recommendations

Communication skills emerged as the over-arching theme and implies that there is a need not only for continual

pre- and post-registration bereavement training, but also suggests that parents may benefit from early intervention from specialist bereavement midwives to provide continuity of care. Training in sensitive communication will also enable healthcare professionals to appropriately prepare the parents for meeting their baby (Downe, 2013; Säflund et al, 2004; Trulsson and Rädestad, 2004; Rädestad, 2001; Samuelsson et al, 2001).

Bereavement care should become a mandatory part of training with annual updates, and given the same level of importance as the need to manage an obstetric emergency, as both have the potential for equally devastating consequences if managed insensitively. The training could also incorporate other aspects of care, such as how to obtain and preserve good quality mementos, for example photographs.

Other themes were highlighted during the review process, however, due to the focus of this review they were not explored. These included exploring different cultures' experiences and rituals when faced with a stillbirth; midwives' experiences of dealing with a stillbirth; and appropriate ward environments with a recommendation of specialist bereavement suites in all units. Research exploring these areas would provide highly valuable evidence in a society of diversity and multi-ethnicity. This will also ensure that midwives are providing appropriate care that is evidence based, in line with the NMC (2015) code that regulates midwifery conduct.

Conclusion

In view of the ethical considerations surrounding the sensitive nature of the research, an adequate amount of material was available for review and provided a balanced view of the parents' experiences. Although studies are lacking from the UK, studies from countries with a comparable maternity service provision, such as Sweden, were available.

The importance of involving the father in communication and decision-making emerged as an important aspect of care. Many of the studies demonstrated a link between women's anxieties and the lack of staff education and communication skills provided to support grieving women and their families.

Effective communication is a vital skill needed during the interim period between diagnosis and birth. The need for individualised care plans for the timing of induction is also a significant factor in assisting parents through the experience of stillbirth, as was the quality of the mementos they received. Downe et al (2013: 3) talked about having 'only one chance to get it right' and highlighted the importance of guiding the parents on their journey giving the best care possible in the worst imaginable scenario.

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A critical literature review of epidural analgesia

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Abstract

Background. Increasing intervention in birth continues to be a cause for concern and epidural analgesia is an ever more common intervention. A major influence on rising intervention rates is the complex relationship society has with technology. Influenced by various political and cultural narratives, there has been a tendency to view technological advance as both neutral and superior in the human quest for progress.

Aim. In this paper, the authors trace the dialectical relationship between culture and technology in order to investigate the way epidural analgesia is portrayed in the biomedical literature.

Method. A purposeful literature search was conducted, with databases including CINAHL, MEDLINE, Scopus, Google Scholar, Academic Search Premier and thesis repositories. Relevant literature was identified and analysed using the analytic framework of critical discourse analysis and drawing on critical medical anthropology and Foucault's discourse analysis.

Findings. The biomedical literature on epidural analgesia concerned itself with particular outcomes, such as increases in CS and instrumental birth rates, and yet maintained its narrative of epidural as 'safe and effective'.

Implications. By exposing the contextual nature of knowledge, another standpoint is offered from which evidence and practice can be reviewed. This critical literature review provides an alternate reading of epidural text and challenges some of the assumptions made about epidural analgesia, and the practices that stem from these beliefs.

Key words: Childbirth, epidural analgesia, technology, Foucault, critical medical anthropology, discourse analysis, evidence-based midwifery

Introduction

The epidural is considered a 'routine' analgesic choice for healthy women in labour, and its use is increasing in Australia and other high-income nations (Walsh, 2009; Lain et al, 2008). In Australia in 2012, 32.5% of women in labour used regional analgesia for labour (Hilder et al, 2014). While epidural analgesia has substantial analgesic properties it is also associated with increased risk of adverse outcomes. Significantly, the use of epidural analgesia during birth transfers a labouring woman out of the category of 'normal' labour and increases her risk of intervention (Walsh, 2009; WHO, 1996).

This paper is a critical review of the epidural literature as it related to the doctoral research of one of the authors (EN). The research, an ethnography that examined influences on women in their decision to use epidural analgesia used critical medical anthropology as the primary theoretical framework and also drew on Foucauldian and feminist theory. These encourage examination and critique of the power relationships that serve to normalise particular behaviour through which medicine is identified as a dominant discourse (Newnham, 2014).

Foucault's description of dominant discourses (termed 'power/knowledge') includes formations of practice that, given particular social and historical conditions of existence, come to define what is known and accepted and therefore what is played out in the social world. Discourses shape social understanding and practice by imposing boundaries on what can be articulated by who, by deciding which knowledge is to be kept, which excluded and by circulating certain statements and censoring others (Foucault, 1991).

Notions of context and contingency central to the Foucauldian argument are also present in critical theory, and are drawn on here in the examination of the ubiquity and the claim to authority of the medical model of birth. This critical review of the medical research into epidural analgesia highlights the contradictions and distinctions of current ideas, delineating the way that epidural is constituted as a safe intervention in the biomedical discourse. Fundamental to the location of frameworks of power in critical research is the reflexive positioning of the researcher (Singer and Baer, 1995; Thomas, 1993).

The authors of this paper were expressly looking for other ways to think about epidural use to add to the 'epidural evidence' of biomedicine. The declaration of the epistemological position held by the researcher works in two ways: by being honest in the declaration, potential bias is laid open to discussion and critique; the researcher then seeks to examine the data in a way that is framed by their position, but not held to it. There is a promise that by revealing their position, in being epistemologically transparent, data are not plied to say one thing or another.

Method

Literature relating to epidural analgesia, labour and childbirth, technology and relevant critical theory were accessed from databases including CINAHL, MEDLINE, Scopus, Google Scholar, Academic Search Premier and thesis repositories. Reference lists of relevant books, theses and articles were read and further literature identified. The critical literature review presented here forms the first part

of a broader critical discourse analysis of epidural analgesia, using Fairclough's (1995) critical discourse analysis (CDA) methodology. In keeping with Foucauldian ideas of 'power/knowledge', CDA accepts that 'hegemony is constituted in the discursive practices of institutions' (Fairclough, 1995: 91). Outlining his theory of three-dimensional CDA, Fairclough identifies the importance of linking the macro-discourse of state and policy to the discursive practices identified at the micro-level through the use of three levels of analysis: wider social understanding, the properties of the texts themselves, and how the texts are produced and consumed (Fairclough, 1995). Working with these three levels of discourse, the first level – the broader medical and social understandings of epidural – is unpacked in this critical literature review. This provides the background for the two remaining levels of three-dimensional CDA. The discursive properties of the texts themselves were explored in an analysis of the language of risk and safety within hospital and policy documents (Newnham et al, 2015). The third level – the production and consumption of text and the effect of discourse on individual experience – is where discourse intersects with the lives of women, including the information they receive and the choices they are able to make. According to Fairclough (1995), the inclusion of all three aspects of discourse is necessary for comprehensive analysis. Without the broader context (in this case, medical constitution of epidural knowledge), the micro-experience cannot be made sense of, or is perhaps left unquestioned.

From this perspective, this paper first examines the influence of the 'evidence-based medicine' discourse and how it affects the way in which particular knowledge is produced. It then examines the significant epidural literature in the medical field, specifically primary research and systematic reviews. Employing the chosen theory, a critical 'reading' of this literature is provided identifying the role of technological rationalism and the impact of these dominant discourses on epidural and birth knowledge.

Findings

Questioning epidural analgesia

From an anaesthetic risk perspective, improvements in drug dosage and administration have made epidurals relatively safe and they are particularly useful in situations where caesarean section (CS) is necessary, enabling women to remain conscious and decreasing risk for mothers and babies by avoiding general anaesthetic. Yet intervention in labour, including the use of epidural, can dramatically change the birth outcome for otherwise low-risk women (Tracy et al, 2007). Despite this, biomedical research on epidural use in labour perpetuates a discourse of the 'safety' of the epidural, even while examining its negative consequences. This perpetuation of epidural safety in medical discourse, despite its effect on birth outcomes calls for a closer investigation of epidural knowledge and practice.

The prominence of medically-focused research perpetuates one particular kind of knowledge about epidural analgesia resulting in the acceptance of this technology as a 'common

sense' option in Western birth culture (Downe and McCourt, 2008; Wendland, 2007). As a result other options for birth are marginalised by their absence in the literature and the resulting lack of alternatives. While judicious use of epidural analgesia may be beneficial in particular situations, its use as a common analgesic option requires closer examination.

Evidence based: biomedicine as a dominant discourse

One of the main claims by biomedicine over other knowledge disciplines is its unbiased truth and rationality. Although useful in providing measurable evidence, the claim by science to a lack of bias is contested as scientific knowledge is embedded within a historical context influenced by economic and social structures. Evidence-based medicine with the randomised controlled trial (RCT) at its pinnacle, is problematic because although evidence-based principles have their place and have been particularly useful in removing questionable practices in midwifery and obstetrics, they also pose a potential dilemma (Walsh, 2012; Johnson, 1997). Privileging the RCT over other research methods can flaw trial design by prompting researchers to fit projects into an RCT design, also affecting the kinds of questions being researched (Steen and Kingdon, 2008; Kotaska, 2004; Keirse, 2002). Murphy-Lawless (1998: 14) expresses this dilemma as 'what is measured is often meaningless but without measurement there is no science'. Insofar as they mediate which questions are being asked, the RCT – and other scientific methods – are biased in that they derive from a worldview that privileges one kind of knowledge over other forms (Roome et al, 2015).

Much mainstream research – with its assumptions about knowledge, empiricism and medical authority – serves to embed particular worldviews, for example, of women's bodies as uncertain, of technology as safe, or of the doctor as rescuer. With these ideas promulgated in the collective understanding comes a concomitant normalisation of the safety of intervention. Conversely, normal physiology labelled as unpredictable, becomes risky. As these ideas become entrenched into practice they circulate the power/knowledge of medical birth discourse (Newnham et al, 2015; Foucault, 1980), to which the authors now turn in the context of epidural research.

Epidural analgesia: exploring the evidence

The physiological problems associated with epidural use in labour that can lead to birth intervention include: altered uterine activity (either increased or decreased); labour dystocia (thought to be due to relaxation of pelvic floor and malrotation of the fetal presenting part) slower dilatation of the cervix; decreased oxytocin release by the pituitary gland and subsequent need for oxytocin augmentation; and decreased maternal bearing down efforts due to motor block (Gaiser, 2005; Jain et al, 2003; Finster and Santos, 1998).

However, research into epidural use has been conflicting, with early research showing high rates of instrumental and CS births associated with epidural use. One extensive review of epidural research identified how the relationship

between epidurals and CS found in previous decades has since been attributed to the denser motor block of those early epidurals (Gaiser, 2005). Research looking at the effects of newer, low-dose epidurals has found a strong causal relationship between epidural and instrumental deliveries, and motor weakness remains considerable, even with low-dose techniques (Jain et al, 2003). Additionally, studies are still identifying a relationship between epidural analgesia and CS (Ros et al, 2007; Tracy et al, 2007; Kotaska et al, 2006). However, as no causal link has been isolated, it is possible that epidural use and CS are outcomes from an as yet unknown common cause. One of the difficulties with epidural research is distinguishing the reverse causality between the need for epidural and the presence of a pre-existing labour dystocia (Gaiser, 2005). The most recent Cochrane systematic review, which compared epidural to non-epidural or no analgesia in labour, noted the conflicting findings of previous research about whether or not epidural analgesia increased the risk of CS and concluded that while epidural use does not increase the overall risk of CS, it does increase the risk of instrumental birth by 40% (Anim-Somuah et al, 2011).

Identification of any causal relationship is challenging because epidural analgesia is not a sole intervention but brings with it numerous other interventions such as intravenous fluid administration, electronic fetal monitoring (EFM) and labour augmentation, making it difficult to extrapolate any particular influence. For instance, two studies looking at the difference in birth outcomes when inserting epidural analgesia early or late in labour showed no difference in instrumental delivery rates. What they did identify was a positive correlation between intravenous oxytocin and the CS rate (Wang et al, 2009; Chestnut et al, 1998). If epidural analgesia necessitates exogenous oxytocin use and oxytocin use increases the risk of CS then epidural analgesia is going to influence, if not directly cause, this outcome. Similarly, EFM has been shown to increase CS rates (Alfirevic et al, 2013; Devane et al, 2012). Also confounding attempts at correctly ascertaining the effects of epidural analgesia have been 'natural experiment' studies whereby changes in policy or accessibility that either increase or reduce epidural rates have not resulted in a corresponding relationship in numbers of instrumental birth (Gaiser, 2005). Gaiser (2005) stated that with the new research demonstrating the effectiveness (or at least diminishing the connection between epidural and CS) of new epidural techniques, obstetricians declared that epidural analgesia should be accessible to all women unless medically contraindicated.

Despite this optimism, more recent studies have confounded the existing evidence. The Comparative Obstetric Mobile Epidural Trial (COMET) (Cooper et al, 2010) compared two types of low-dose with traditional (high-dose) epidural. A no-epidural comparison control group was matched for mode of delivery. The authors stated: 'The mode of delivery and numbers recruited to each group illustrate the previously reported findings of an increase in spontaneous vaginal delivery with both mobile techniques and the expected higher number of spontaneous

vaginal deliveries and fewer operative deliveries, especially by CS, in the comparison group' (Cooper et al, 2010: 32). So, while some researchers are declaring an impasse in relation to epidural research and a green light for routine epidural use, these authors were expecting higher rates of instrumental and CS delivery in their epidural groups. The figures demonstrate this with the spontaneous vaginal birth (SVB) rate in the no-epidural group (approximately 75%) double that of the SVB rate in the high-dose epidural group (approximately 35%) and still much higher than in both of the low-dose groups (both approximately 43%). Conversely, all three epidural groups had rates of CS nearing 30%, while the no-epidural group had a 9% rate. Instrumental births were around 40% in the high-dose group, 30% in the low-dose groups and 15% in the no-epidural group. An Australian population-based descriptive study also showed a three-fold increase in CS rates with epidural alone, as well as when used in combination with oxytocin (Tracy et al, 2007). A survey conducted in the US found that of 750 first-time mothers with term pregnancies, 47% were induced and of those having an induction, 78% had an epidural and of mothers who had both attempted induction and an epidural, the unplanned CS rate was 31%. Those who experienced either labour induction or an epidural but not both, had CS rates of 19% to 20%. For those first-time mothers who neither experienced attempted induction nor epidural, the unplanned CS section rate was 5% (Declercq et al, 2013). While one cannot infer causality in this study, these practices contribute to the 'cascade of intervention' that can lead to CS.

A small number of studies call for caution with regard to epidural analgesia, and suggest solutions, such as restricting use (Hemminki and Gissler, 1996), the need for further research (Nystedt et al, 2004), and the provision of comprehensive informed consent about the risks (Kotaska et al, 2006). It is concerning that there is only minimal reference in the literature to the fact that maternal oxytocin production is inhibited by epidural use (Gaiser, 2005; Rahm et al, 2002). As well as contributing to the need for exogenous oxytocin, reduced endogenous oxytocin may be the causative factor in reduced breast-seeking behaviour in the newborn and reduced breastfeeding rates in women who have had an epidural (Wiklund et al, 2009). Although the reduced effects of endogenous oxytocin with epidural analgesia, as well as the detrimental effects of exogenous oxytocin are now recognised there is a lack of robust research in this area (Buckley, 2015; Foureur, 2008; Uvnäs Moberg, 2003).

Although there were efforts to decrease problems that are associated with epidural use such as: ceasing the epidural when the woman is 8cm dilated, decreasing the amount of local anaesthetic used in order to decrease motor block while still maintaining sensory block, allowing a longer second stage for women using epidural analgesia and waiting for descent of the presenting part before beginning active pushing (Gaiser, 2005; Finster and Santos, 1998), the early findings of increased CS and instrumental birth rates did not lead to a concerted effort by the medical community to avoid

epidural analgesia altogether. The increasing popularity of epidural analgesia, despite unfavourable research results, can be explained in part by the continuing discourse of 'safe and efficacious pain relief' (Drysdale and Muir, 2002: 99). Clearly the high CS and instrumental birth rates were cause for concern. But rather than discontinuing epidural use – as happened so rapidly, for example, with the discontinuation of vaginal breech birth after the term breech trial (Downe and McCourt, 2008; Steen and Kingdon, 2008) – research continued for some decades. Not simply because epidural is an effective analgesic agent, but, this paper proposes, because epidural use, instrumental birth and CS fit within a medical discourse that favours control, technology and intervention (Walsh, 2009).

Moreover, it appears that the consequences of epidural analgesia were also ignored because they affected women's experience, rather than measurable medical outcomes. Therefore, while instrumental delivery appears as a consequence of epidural analgesia in the biomedical literature, the consequences of instrumental birth for women, and their future health and wellbeing are not discussed (Sharma et al, 2004). With the exception of one study (Cooper et al, 2010) which looks at satisfaction rates, instrumental birth as an outcome is largely dismissed and there is a tacit assumption that increased obstetric intervention is an acceptable risk factor. However, for women, instrumental birth may not be an acceptable risk factor. Both instrumental birth and coached pushing, rates of which are increased with epidural analgesia, increase the likelihood of third- and fourth-degree tears. The sequelae of this severe perineal trauma can include pain, fear of birth, incontinence, sexual dysfunction, post-traumatic stress disorder and depression (Rådestad et al, 2008; Hayman, 2005; Creedy, 1999). These outcomes, and their corollaries, indicate that instrumental birth rates need to be a serious consideration in the epidural analgesia debate.

After 40 years of medical research into the risks of epidural analgesia, there are still no definitive findings about its effect on childbirth (Toledo et al, 2009; Gaiser, 2005; Jain et al, 2003), although it is likely that it does increase instrumental birth rates (Anim-Somuah et al, 2011). The only outcome that is clearly upheld throughout current research is that, despite the still unproven effects of epidural analgesia on labour, it provides the most effective analgesia (Cooper et al, 2010; Wang et al, 2009; Jain et al, 2003). A discussion of the safety and effectiveness of epidural analgesia prefaces the majority of the research articles and epidural analgesia is cited as the 'gold standard for analgesia in labour' (Norman, 2002: 28). This emphasis on the relief of pain at any cost is indicative of what is important to biomedical culture, which both influences and reflects wider cultural norms.

A critical reading of the evidence

'The influence of the ideology of technology becomes most clear when medicine is on the scene... things that can be quantified are made real; those that cannot be quantified come to seem unreal. Infection rates are an observable measure for childbirth; joy is not' (Rothman, 1989: 86).

Biomedicine continues to implement practices based on technology and intervention by upholding a fairly circumscribed research agenda. In disseminating particular kinds of data in specific ways there are things that are not identified; that are left silent. These include maternal subjectivity, consequences for the mother-newborn dyad, and long-term health outcomes (Wendland, 2007). In effect, by their lack of representation in the data, biomedical research reproduces underlying Western cultural values by minimising the importance of women's experiences and implementing simplistic, mechanistic answers to complex problems. Ramin et al (1995: 788) comment that 'pain relief during labour is of paramount importance and in most circumstances the two-to four-fold increased risk of CS delivery associated with epidural analgesia is a secondary consideration'. This illustrates the medical perspective of the 'abnormality' of labour pain and the priority to alleviate it and normalises technological intervention such as CS, while ignoring its significant risks. It also focuses on the pain of the physiological event, while ignoring the pain caused by the intervention. It is unlikely that CS is a secondary consideration for women. Pain in labour is complex and when women have been asked, labour pain (and its relief) is not necessarily of paramount importance (Karlsdottir et al, 2014; Leap and Anderson, 2008), so from many women's perspective the opposite is the case. In rejecting women's experiences as important data, research in this field can fail to include interventions that seem insignificant to medicine, but may be highly significant to women (Baker et al, 2005).

Compared to biomedical research, there are fewer studies concerned with women's experiences of birth, although research of this nature is increasing. Not discounting the importance of medical research, comparing the two does generate a clear picture of what is seen as important (van der Gucht and Lewis, 2015), and this appears to be the advancement of technology and medicine rather than the experience of women and protecting birth from unnecessary technological intervention. Indeed, evidence that supports non-technological practices is not easily implemented, while technologically-focused evidence is often taken up instantaneously (Romano and Lothian, 2008). What this shows is that although 'evidence-based' medicine can have a positive impact, it is not a paragon of unbiased universal answers, but is subject to, and replicates, powerful social discourses such as scientific and technological rationalism.

Rationalising technology

There is a common point of view that holds technology to be politically neutral, ahistorical and autonomous with little human control or direction except in the luck or genius of those who can discover its secrets (Hill, 1988). Termed 'technological determinism', this viewpoint has been criticised for failing to acknowledge the social, historical and economic influences on the construction of scientific knowledge. Critics of the technological determinist position call for scrutiny of the underlying assumptions of technology use. Some decades ago, Marcuse observed that

'in the contemporary period, the technological controls appear to be the very embodiment of reason for the benefit of all social groups and interests – to such an extent that all contradiction seems irrational and all counteraction impossible' (Marcuse, 1972: 22).

Technological determinism depends on the perpetuation of ideas that suggest all progress is the embodiment of reason, a position of techno-rationalism. Progress is positioned as a moral good within society. Arguments that critique progress are therefore defined, by their juxtaposition to the 'rationality' of advancement, as unreasonable and irrational (Blackwell and Seabrook, 1993). This argument is reflected in the 'pain relief as progress' theme in the epidural literature. Crowhurst and Plaat (2000) say labour analgesia is a part of the modern Western lifestyle, along with 'air travel, the mobile phone and the personal computer', implying that any other choice is irrational and archaic. They state: 'The greatest advances in analgesia and anesthesia for labour and childbirth in the 20th century have been (1) the discovery and development of today's safe and efficacious analgesic techniques; (2) the social acceptance that it is unnecessary for parturients "to bring forth children in pain and sorrow"' (Crowhurst and Plaat, 2000: 164).

The reverse of this argument is that anyone who wants to argue the merits of pain is relegated to a regressive paradigm of anti-progress. The implicit assumption of the 'pain relief as progress' theme is that not wanting to relieve the pain of childbirth must be absurd. However, as Leap and Anderson (2008) suggest, there are positive and purposeful aspects to labour pain: it summons support, heightens joy, reinforces triumph and triggers neurohormonal cascades. Pain in labour is not a simple or reducible medical problem. However, the relief of pain in labour is an ongoing concern of biomedicine, particularly within anaesthetics and has even been described as a 'human right' (Cohen, 1999: 224).

Problematically – and noted by midwives from the time of their introduction – medical technologies can interfere with the process of being present at labour; that commitment to women's embodied experience that midwifery philosophy upholds (Leap, 2000). Low-tech interventions, such as continuous support during labour, can decrease women's need for analgesia, as well as operative birth rates (Hodnett et al, 2013). This more traditional midwifery practice of providing physical and emotional labour support contributes to a shared embodied experience. Some women and midwives expect and put their faith in the use of technology (Sinclair, 2011; Sinclair and Gardner, 2001) and, in some cases, it is both useful and necessary. However, reliance on technologies establishes the indirect surveillance of disembodied processes that neglects the historic embodied relationship between the woman and midwife (Sandelowski, 2002; 1998; Barger-Lux and Heaney, 1986). Knowledge and practice that support the normal process of birth and women's embodied experiences are typically not supported in medical birth settings. The positioning of obstetrics with 'technology' provides access to dominant techno-rational norms of science and safety, and allows the perpetuation of technologically-oriented

practices that are not clearly evidence based over simpler, low-tech midwifery practices that can reduce childbirth intervention rates.

Despite the lack of conclusive evidence, the salient assertions in the biomedical epidural literature are that epidural analgesia is essentially safe, should be available for all women and is a 'human right'. Underlying this is the unease about epidural outcomes and there are constant recommendations that research needs to focus on improving these by varying the doses and/or drugs used.

Challenging paradigms

The 'pain relief as progress' discourse in the epidural literature forms part of what Leap and Anderson (2008: 38) have termed the 'pain relief paradigm', whereby midwives who have internalised the techno-rational assumptions outlined above perpetuate a belief that women cannot endure the pain of birth. These authors recommend that midwives examine their own beliefs about pain and if possible adopt a 'working with pain' approach, which accepts pain as a normal part of the birth process (Leap and Anderson, 2008), and this support can actually reduce women's desire for analgesia (Romano and Lothian, 2008; Walsh et al, 2008). Pain is also viewed positively by some women as a rite of passage that brings a sense of pride and accomplishment (van der Gucht and Lewis, 2015; Karlsdottir et al, 2014; Lundgren and Dahlberg, 1998).

Satisfaction with the birth experience is not necessarily related to pain relief, and is complex and multi-faceted (Hodnett, 2002; Kannan et al, 2001; Lundgren and Dahlberg, 1998), illustrated by the fact that some women who have had an epidural express less satisfaction with the birth process than those who have not had one (Waldenström et al, 2004). It has been suggested that the need for an epidural in labour may not be related to actual levels of pain, but to a woman's pre-existing 'birth ideology' (Heinze and Sleigh, 2003: 330). It has also been proposed that increasing uptake of epidural analgesia could be due more to unsupportive and fragmented maternity care than actual pain relief requirements (Walsh, 2009). From this perspective, epidural analgesia is not so much a 'human right' and 'rescuer of women in pain' as a potentially unnecessary intervention: one that is not well-explained, does not always alleviate women's 'suffering' in labour, and might actually decrease women's joy in the birth process.

Conclusion

Epidural analgesia has been promoted as safe, efficacious and necessary, by the biomedical literature, while demarcating its potential negative side-effects. The problem with wholesale acceptance of 'evidence-based' scientific research is the lack of transparency of its own philosophical premises. Dominant ideologies, such as technological rationalism, are renegotiated and perpetuated as if they represent a universalised reality. Most women will have been exposed to these social discourses of pain and epidural use and may not have been exposed to knowledge that

challenges this paradigm. However, in light of the ongoing uncertainty about research findings, there needs to be a robust and informed debate about the appropriate use of epidural analgesia in low-risk labour.

This critical analysis of the discourse surrounding epidural analgesia has explored some of the ways in which medical, scientific and technological discourses have influenced Western birth practices in relation to the production of information about epidural analgesia. It adds to the growing knowledge base about social contexts of birth, and delineates the way in which dominant ideas about

pain/relief are perpetuated. Childbearing women have to negotiate increasing amounts of information from various sources, are faced with obstetric practices that may not be evidence based, or be denied midwifery practices which are. Midwives and others interested in the wellbeing of birthing women need to have an understanding of how various discourses – such as the biomedical epidural discourse – are sustained, as well as an awareness of alternate perspectives in order to fulfil the midwifery responsibility to provide advocacy, information sharing, and to work in partnership with women.

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Sensitivity and specificity of electronic databases: the example of searching for evidence on child protection issues related to pregnant women

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Abstract

Background. There are increasing demands on health and social care (HSC) professionals to make decisions based on best evidence to inform their practice. To do this, they must be skilled in searching the literature. A robust approach to literature reviewing that results in optimal outcomes is highly desirable in a climate where time and resources are limited.

Aim. This paper explores the processes of undertaking a structured literature search and measuring the effectiveness of five commonly used health and social care databases.

Method. A review question was posed using the qualitative version of PICO (Population, Interest, Context and Outcome): 'How do HSC professionals (P) make decisions (I) in relation to pregnant women (C) where there is a safeguarding concern (O) regarding an unborn child?' Databases selected for review were: ASSIA, CINAHL Plus, Ovid MEDLINE, PsycINFO and Social Care Online. Searches were undertaken from October 2014 to April 2015. A rapid update was undertaken in March 2016 prior to publication. Papers were screened for their suitability for inclusion using a screening tool developed by the research team. Papers were required to report empirical research; to have been published in peer-reviewed journals, as an indicator of a measure of quality; and to be available in the English language. Full-text papers were chosen if the data were gathered from or about decision-making regarding safeguarding in pregnancy by midwives, nurses, social workers and professional managers. The quality of the chosen databases was determined by sensitivity (capacity to retrieve a satisfactory number of papers), precision (to prevent the retrieval of too many irrelevant papers) and Number Needed to Read (NNR) – number of papers needed to read to find one paper to include.

Results. A total of 866 papers were identified, titles and abstracts were reviewed by the researcher and full-text papers were further reviewed by the research team, both using a screening tool. These results were discussed and nine papers were identified for review. Sensitivity was greatest on CINAHL Plus and Ovid MEDLINE. Precision scores were generally low; CINAHL Plus scored the highest at 4%. CINAHL Plus was found to be most effective with an NNR score of 26%, followed by PsycINFO with an NNR score of 36% and Ovid MEDLINE was the lowest precision with an NNR score of 45%.

Implications. The challenges of robust searching for literature indicate that if evidence-based practice is to become a reality, regular training for midwives, social workers and other healthcare professionals in database searching is essential

Key words: Search methodology, systematic literature searching, sensitivity and precision, decision-making, child safeguarding, pregnancy, evidence-based midwifery

Introduction

This paper discusses the methodology for searching the literature to retrieve papers using an example of professional decision-making around child safeguarding in pregnancy. It specifically focuses on sensitivity and precision measures of database quality, appropriateness and effectiveness of the search strategy and its ability to be replicated by future researchers in this area of study (Taylor et al, 2007). With the increasing demand on midwives and social workers to make decisions based more explicitly on best evidence, effective and efficient strategies need to be available to facilitate access to online resources for research (Beall, 2007).

Background

Service provision is grounded in a solid foundation of evidence-based practice. The term 'evidence-based practice'

indicates the quality, robustness or validity of evidence and is applied to current issues within the health service (Hoagwood et al, 2001). The importance of combining clinical and research knowledge is imperative in professional decision-making in order to deliver effective services or indeed improve current service provision (McCullough et al, 2014) as many research questions emerge from clinical practice issues (Polit and Tatano Beck, 2014).

There is growing demand on those in the health and social care (HSC) professions to further develop their skills in collating, synthesising and critiquing information for the advancement of their profession and for use within clinical practice (Rees, 2011). There is increasing pressure from government, taxpayers and managers of HSC services for evidence of money well spent and efficient delivery of services (Taylor and Campbell, 2011). Both the code (NMC, 2015)

for midwives and nurses and the code of ethics for social work (BASW, 2012) for social workers make it clear that professionals are responsible for maintaining and improving their knowledge, skills and practice and must act with the best evidence possible at that time. Therefore, there is an assumption that all professionals should learn core skills, such as literature searching of databases, and regularly update their knowledge in this area.

In the process of undertaking scientifically robust research, careful consideration must be given to analysing the evidence that exists within the literature. A systematic approach to literature searching has the potential to provide robust data and this evidence will subsequently inform clinical practice (Taylor et al, 2007). This approach must be undertaken in an unambiguous, transparent and replicable manner, beginning with a comprehensive literature search strategy (Arthur et al, 2012). Careful scrutiny of the literature will aid in the identification of the body of knowledge that currently exists on a topic and also highlight the gaps where further investigation is needed (Ford and Pearce, 2010).

However, the enormity of this task should not be underestimated. The advancement of technology has seen a move away from the use of traditional print journals towards journals based on electronic bibliographic databases that are accessible online (Best et al, 2014). Ironically, accessibility of journals may be improved through their availability online but the process of identifying and wading through material can be time consuming, and a daunting task (Rowley and Johnson, 2013). This requires a skilled researcher, librarian or search coordinator with a carefully designed search strategy and the ability to identify the relevant papers from those that are irrelevant (Creaser et al, 2006).

Method

Data sources

In consultation with a subject librarian at the university, five electronic databases (ASSIA, CINAHL Plus, Ovid MEDLINE, PsycINFO and Social Care Online) were accessed for the purpose of this study. All databases provide abstracts of journal papers to professions including midwifery/nursing and social work, academia and managers and were deemed appropriate for use with this study topic. CINAHL Plus, Ovid MEDLINE and PsycINFO use individualised controlled vocabulary thesaurus for indexing papers. CINAHL Plus (subject headings which are adapted from Medical Subject Headings (MeSH), Ovid MEDLINE (MeSH) and PsycINFO (American Psychological Association (APA) thesaurus of Psychological Index Terms).

ASSIA and Social Care Online use phrase searching and are aimed at those in social science. Nevertheless, using a wide variety of databases ensures a comprehensive search across both professions (Finfgeld-Connett and Johnson, 2013). To compete with HSC professionals' time demands, it is crucial that a search undertaken in these databases produces relevant papers in a replicable approach. Good sensitivity (retrieving a high number of relevant papers from a database) and good precision (low number of irrelevant papers retrieved) scores depend upon the

researcher's ability to design an effective search strategy, the effectiveness of the indexing against the thesaurus, the number of journals abstracted and how well the database supports the searchers in their searching (Taylor et al, 2007). High sensitivity and precision scores are indicative of an effective search strategy which emphasises the importance of securing this from the outset (Lee et al, 2012).

The majority of journal papers, PhD theses and research reports rest on a foundation of a solid review undertaken of previous literature to ascertain gaps in knowledge that also informs evidence-based practice within the HSC setting (Taylor et al, 2007). The Cochrane and Campbell Collaboration reviews focus on questions of effectiveness and mainly on research designs that are experimental in nature. However, different types of research questions, similar to this study on decision-making, require different study designs. The methodology and systems for identifying studies, appraising quality and synthesis are not as well developed as they are for questions of effectiveness. This paper hopes to complement existing knowledge by adding an additional layer of scrutiny to the process, which includes sensitivity and precision measurements of databases.

Search question

Prior to choosing appropriate databases, it is important to have a clear review question using the PICO framework. This framework is used to structure clinical questions for systematic review and to increase the likelihood of retrieving papers which are relevant to the question (Schartdt et al, 2007). There are two versions of PICO, depending upon whether the search is for qualitative or quantitative reviews. Searching for quantitative studies uses the Patient, Intervention, Comparison and Outcome (PICO) version. However, the qualitative version, Population, Interest, Context and Outcome (PICO) was used to frame the search question for this paper (Lewensen and Truglio-Londrigan, 2015). Consequently, the question was framed as 'How do HSC professionals (P) make decisions (I) in relation to pregnant women (C) where there is a safeguarding concern (O) regarding an unborn child?'

Inclusion criteria for search

This paper focuses on the rigour of the searching process but does not include the synthesis of literature to create a systematic narrative review on the search question posed. Predetermined criteria were established for the purpose of this. Papers retrieved from this search were screened for their suitability for inclusion using a screening tool developed by the research team. Papers were required to report empirical research; to have been published in peer-reviewed journals as an indicator of a measure of quality (Best et al, 2014); and to be available in the English language. Full-text papers were chosen if the data were gathered from or about decision-making regarding safeguarding in pregnancy by midwives, nurses, social workers and professional managers. Papers focusing on the risk factors identified by professionals' child safeguarding in pregnancy were excluded. In addition, papers

that focused on assessment tools used in practice to assess the risk of harm to an unborn child were also excluded.

Selection of databases

In the process of systematically identifying and retrieving literature, it is recommended that more than one database should be used to ensure a comprehensive and rigorous search process (Whiting et al, 2008). Five academic and professional databases were chosen in consultation with an experienced subject librarian for use within this review. Applied Social Sciences and Abstracts (ASSIA), Cumulative Index of Nursing and Allied Health Literature (CINAHL) Plus, Ovid MEDLINE, PsycINFO and Social Care Online. These databases were selected based on their availability at the university and their suitability to capture the relevant subject fields as indexing of papers varies between databases. Papers retrieved from CINAHL Plus, PsycINFO and Ovid MEDLINE are indexed using either Medical Subject Headings (MeSH), an adaptation of MEDLINE (MeSH) or APA Thesaurus of Psychological Index Terms. However, searches within ASSIA and Social Care Online, which do not have an indexing system, relied heavily upon retrieving papers through the use of relevant phrase searching. All these databases are large interdisciplinary international databases, available in both the UK and the US. CINAHL Plus, Ovid MEDLINE and PsycINFO include papers from the professions of psychology, nursing and medicine and ASSIA and Social Care Online (provided by the Social Care Institute for Excellence) include papers from social care and social work. A piloting exercise to test and refine the search formula was undertaken which revealed sufficient numbers of papers were available.

Search formulae and filters

The use of Boolean operators within the search forms relationships between concepts or words for the purpose of establishing search parameters (Best et al, 2014). The most frequently used Boolean operators are AND (used between terms to capture papers containing both terms), OR (used to retrieve papers using either term) and NOT (to narrow or refine a search) (Houser, 2012). The search formula used for CINAHL Plus, Ovid MEDLINE and PsycINFO is shown in Figure 1. The use of truncation facilitated the retrieval of papers using singular and plural words with different endings (Reznowski, 2011).

For the purpose of this review, truncation was used on several terms including midwi* which returned words such as midwives, midwife and midwifery. Proximity operators, which vary through the databases but are generally represented using N for Near or adjn for adjacent were used to search for terms within a specific number of words from each other, for example, significant N1 harm and was used in CINAHL Plus, Ovid MEDLINE and PsycINFO to retrieve a paper which contains the term 'significant' within one word of 'harm' (Dresch et al, 2015).

The search formula was adapted for use on the databases, but notably on ASSIA and Social Care Online as searches were undertaken using phrase searching such as 'child protection' OR 'child abuse' OR 'child neglect' OR 'child

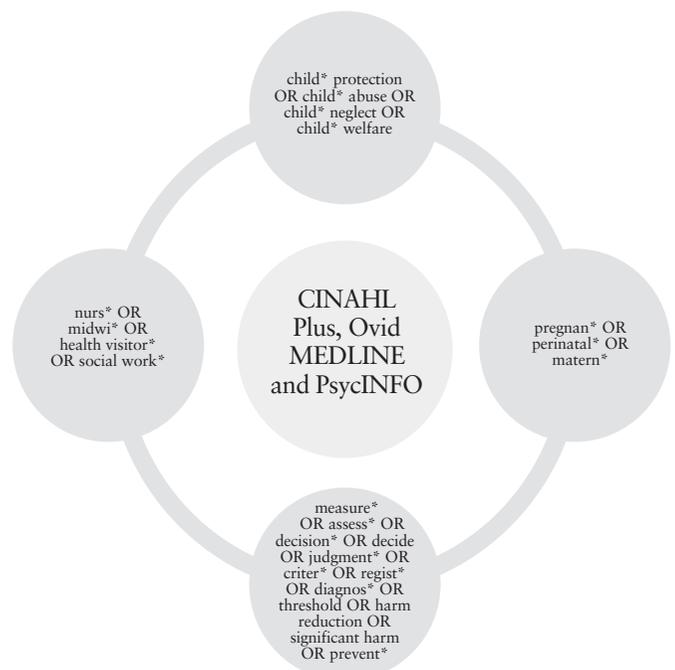
welfare AND nurs* OR midwi*' OR 'health visitor*' OR 'social work*' AND pregnan* OR perinat* OR matern* OR fetus OR foetus OR 'unborn child*' AND measure* OR assess* OR decision* OR decide OR judgement* OR criter* OR regist* OR diagnos* OR threshold OR 'harm reduction' OR 'significant harm' OR prevent. Search filters were applied to narrow the number of papers retrieved to include those papers available in the English language only and exclude books to narrow the search strategy (Schneider et al, 2013).

Sensitivity and precision

Determining the quality of a database can be measured by its capacity to retrieve a satisfactory number of published papers available on the study topic (McFadden et al, 2012). The capacity of the database to do this is generally measured in terms of sensitivity. Sensitivity is calculated by identifying the number of relevant papers retrieved by a database, which is then divided by the total number of relevant papers identified by all searches (Watson and Richardson, 1999). However, adding more terms to a particular search makes it more sensitive, resulting in the retrieval of papers that are less relevant to the study question (Taylor et al, 2007). Consequently, a second measure of quality is necessary to prevent retrieving too many irrelevant papers, as this would involve a lengthy task of elimination.

Therefore, a calculation of precision was undertaken to determine the number of relevant articles identified by a search (Taylor et al, 2007) using the formulae of relevant number of database hits divided by the total number of database hits (Taylor et al, 2003). Number Needed to Read (NNR) is a further measurement of precision of databases (Best et al, 2014). This measurement indicates the number

Figure 1. Search formula CINAHL Plus, Ovid MEDLINE and PsycINFO (all circles are linked with the operator AND)



of papers that must be read in order to find one paper for inclusion (Terwee et al, 2009). Calculating NNR involved dividing the total number of hits retrieved by the total number of included studies on a database (Golder et al, 2008). Therefore, a low NNR score measured on a database is an indication of high quality.

Identifying unique hits

Within the retrieved searches, unique hits were identified – that is a relevant paper sourced from one database only. This process was undertaken using a method of identifying the database(s) in which each of the final nine papers for review were located. The papers were then listed in chronological order indicating the databases from which they were retrieved.

Results

A systematic search of the databases retrieved 866 papers. Titles and abstracts were reviewed by the researcher using a screening tool. A smaller number of papers were reviewed by the research team and nine papers were identified for review.

Unique hits retrieved

Of the five databases, only two returned unique hits (Table 1). The search on Ovid MEDLINE returned the largest number of unique hits retrieved (three papers) and CINAHL Plus returned one unique paper. ASSIA, PsycINFO and Social Care Online did not return any unique papers in this search.

Sensitivity and precision

The ability of each database to retrieve relevant items was measured producing sensitivity scores. CINAHL Plus (36%) recorded the highest sensitivity, followed by Ovid MEDLINE (28%) and PsycINFO (14%). ASSIA and Social Care Online both scored 0% indicating that they were ineffective for use within this study and retrieved no relevant items. In general, precision scores between all databases were extremely low. CINAHL Plus had the highest precision score (4%) of all the databases indicating that it was the most effective database at avoiding retrieving irrelevant papers. However, PsycINFO had a marginally lower precision score (3%) and Ovid MEDLINE had a precision score of 2%. ASSIA, Social Care Online and the hand search had poor precision scoring

Table 1. Number Needed to Read (NNR) and unique hits

Databases	Total hits retrieved	Relevant hits retrieved	NNR	Unique hits	Sensitivity %	Precision %
ASSIA	45	0	–	0*	0	0
CINAHL Plus	267	10	26	1*	36	4
Ovid MEDLINE	361	8	45	3*	28	2
PsycINFO	144	4	36	0*	14	3
Social Care Online	43	0	–	0*	0	0
Hand search	6	6				
Total	866	28*				

Number asterisked () include total number of hits after duplicates removed*

between 0% and 1%. The NNR scores are a measure of how many papers need to be read to retrieve one relevant hit on each database. CINAHL Plus was found to be most effective with a NNR score of 26%, followed by PsycINFO with a NNR score of 36% and Ovid MEDLINE was the weakest database with an NNR score of 45%. No relevant hits were found in either ASSIA or Social Care Online.

Methodology of retrieved papers

The relevant papers retrieved comprised of qualitative studies (using semi-structured interviews, 11%), surveys (22.4%), mixed methods, including both qualitative and quantitative methods (questionnaires, interviews and focus groups, 33.3%), and quantitative (surveys, 33.3%).

Discussion

Summary of approach

The systematic retrieval of papers from databases is an important aspect of evidence-based practice (Taylor et al, 2007). Consequently, it is essential that identification of relevant databases and accurate search formulae and filters are applied from inception. The development of a sophisticated search formula was key to the retrieval of relevant papers (Best et al, 2014). A search question was established, a screening tool developed to determine inclusion/exclusion of papers, the search strategy piloted to determine the appropriateness and effectiveness of search terms and modified when necessary. The database searches were methodical and the initial search was repeated to ensure it was up to date (Ramlal, 2010). A preliminary search of the databases provided a good indication of the relevant information available and the correct search terms to be used.

Effectiveness of the databases

The study topic of child safeguarding in pregnancy from the perspective of decisions made by social work and midwifery staff indicated that databases had to be chosen which encompassed research from both professional groups. In general, the databases for social sciences were more difficult to navigate than those aimed at professionals in healthcare fields. This may be due to the variation in terminology internationally and also due to the facilities on the databases (McFadden et al, 2012). It could be assumed that the databases predominately aimed at those in social sciences – ASSIA and Social Care Online, in this instance – would generate most of the relevant papers.

However, this study showed the contrary, as no relevant hits were identified on either database. It could be argued that social science databases, ASSIA and Social Care Online are less effective than their counterparts – Ovid MEDLINE, PsycINFO and CINAHL Plus – possibly due to inconsistency in language, as identifying papers depends upon how well they are indexed within databases. The latter three databases are aimed at the nursing (including midwifery) and allied health professionals and index their papers using MeSH headings, which are believed to produce greater specificity than phrase searching used in ASSIA and Social Care Online (McIntosh, 2011).

Measures of sensitivity, precision and NNR

The measure of sensitivity of a database is significantly important to ensure that the papers retrieved from the search are relevant (Haynes et al, 2005). Aiming for a high sensitivity score may reduce the chance of missing papers that are relevant (Pack, 2014). In this study, the highest sensitivity score was calculated for CINAHL Plus and Ovid MEDLINE scored marginally lower. PsycINFO scored disappointingly lower in sensitivity. CINAHL Plus, which indexes considerably fewer papers than PsycINFO, had the highest sensitivity score and included papers from the midwifery profession, but not social work, unlike its counterpart Ovid MEDLINE, which source papers from both. The final two databases – ASSIA and Social Care Online – had a sensitivity score of 0%, indicating that they were ineffective for use within this study. However, they are predominately social work and social science based databases and the previous three databases weighed heavily towards the medical and midwifery professions. Although ASSIA does include social service topics, it does not include midwifery, therefore, papers may be retrieved connected with child safeguarding, but not necessarily in pregnancy. Additionally, Social Care Online is predominately aimed at practitioners and policy-makers with the core material sourced from the UK, therefore restricting its scope. Similarly to ASSIA, Social Care Online covers child safeguarding but, again, does not include pregnancy or maternity research. However, it would be advisable to include both those databases to ensure that a comprehensive search is undertaken (Kemp and Brustman, 1997). Similar to CINAHL Plus, Ovid MEDLINE and PsycINFO, ASSIA is an international database that indexes fewer journals than the other databases but may be aimed at those in academia rather than social work professionals (McFadden et al, 2012).

An effective literature search is reflected through the precision scores of a particular database and the number of relevant hits retrieved (Schardt et al, 2007). Precision within this study was quite low, identifying many papers that were not relevant to the study question (Gough et al, 2012). The highest precision score was recorded on CINAHL Plus and the lowest on Ovid MEDLINE. These higher precision scores could be attributed to the scope of the journal coverage on this specific topic area (Best et al, 2014).

The retrieval of papers that are not found on other databases (unique hits) can give an indication of the best choice of databases to use in the search. Two of the five databases searched within this study retrieved a small number of unique hits. Ovid MEDLINE recovered the highest number of unique hits (3%) followed by CINAHL Plus (1%). ASSIA, PsycINFO and Social Care Online failed to retrieve any unique hits. The use of these latter databases within future searches around the topic of professional decision-making around child safeguarding in pregnancy may be unproductive. It could have been presumed that ASSIA and Social Care Online, both social science databases, would retrieve some unique hits considering the study topic but, in this instance, proved fruitless. As both database searches use phrase searching, developing a standard vocabulary for searching literature, consistent throughout

all databases and across HSC professions may be beneficial (Curran et al, 2007).

In an almost alternative measurement to precision, NNR refers to the number of papers that must be read to find one relevant paper from a database search (Hersh, 2009). A low NNR is an indication of a good and efficient search string narrowing the search of the literature, ensuring that the task is less time-consuming for a busy professional (Pillastrini et al, 2015). However, this depends upon the correct use of language and indexing terms within those databases (Stewart et al, 2014). The relevant papers retrieved for final review included a wide range of research methods confirming the validity of the search strategy and appraisal of papers (McFadden et al, 2012).

Limitations of the review

Every good literature search and retrieval has its limitations that must be acknowledged to assist future research in this study area. Two of the databases in this study, ASSIA and Social Care Online, were less than optimal for this topic area. This was partly due to the limited number of journals they index in comparison with the more medically-based journal databases CINAHL Plus, PsycINFO and Ovid MEDLINE. On reflection, it may have been beneficial to add a further social science database to the search to test its effectiveness, but the results might still have been limited in comparison with those found on more sophisticated databases with advanced indexing facilities and superior user interface.

Implications for practice

Literature searching is a common core skill that HSC professionals are expected to be able to conduct with confidence and skill. This paper provides a new insight for those in management, policy-making, midwifery, nursing and social work with further methods for undertaking a robust literature search, which can inform practice and policy to improve services. Employers and professional bodies need to ensure that employees have access to regulated training in literature searching skills for staff undertaking research and clinical projects designed to improve maternal and child care.

Conclusion

There are increasing demands on the interdisciplinary team to remain updated with research developments in their fields of practice. The task of locating relevant research now relies substantially on the quality of bibliographic databases. This study highlighted low precision in searching five databases on this topic, despite a detailed search formula and the expertise of a specialist librarian. The 'information age' requires investment in systems that are efficient as well as effective if professionals are to make the most use of available knowledge and increase their chances of retrieving relevant literature in an efficient manner. Support from leaders in the HSC organisations and professions to develop the quality of databases is a priority. The development of expertise in identifying relevant research and education on the most robust methods of database searching is a priority if the high ideals of evidence-based practice are to become a reality.

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Information for authors

Evidence Based Midwifery is published quarterly and aims to promote the dissemination, implementation and evaluation of midwifery evidence at local, national and international levels. Papers on qualitative research, quantitative research, philosophical research, action research, systematic reviews and meta-analyses of qualitative or quantitative data are welcome. Papers of no longer than 5000 words in length, including references, should be sent to: rob@midwives.co.uk in MS Word, and receipt will be acknowledged. Suitable papers are subject to double-blinded peer review of academic rigour, quality and relevance. Subject area and/or methodology experts provide structured critical reviews that are forwarded to authors with editorial comments. Expert opinion on matters such as statistical accuracy, professional relevance or legal ramifications may also be sought. Major changes are agreed with authors, but editors reserve the right to make modifications in accordance with house style and demands for space and layout. Authors should refer to further guidance (RCM, 2007; Sinclair and Ratnaik, 2007). Authorship must be attributed fully and fairly, along with funding sources, commercial affiliations and due acknowledgements. Papers that are not original or that have been submitted elsewhere cannot be considered. Authors transfer copyright of their paper to the RCM, effective on acceptance for publication and covering exclusive and unlimited rights to reproduce and distribute it in any form. Papers should be preceded by a structured abstract and key words. Figures and tables must be cited in the text, and authors must obtain approval for and credit reproduction or modification of others' material. Artwork on paper is submitted at the owner's risk and the publisher accepts no liability for loss or damage while in possession of the material. All work referred to in the manuscript should be fully cited using the Harvard system of referencing. All sources must be published or publicly accessible.

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News and resources

Research scholarships open

Midwives can now apply for a scholarship from the Florence Nightingale Foundation. Among the research scholarships it is offering this year are an NHS Professionals Scholarship for research that directly benefits patients and the wider profession. There is also a scholarship for midwives and nurses who work for Bupa in the UK. The scholarships provide up to £5000 to undertake a course in research methods, research modules or a thesis, as part of an academic course of study. The foundation will also consider post-doctoral midwifery research. For more information and the application criteria and guidance on how to apply, visit florence-nightingale-foundation.org.uk

RCM conference theme announced

'Safety, Standards, Experience' will be the theme of the RCM Annual Conference 2016. Topics will include balancing outcomes and enriching services, exploring wide variations in standards and personalised care. The two-day conference will be held at the Harrogate International Centre on 19 and 20 October. It will feature an array of national and international speakers from within and beyond maternity care. Hot topics will be debated through a series of keynote, plenary and concurrent sessions and there will be a conference exhibition. Early bird bookings are open until 16 July. For more information and to book a place, visit rcmconference.org.uk

Events for health professionals

Imperial College London has revealed details of its health research events that are scheduled for the rest of the year. The topics covered range from the impact of pregnancy on early years development to essential obstetric medicine in primary care. The college has 11 clinical research and practice events for the rest of the year. These vary from one to five days and are designed to keep health professionals who work with women and babies up to date on the latest evidence and developments. For more information and to view all forthcoming events, visit symposia.org.uk

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CONTENTS

- Editorial: Past, present and future reflections on health technologies: male dominance, electronic research and sensor technologies. 3
Marlene Sinclair
- A public health intervention to change knowledge, attitudes and behaviour regarding alcohol consumption in pregnancy. 4
Fiona Crawford-Williams, Andrea Fielder, Antonina Mikocka-Walus, Adrian Esterman and Mary Steen
- Informing the midwife on rare genetic disorders and their effects on mothers breastfeeding – a mixed methods study. 11
Tom Laws, Lemuel Pelentsov, Mary Steen and Adrian Esterman
- Parents' experience of the care they received following a stillbirth: a literature review. 16
Hayley Coffey
- A critical literature review of epidural analgesia. 22
Elizabeth Newnham, Lois McKellar and Jan Pincombe
- Sensitivity and specificity of electronic databases: the example of searching for evidence on child protection issues related to pregnant women. 29
Helena Mc Elhinney, Brian Taylor, Marlene Sinclair and Mary Rose Holman
- Information for authors, news and resources. 35