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EVIDENCE BASED MIDWIFERY



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Optimal screening for Down syndrome: non-invasive prenatal testing?

Key words: Down syndrome, screening, technology, non-invasive prenatal diagnosis, evidence based midwifery

Statistics from the WHO on Down syndrome estimate an effect size of 1:1000 to 1:1100 live births each year (WHO, 2014). Recent UK statistics, produced from the *National Down Syndrome Cytogenetic Register* (Morris et al, 2014), report the rate 2.7:1000 births for babies born in England and Wales. They also report a significant increase in the proportion of women diagnosed prenatally, from 45% in 2008 to 77% in 2012 for women under 35 years, and from 68% in 2008 to 80% for women over 35 in 2012.

Historically, recognition of Down syndrome was evidenced three centuries ago by Dr John Langdon Down, a medical doctor from Cornwall, who first described and classified Down syndrome in 1862 under the label of a 'Mongolian idiot' (Dunn, 1991). Today, it is the most common chromosomal abnormality present at birth and has become a major focus for prenatal screening worldwide. New screening technologies have made remarkable advances in the past 15 years and this is most visible when we look back at recommendations from the UK National Screening Committee in 2001, which advised that all pregnant mothers should be offered one of the available screening tests for Down syndrome. The committee recommended that by 2010 the screening tests should have a positive rate of less than 3% and a detection rate of more than 75%. Major advances in screening technology have taken place since and the American College of Medical Genetics and Genomics (2012) refer to the current gold standard antenatal screening for Down syndrome as a combination of data from the first trimester collected between 11 and 14 weeks' gestation, including assessment based on maternal age, ultrasound for nuchal translucency thickness and maternal serum analytes (free beta human chorionic gonadotrophin and pregnancy-associated plasma protein A). They report this assessment has 90% sensitivity and 95% specificity for predicting Down syndrome.

Technology has advanced rapidly and we have next-generation sequencing of circulating cell-free DNA in maternal plasma capable of identifying nearly all Down syndrome pregnancies with low false-positive rates based on a single maternal blood test for non-invasive prenatal screening (Glen et al, 2012). The blood test is undertaken around 10 weeks' gestation and the results are available within 10 to 14 days.

The test costs between £99 and £800, depending on the provider (currently available from medical staff in Harley Street in London and independent diagnostic companies). It is not free within the NHS at this time, but may become so following the results of the National Institute for Health Research funded UK study looking specifically at non-invasive prenatal testing (NIPT) for Down syndrome. The study is being led by the RAPID team from Great Ormond Street Hospital for Children in London and involves six sites where women who have a risk of a Down syndrome baby - >1:1000 - will be offered NIPT. There is some persuasive

research evidence reporting NIPT tests have 100% sensitivity and 100% specificity (Zimmermann et al, 2012). However, amniocentesis or chorionic villus sampling is still being performed for confirmatory diagnosis.

Recent UK research explored NIPT preferences of 335 women and 181 health professionals using discrete choice experiments (Hill et al, 2012). The results demonstrated preference for 'safe' tests conducted early in pregnancy, with high accuracy. For women, the key attribute was 'no risk of miscarriage, whereas for health professionals it was accuracy'.

In 10 years, based on current knowledge of personalised medicine, epigenetics and values-based medicine, one can envision a maternity service where optimal NIPT for Down syndrome and other chromosomal abnormalities will be incorporated into everyday antenatal care. The technology used in NIPT can scan the entire genetic code of the fetus leading to the need for sound bioethical principles to be put in place. The challenge for us as midwives is to remain committed to listening to the voices of the women we serve, while maintaining our professional, legal, moral and academic integrity in the midst of a sea of turbulent cultural and technological change.

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Women's preferences for antenatal screening for Down syndrome in Northern Ireland: a choice experiment

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Abstract

Background. Despite an increasing international trend towards the implementation of antenatal screening programmes for Down syndrome, there is currently limited information relating to women's choices or preferences for such screening. Information about women's preferences for and insight into the potential value they may derive from any change to screening programme design are essential components of evidence-based policy decision-making. This paper reports on a choice experiment undertaken to examine the preferences of a sample of pregnant and non-pregnant women of childbearing age with respect to antenatal screening for Down syndrome in Northern Ireland, where the offer of screening is not universal and selective abortion on the grounds of fetal abnormality is legally inaccessible.

Method. The choice experiment was conducted using an internet-based survey to obtain the preferences of a volunteer sample of 50 pregnant and 73 non-pregnant women for screening tests that varied according to six test characteristics or attributes derived from an earlier focused ethnographic study. These attributes were: source of screening information, time of test in pregnancy, accuracy of test results, cost of test as an 'out-of-pocket' expense, waiting time for test results, and risk of miscarrying a baby unaffected by Down syndrome as a result of subsequent diagnostic testing.

Results. Pregnant and non-pregnant women prefer screening tests for Down syndrome offering results with accuracy levels of 90% and above, and where the risk of subsequent diagnostic procedure-associated miscarriage is 2% and below. Women preferred screening tests offering more accurate results over no risk of miscarriage. Pregnant women place more value than non-pregnant women on tests carried out during the first trimester.

Conclusion. Policies for the implementation of antenatal screening programmes for Down syndrome must consider the preferences of pregnant and non-pregnant women to ensure that the needs of current and potential future service users are met. Effective pre-test counselling is essential to ensure that women understand the attributes of any screening test and its possible implications.

Key words: Choice experiment, Down syndrome, screening, women's preferences, evidence-based midwifery

Background

Despite variations in national policies, there is an increasing international trend towards the implementation of antenatal screening programmes for Down syndrome (National Screening Unit, 2009; Boyd et al, 2008; NICE, 2008; American College of Obstetricians and Gynecologists Committee on Practice Bulletins, 2007). Ultimately, individual or population preferences determine the acceptance and participation in any screening programme, and therefore are integral to the realisation of expected population health gains from the programme (Kruisjhaar et al, 2009). It is suggested that traditional decision modelling is insufficiently capable of including process effects, such as preferred source of screening information, and non-health outcomes, such as perceptions of risk associated with subsequent diagnostic interventions, and that they fail to identify the optimal screening programme (Drummond et al, 2005; Gyrd-Hansen and Søgaard, 2001). Choice experiments have been proposed as a means to improve systematic assessment of pregnant women's preferences for,

or acceptance of, screening programmes (Reid et al, 2008). In addition, choice experiments offer policy decision-makers viable alternatives and complements to existing methods of valuation and preference elicitation when planning the implementation and delivery of maternity care interventions (Lanscar and Louviere, 2008).

A small number of choice experiments have described the preferences of pregnant women or current service users for antenatal screening for Down syndrome (Seror and Ville, 2009; Lewis et al, 2006; Bishop et al, 2004; Spencer and Aitken, 2004). Although incorporating pregnant women's preferences and delivering woman-centred maternity care is the centrepiece of evidence-based policy initiatives (Department of Health, Social Services and Public Safety (DHSSPS), 2012; Department of Health (DH), 2007), there has been a tendency to overlook the preferences of non-pregnant women of childbearing age. It has been argued that the preferences of non-pregnant women of childbearing age who may potentially become engaged in screening decision-making (potential service users) together with information

on the potential value derived by women from any change to screening programme design may further assist policy decision-makers to ensure that a screening programme for Down syndrome represents and serves the needs of contemporary society and to predict the programme's future use (Petrou and McIntosh, 2011; Bryan and Dolan, 2004). This raises the methodological issue of presenting a choice experiment to women with perhaps no experience of screening. It has nonetheless been reported that by applying a 'think aloud' qualitative technique to choice experiment responses, respondents are capable of expressing preferences for unfamiliar goods (Ryan et al, 2009a).

Northern Ireland provides a unique setting where the offer of antenatal screening for Down syndrome is not universal and selective abortion on the grounds of fetal abnormality is legally inaccessible. There is no clear regional policy relating to screening despite a UK-wide screening strategy recommending that all pregnant women should be offered screening as part of a screening pathway, which includes further potential choice options relating to diagnostic testing and selective abortion (UK National Screening Committee, 2009). Local variations exist not only in what screening test is offered but also in those pregnant women to whom it is offered. Despite ongoing debate and recent public consultations, the option of selective abortion on the grounds of positive fetal diagnosis of Down syndrome remains prohibited by existing abortion legislation in Northern Ireland (DHSSPS, 2009). Women who seek selective abortion must therefore travel overseas, usually to England and Wales.

The aim of this choice experiment was to describe the preferences of pregnant and non-pregnant women of childbearing age (18 to 50 years) with regard to antenatal screening for Down syndrome in Northern Ireland.

Method

Study sample

A volunteer sample of pregnant women (at any stage during pregnancy) and non-pregnant women of childbearing age (18 to 50 years) was recruited via advertisements placed in regionally available journals, radio and websites, inviting women to access the study website if they were interested in participating. The authors decided not to recruit through organisations or online communities specifically dedicated to antenatal screening and/or Down syndrome, which may potentially have attracted respondents who had a specific interest in the topic (Hewson et al, 2003).

The sample size was not pre-determined, as no specific sample size power calculator for adaptive choice experiments exists (Orme, 2006). Nevertheless, a rule of thumb for choice experiments uses the formula $(n \times t \times a/c) \geq 500$, where 'n' equals the number of women participating, 't' equals the number of scenarios, 'a' equals the number of choices per scenario (excluding the none option), and 'c' equals the largest number of levels for any one attribute (Orme, 2006). Thus in this choice experiment where each woman will be asked to complete 16 scenarios (t), with two choices per scenario (a), and the largest number of levels for any one

attribute is seven (c), the sample size calculation is $(n \times 16 \times 2/7) \geq 500$. Hence, the minimum sample size was 110.

Design

This study was conducted using a discrete choice experiment. A discrete choice experiment is a quantitative technique for eliciting individual preferences for a programme, service or intervention. Individuals are offered a series of choice scenarios. They are asked to choose in each scenario between two or more alternatives. Each alternative is described by several key characteristics, known as attributes, and responses are used to infer the utility placed on each attribute and the individual's willingness to trade between attributes. Utilities are numerical scores of how important each attribute is to an individual's overall preference for a specific programme and is determined by the particular combination of attributes, and by the individual's personal characteristics. Combining the utilities for different attributes provides individuals' overall relative preferences for a programme. The assumption is that individuals prefer to choose those programmes on which they place the highest overall utility value. Willingness to trade or marginal rates of substitution are measures of how much of an attribute an individual might be willing to give up or trade, in exchange for more of another attribute, while maintaining the same level of utility. Study design and analysis followed current guidelines for conducting choice experiments (Bridges et al, 2011; Ryan et al, 2009b; Lanscar and Louviere, 2008).

Identifying the key characteristics or attributes of screening

To achieve content validity, attributes must reflect as closely as possible the key drivers of women's screening choices while also reflecting the interests of healthcare policy decision-makers and providers (Reid et al, 2008). The six key attributes used in this choice experiment consisted of five process and one outcome attributes (see Table 1) derived from an earlier focused ethnographic diary study exploring the screening decision-making processes of pregnant women (n=21) and a focus group study examining the factors influencing screening decisions from the perspectives of pregnant women (n=14), midwives (n=19) and mothers of children with Down syndrome (n=16) (Reid, 2010). This study found that women's confusion

Table 1. Key attributes of screening for Down syndrome identified from diary and focus group studies

Source of screening information
Timing of screening test in pregnancy
Accuracy of screening test results ('accuracy' used by women to denote sensitivity)
Cost of screening as an 'out-of-pocket expense'
Waiting time for screening test results
Risk of miscarrying a baby unaffected by Down syndrome as a result of subsequent diagnostic testing*

*Only included/involved in sub-experiment 2

with respect to the difference between screening and diagnostic testing was reflected in their associating the risk of miscarriage with screening rather than with diagnostic testing, often declining screening for this reason. The researchers therefore included the 'risk of miscarrying a baby unaffected by Down syndrome as a result of subsequent diagnostic testing' as an outcome attribute due to concerns that women would express a very strong preference for 0% 'risk of miscarriage', and therefore be unwilling to trade among other attributes (Ryan et al, 2009b; Lloyd, 2003). Such a dominant preference would render the calculation of willingness to 'trade' or marginal rates of substitution meaningless. Accordingly, the authors decided to generate a choice experiment consisting of two sub-experiments. The first sub-experiment excluded 'risk of miscarriage' as an attribute while the second sub-experiment included it. In this way, it was possible to ascertain the impact of 'risk of miscarriage' upon women's screening decisions.

Assigning levels to attributes

Assigning levels to the attributes involved specifying for each attribute a number of levels or values that were numerical or ordinal. The levels assigned to each attribute had to be plausible, reflecting what is relevant to current screening experience (Ryan and Farrar, 2000). Most importantly, the attribute levels had to be capable of being traded, in that the range of levels would provide enough variation while simultaneously being narrow enough to create competitive choices for women (Ryan, 1999). For this choice experiment, attribute levels were derived from the findings of diary and focus group studies and from existing research literature (Mujezinovic and Alfirevic, 2007; Heyman et al, 2006; Lewis et al, 2006; Bishop et al, 2004).

Data collection

Preference data were collected by means of an internet-based survey developed using Sawtooth Software CBC version 6.4 and hosted by a university-based website. Women were firstly asked to provide demographic details. They were then presented with a series of hypothetical choice scenarios created by combining different levels of each attribute. Finally, women's views on screening methods and abortion were ascertained. By asking women to consider specific screening alternatives, scenarios made trade-offs between competing alternatives explicit (Fraenkel et al, 2004). As recommended (Mangham et al, 2008), a fraction of the full set of scenarios was used with 16 scenarios being presented to women (each sub-experiment consisting of eight scenarios). Each scenario contained two test alternatives together with a 'No, I don't wish to have either of these two tests', as in practice women may choose to decline screening. The scenarios were generated using the same Sawtooth Software. This programme facilitated approximate orthogonality, that is, attribute levels were chosen independently of other attribute levels so that each attribute level's utility could be measured independently of all other effects (Street et al, 2008). To enhance reliability, the software allowed for the viewing of only one choice set at a time (initially those choice sets without the outcome attribute and then those choice

sets with this attribute) and thus prevented women from returning to already completed scenarios and making choice changes in light of decisions made in subsequent scenarios.

The survey was piloted with seven women to determine ease of understanding and completion. Following this pilot, changes were made to the wording in the survey describing the attributes, but not the overall design of the choice experiment. Data collected during the pilot study were not included in the main study.

Statistical analysis

Preference data derived from the choice experiment were imported into Sawtooth Software SMRT and merged with the participant demographic data set. Data from each sub-experiment were analysed separately and then merged to ascertain the impact of introducing the outcome attribute, risk of miscarriage, upon women's screening preferences. Sawtooth Software SMRT facilitated the analysis of data using three methods. Firstly, estimations for main effects and for two-way interaction effects were calculated using counts or proportions. A main effect is the direct independent effect that each attribute has on choice (Hensher, 2005). A two-way interaction effect is the effect upon choice of combining two attributes with such an effect not necessarily having been observed had each of the attributes been estimated separately (Hensher, 2005). This method was also useful for understanding variations in patterns of demand for specific attribute levels. Secondly, a multinomial logit (MNL) model was used to estimate the utilities that represent the contribution of each attribute level to the overall choice outcome. Such utilities were analogous to the relative desirability or value of each attribute level studied. Attribute levels with higher utility values were considered more desirable or beneficial by participant women. The computation started with estimates of zero for all effects or utilities. Pertinent information was found in the relative differences between the utilities.

Thirdly, 'what if' screening tests were then built to assess the impact of varying screening attribute levels on women's preferences. In other words, it was possible to generate different combinations of attribute levels and sum their corresponding utilities in order to estimate the overall utility that women would derive from different screening tests. It was also possible to predict the percentage of women projected to choose each test. In this way, marginal rates of substitution were calculated by varying the levels of one attribute within a particular 'what if' screening test, the levels of all other attributes being kept constant. In this way, it was possible to compute the incremental increase or decrease in utility for each level of an attribute.

Ethical approval

Ethical approval was obtained from the Office for Research Ethics Committees Northern Ireland (reference 07/NIR01/40).

Results

Respondent characteristics

Of the 142 women who accessed the survey, 127 (89.4%)

completed the first sub-experiment and 123 (86.6%) completed both sub-experiments. A total of 50 women (40.7%), who completed both sub-experiments, reported an ongoing current pregnancy and 23 (46%) reported being offered screening for Down syndrome, with 13 (56.5%) accepting the test.

When asked about method of screening, 79 (64.2%) of the 123 women who completed both sub-experiments stated that they would prefer a combined blood (biochemical) and ultrasound scan screening test. A further 36 of these women (29.3%) expressed a preference for screening to be carried out by ultrasound scan. Only eight women (6.5%) expressed a preference for blood (biochemical) testing.

In the event of a positive antenatal diagnosis of fetal Down syndrome, 76 (61.8%) of the women who completed both sub-experiments reported that they would continue with the pregnancy, 14 (11.4%) reported that they would not continue with the pregnancy and 33 (26.8%) did not know what they would do. Women's attitudes were further examined by age (less than or greater than 35 years, $p=0.4475$), religious affiliation (Roman Catholic or other values obtained for some categories did not allow for Protestant or other, $p=0.7159$), and educational attainment (degree level or above/other, $p=0.4432$). These factors were not found to be statistically significant.

Estimation of main effects and two-way interactions

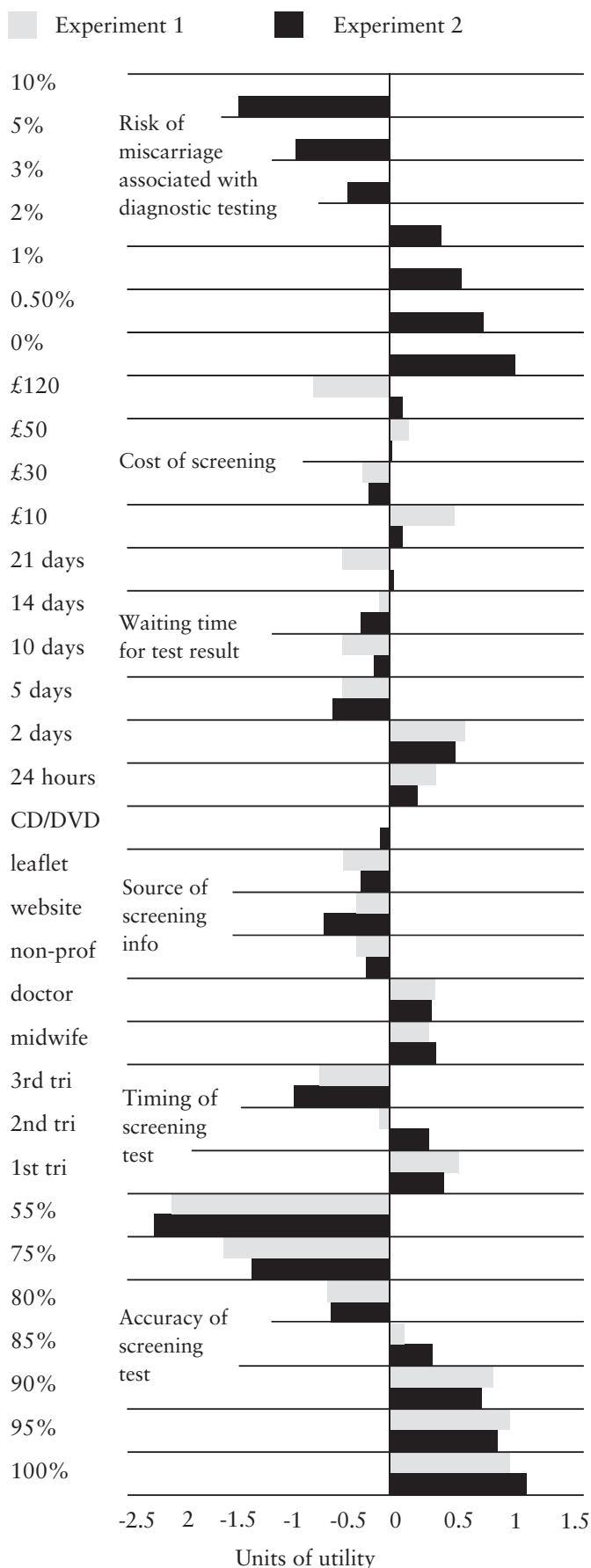
Main effects were calculated for all attributes studied with timing of the screening test during pregnancy and the accuracy of screening test results being found to be statistically significant when making choices about screening for Down syndrome ($p<.01$). When making choices about screening in conjunction with future diagnostic testing, women considered these two attributes together with the risk of procedure-associated miscarriage ($p<.01$) to be the most important of those attributes studied. Two-way interaction effects were calculated for all attributes but only one such effect, namely the impact of timing of the screening test on accuracy of screening test results, was found to be statistically significant for deciding about screening but, somewhat surprisingly, not significant when deciding about screening in conjunction with future diagnostic testing.

Pregnant and non-pregnant women's utilities

Figure 1 charts the respondent utilities for each attribute and attribute level studied. The bars of the left-hand side represent negative utilities and those on the right-hand side represent positive utility.

For both sub-experiments, women derived greatest utility or value from screening tests that offered 100% accurate test results. Women's utility for such test results increased by 7.8% when the prospect of future diagnostic testing became a decision-making factor. The greatest gains in utility were achieved for tests that offered results with accuracy levels of 90% and above. By contrast, women had an aversion to tests that offered results with accuracy levels of 80% and below. When deciding about a screening test only, women did not have a preference for, or against, a second trimester test.

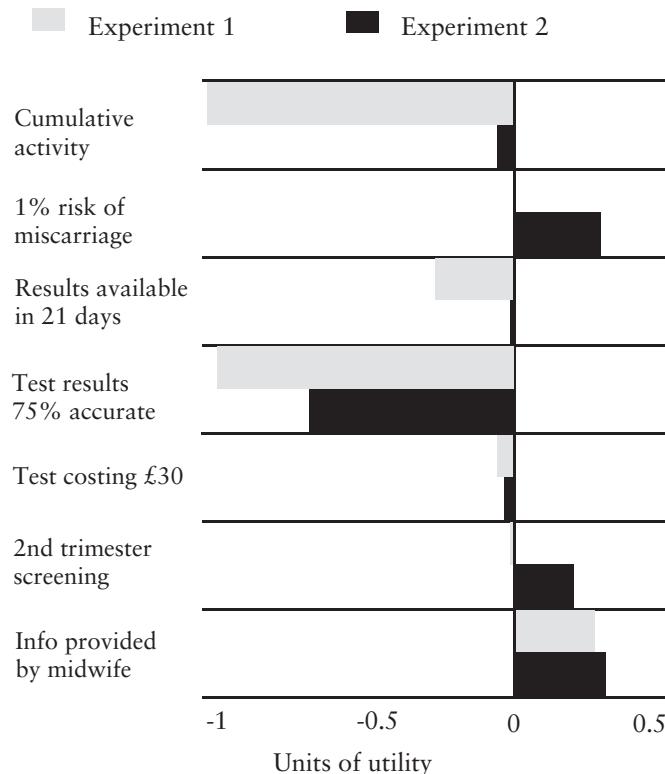
Figure 1. Pregnant and non-pregnant women's utilities for screening attributes studied



Nevertheless, women derived some minimal utility from tests carried out during the second trimester when deciding about screening and diagnostic testing. Yet, even for these women approximately 2.5 times greater utility was derived from tests carried out during the first as compared to the second trimester. With respect to source of screening information, women in both sub-experiments expressed positive preferences for face-to-face contact with midwives or hospital doctors. Midwives were women's preferred source of screening information. The utility women derived from information provided by midwives increased by 11.2% when the potential future risk of diagnostic procedure-associated miscarriage was introduced. Women were indifferent to screening information provided by CD or DVDs, but tended to avoid information provided by non-healthcare professionals, hospital websites and information leaflets. Women in both sub-experiments expressed positive preferences for screening tests that provided results within 24 hours or two days. Interestingly, women derived greater utility from waiting times of two days as compared to waiting times of 24 hours. This may indicate that women perceived two days to be a more realistic waiting time for test results. Women were found to be more responsive to cost when deciding about a screening test only. Positive utility was derived from a nominal cost of £10 with comparable negative utility being derived from a cost of £120. By contrast, women were indifferent to cost when deciding about screening in conjunction with future risk of diagnostic procedure-associated miscarriage.

When the relative differences between accuracy and risk of diagnostic procedure-associated miscarriage were examined for the second sub-experiment, women were found to derive

Figure 2. Women's utility for current Down syndrome screening practice in Northern Ireland



greater utility from 100% accurate test results as compared to a 0% risk of miscarriage. Greater negative utility was derived from 55% accurate test results than a 10% risk of miscarriage. Women valued screening tests where the risk of future diagnostic procedure-associated miscarriage was 2% and below. Women felt that a 0% risk of miscarriage was almost six times more valuable than a 2% risk. Negative preferences were expressed for tests when the risk of miscarriage was greater than 3% as compared to the positive utility derived from tests where the risk of miscarriage ranged from 0% to 2%. As anticipated, women appeared to derive greater utility from the 'No test' alternative when the risk of procedure-associated miscarriage was included as a decision-making factor.

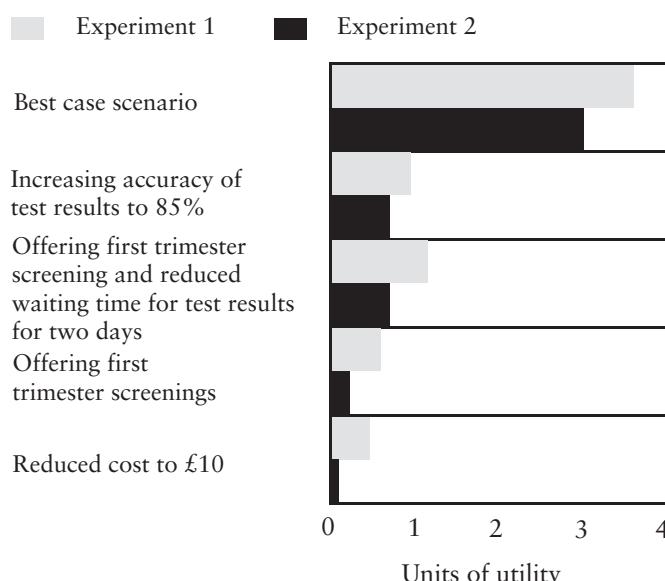
Marginal rates of substitution

Figure 2 represents current Down syndrome screening practice in Northern Ireland in terms of attribute levels. Women's utilities for each of these levels are those already presented in Figure 1. Cost was included as pregnant women attending some maternity units until recent years were required to pay approximately £30 for a screening test. The negative cumulative utility derived from a screening test only was of a much greater magnitude than that derived from screening and diagnostic testing. A 1% risk of miscarriage increased the cumulative utility derived from testing by 93%. While the risk of diagnostic procedure-associated miscarriage may generally be perceived negatively, the authors suggest that this finding supports the view that women valued additional information about risk of miscarriage provided the potential for such risk actually occurring remained low.

Women's utilities for current practice were then used as comparators to assess how controllable and uncontrollable changes or 'best' case scenarios in attribute levels impacted on women's utilities for screening test alternatives. For example, realistic controllable changes incorporated the inclusion of a first trimester screening test with 85% accurate test results thereby reflecting the timing and detection rate of the existing 'combined' screening test (biochemical and nuchal translucency scanning) (List et al, 2006). Figure 3 charts the magnitude of difference between the cumulative utilities associated with such simulated tests and the current practice or base case scenarios (denoted as zero on the x-axis). Importantly, all simulated tests improved upon the cumulative utility of current practice.

The findings indicate that a reduction in the cost of screening tests to a nominal £10, while keeping all other attribute levels constant, would cause an increase in women's cumulative utility from that of current practice for a screening test only. When again compared to current practice, the cumulative utility derived from reducing cost would be much less when screening is considered in conjunction with diagnostic testing. As compared to current practice which offers second trimester screening, it is predicted that offering screening tests only during the first trimester of pregnancy would cause an increase in women's cumulative utility. Reducing the waiting time for screening test results to two days in conjunction with first

Figure 3. Impact of simulated screening tests on current practice cumulative utilities



trimester screening would result in women deriving positive cumulative utility from tests regardless of whether risk of miscarriage is a decision-making factor. Indeed the greatest leverage in controllable cumulative utility for screening tests only is provided by first trimester screening offering results within two days. By contrast, it was found that a moderate increase in the accuracy of screening test results from 75% to 85% would provide the greatest leverage in controllable cumulative utility when screening was considered in conjunction with diagnostic testing. When faced with potential decision-making that includes risk associated with future diagnostic testing, efforts to improve the accuracy of screening tests are valued more by women than efforts directed towards providing less expensive, earlier and more expedient screening test results.

Although such realistic or controllable changes to current practice may be desirable to women, they fall well short of the optimal cumulative utilities as described by the maximum achievable or 'best case' scenarios for both sub-experiments.

Sub-group analysis for pregnant and non-pregnant women
Demographic characteristics of age (less than or greater than 35 years, $p=0.2853$), marital status (married or other, $p=0.5167$), and educational attainment (degree level or above/other, $p=0.3331$) were not statistically significantly different for pregnant and non-pregnant women who had completed both experiments.

With respect to the method of screening, a higher proportion of pregnant women (34%) expressed a preference for screening using ultrasound scanning only as compared to non-pregnant women (26%). By contrast, a higher proportion of non-pregnant women (68.5%) preferred combined ultrasound and maternal serum screening as compared to pregnant women (58%). In the event of a positive fetal diagnosis of Down syndrome, 56% of pregnant women stated that they would continue with

the pregnancy as compared with 65.7% of non-pregnant women. This finding appears counter-intuitive as the subjective attachment to the fetus associated with an ongoing pregnancy would have been anticipated to negate against women's consideration of selective abortion (Johansson-Stenman and Svdsäter, 2007). Nevertheless, a greater proportion of pregnant women (32%) expressed uncertainty with respect to decision-making in the event of a positive diagnosis of Down syndrome as compared to non-pregnant women (23.3%). Pregnant and non-pregnant women's attitudes towards Down syndrome and selective abortion were not statistically significantly different ($p=0.737$).

Main effects were estimated for all attributes studied with both pregnant and non-pregnant women reporting that the accuracy of screening test results had a statistically significant impact on their screening choices. Pregnant women amplified an increasing demand for more accurate test results when making decisions about a screening test only or a screening test in conjunction with diagnostic testing. By contrast, non-pregnant women expressed indifference towards tests offering between 75% and 85% accuracy. These women tended to 'shy away' from the offer of 100% accurate results when considering a screening test only, preferring instead a test offering 95% accuracy. Pregnant and non-pregnant women were found to have different preferences with respect to timing of screening tests during pregnancy. Pregnant women expressed significant positive preferences for earlier screening when deciding about a screening test only or a screening test in conjunction with diagnostic testing. These women expressed clear preferences for first trimester screening and indicated decreasing demand for screening as pregnancy progressed. Non-pregnant women's preferences for timing of tests were statistically insignificant when considering a screening test only. They had no strong preferences for first or second trimester screening when diagnostic testing became a decision-making factor.

The associated risk of miscarrying a baby unaffected by Down syndrome as a result of diagnostic testing was found to significantly affect decision-making for both pregnant and non-pregnant women ($p<.01$). Pregnant women were indifferent to risk of miscarriage between 1% and 3% but indicated greatest reduction in demand for screening tests when such risk exceeded 3%. By contrast, non-pregnant women displayed a steadily decreasing demand for screening as risk of miscarriage increased. Pregnant women expressed slightly greater preferences for obstetricians rather than midwives as sources of information when considering diagnostic testing in conjunction with screening tests. This was not the case for non-pregnant women.

Discussion

Main findings

The findings of this study show that, for the attributes studied, both pregnant and non-pregnant women preferred combined biochemical and ultrasound scan screening tests conducted during the first trimester of pregnancy offering results with accuracy levels of 90% and above, and where the risk of subsequent diagnostic procedure-associated

miscarriage was 2% and below. They also preferred to have screening information provided by healthcare professionals during face-to-face consultations, screening tests that provided results within two days, and to pay a nominal cost of £10 for any such test. Women who participated in this study valued information about the risk of potential subsequent diagnostic procedure-associated miscarriage provided that risk remained low. However, they preferred screening tests offering more accurate results over no risk of miscarriage. Although women in the diary and focus group studies expressed a very strong preference for 0% 'risk of miscarriage' (Reid, 2010), the findings of this study point to value of choice experiments in 'teasing out' women's preferences. Given that the majority of women who participated reported that they would continue with the pregnancy in the event of a positive antenatal diagnosis of fetal Down syndrome, it may be suggested that preferences for earlier and more accurate screening test results were indicative of a straightforward desire for information or a 'need to know'. While this study demonstrated that pregnant women and non-pregnant women of childbearing age shared similar relative values regarding accuracy of screening test results and the risk of diagnostic procedure-associated miscarriage, they differed in the value they attached to the timing of screening tests, with pregnant women placing more value than non-pregnant women on tests carried out during the first trimester.

Strengths and limitations

A major strength of this study is the use of screening attributes derived from focused ethnographic study data, thereby reflecting as closely as possible the key drivers influencing women's choices (Reid et al, 2008). While this study helps to 'tease out' women's screening choices, it is not possible to generalise the findings as women in this study were self-selected and selection bias may have impacted on the results. Future research would benefit from a larger sample size incorporating a wider demographic profile.

In addition, the study raises methodological issues with respect to the development and use of choice experiments. Firstly, we have used a within-sample design to ascertain the impact of the outcome attribute, 'risk of miscarriage', upon women's screening decisions by constructing two experiments completed by the same sample of women. A between-sample experiment may have provided an alternative design. However, there is still some debate in the literature as to whether hypothetical bias is much minimised with a between-sample over a within-sample study design (Johansson-Stenman and Svärd, 2007; List et al, 2006; Lusk and Schroeder, 2003). The recent ISPOR task force report (Johnson et al, 2013), which evaluated alternative approaches to experimental design for choice experiments, made no reference to a preference for one such design over the other. Secondly, it is probable that the statistical power to estimate main effects may have been enhanced by utilising a minimum sample size for each of the two experiments rather than a combined minimum sample size. However, sample size calculations are recognised as being particularly

difficult for choice experiments (Rose and Bliemer, 2013; Bridges et al, 2011). Traditional orthogonal designs and existing sampling theories do not adequately address the issue, and no single strategy is available that can be used to state unequivocally what sample size will be required for a choice experiment (Rose and Bliemer, 2013). Hence researchers have had to resort to rules of thumb as in this study.

Interpretation

This study is the first to describe the preferences of pregnant and non-pregnant women of childbearing age for antenatal screening for Down syndrome in Northern Ireland. The authors are aware of no other studies that have used discrete choice methods to quantify the preferences of both these groups of women. In addition, this study was undertaken in a unique setting where the offer of screening is not at present universal and selective abortion on the grounds of positive fetal diagnosis of Down syndrome is legally inaccessible.

An earlier study used a screening options questionnaire to survey 1127 women attending antenatal clinics in England for Down syndrome screening (Spencer and Aitken, 2004). Adopting a false-positive rate of 5% and tests offering 90% accurate results, it was found that 75% of women preferred first trimester screening, which used serum screening and ultrasound scan, as compared to integrated first and second trimester screening (24%) and second trimester screening (1%). Women were also more likely to prefer a one hour result option. These findings are consistent with the findings reported in this study in terms of method and timing of screening. However, the study did not explore the impact that false-positive rates might have on women's choices. The authors therefore cannot discount that if accuracy of screening test results were fixed at the same level for all tests and false-positive rates varied, women may show a preference for tests with the lowest follow-up rates.

Two further studies investigated how women's and healthcare professionals' preferences for screening differed, not only in terms of timing and accuracy of test results, but also in terms of the risk of subsequent diagnostic procedure-associated miscarriage. Using conjoint analysis, a study carried out in England found that while both groups valued screening tests carried out during early pregnancy with associated highly accurate test results, professionals valued earlier tests more highly than women (Bishop et al, 2004). Similar to the findings of the authors' study, women had a weaker preference for an earlier test relative to accuracy of test results. These findings were confirmed by a replicative Australian study (Lewis et al, 2006). However, both studies conflated the risk of diagnostic procedure-associated miscarriage with screening tests and reported that women's screening preferences were largely determined by this attribute. By contrast, the authors' study found that women's preferences for screening tests only would be determined by earlier tests offering more timely results whereas women's preferences for screening considered in conjunction with diagnostic testing would be determined by offering more accurate test results.

One reason forwarded by earlier studies for women's preference for earlier screening relates to the possibility of a first trimester selective abortion in the event of a positive diagnosis of fetal Down syndrome (Lewis et al, 2006; Bishop et al, 2004; Spencer and Aiken, 2004). However, the authors' study found that only 11.4% of pregnant and non-pregnant women of childbearing age would not continue with such a pregnancy. Even when those women whose uncertainty is taken into consideration, such a proportion is much lower than the previously reported 48% of the general population of Northern Ireland who conditionally approved of selective abortion (Halman et al, 2001). A retrospective study conducted in Uruguay, where abortion is also legally inaccessible, found that 89% of women would terminate a Down syndrome affected pregnancy (Quadrelli et al, 2007). Although, such diverse findings may be partially explainable in terms of sampling issues and study timing, further sensitive exploration of women's views regarding selective abortion is warranted.

This study's finding that women derived greater utility from paying a nominal cost for screening as compared to the approximate or higher costs is contradictory to other reported findings (Seror and Ville, 2009). Using hierarchical cluster analysis, it was found that women in France were willing to pay on average €96 for a screening test, more than twice the sum of €39 which was charged and subsequently reimbursed by the French health insurance system (Seror and Ville, 2009). In addition, women deciding about screening in conjunction with future risk of diagnostic procedure-associated miscarriage were willing to pay €150 or more for screening, whereas women in the authors' study were indifferent to cost when making such decisions. Women in some countries may be accustomed to paying 'out-of-pocket' expenses in an insurance-based healthcare system as compared to women in a 'national' healthcare system where services are free at the point of use.

The authors' study should also be considered within the context of current screening policy in the UK, which recommends that all pregnant women be offered the 'combined test' and, if accepted, this test should be performed before the end of the first trimester (UK National Screening Committee, 2011). This test should provide women with results offering a detection rate of more than

90%, for a screen positive rate of less than 2% (of affected pregnancies). The waiting time for results is to be determined locally. The risk of subsequent diagnostic procedure-associated miscarriage is recognised as being between 1% and 2% (UK National Screening Committee, 2006). Such policy recommendations concur with the preferences of women in this study. However, these recommendations are not currently implemented in Northern Ireland where an ad hoc offer of second trimester screening is made to high-risk pregnant women. In addition, women's preferences for screening tests offering results with accuracy levels of 90% and above is of particular importance given that women in Northern Ireland are screened using the triple test with a detection rate of 67% to 70% for a false-positive rate of 3% (UK National Screening Committee, 2011; List et al, 2006). However, the combined test as recommended involves a two-stage testing approach during the first trimester and this study did not establish women's acceptability of such an approach. Finally, these findings pose a dilemma for women, healthcare professionals and policy decision-makers where the lack of access to selective abortion in Northern Ireland appears to be incongruent with national and international screening pathways (National Screening Unit, 2009; UK National Screening Committee, 2009; NICE, 2008; American College of Obstetricians and Gynecologists Committee on Practice Bulletins, 2007), and the principles of equity and choice which underpin current maternity care policy (DHSSPS, 2012; DH, 2007).

Conclusion

Women's preferences for antenatal screening tests for Down syndrome involve complex trade-offs and interactions between attributes pertaining both to the process and outcome of screening. Policies for the implementation of antenatal screening for Down syndrome need to be informed by this study and future research which consider these preferences to ensure that the needs of current and potential future service users are met. Particular attention needs to be given to the development of a clear regional policy which is congruent with the current national UK screening strategy. Effective pre-test counselling and informed consent processes are essential to ensure that women understand the attributes of any screening test and its possible implications.

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Understanding support in labour: the potential of systematic observation

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Abstract

Objective. To explore the potential of the systematic observational method of enquiry to address key questions in maternal health and midwifery research.

Background. The systematic observational method was developed in the field of behavioural psychology. The approach enables the researcher to record detailed information about the quantity and frequency of particular behaviours of interest in an observed interaction. The quantitative data produced can be analysed to identify any correlations between the observed behaviours and outcomes of interest. This paper explores the potential of this method of enquiry to answer questions of interest in maternity care, using the example of midwifery intrapartum support and its relationship with key birth outcomes.

Method. This discussion paper explores the potential for the use of systematic observation as a central method of enquiry in research in maternity settings. The discussion is drawn from the findings of a targeted review of the literature on systematic observation. The review included the use of the method in non-maternity settings and its use in the intrapartum setting.

Findings. The review of systematic observational approaches in non-maternity settings revealed the potential of the systematic observation approach to explore questions relating to the measurement of both the quantity that particular behaviours are displayed and the quality of the interactions observed. The review of systematic observational research of labour support identified the rich data gathered using this approach about the quantities of different support behaviours.

Conclusion. Systematic observation has the potential to successfully address key questions of interest in midwifery research, including the quantity and quality of professional intrapartum support and their relationship with birth outcomes.

Key words: Intrapartum support, systematic observation, ethnographic observation, methodology, evidence-based midwifery

Introduction

A range of questions in maternal health and midwifery research relate to the relationship between the actions and behaviours of the maternity care provider and clinical outcomes. The identification of the correlation between a practitioner's behaviours and key outcomes enables the development of clear definitions and descriptions of the content of high-quality maternity care. To identify correlations, it is necessary to define the range of behaviours of interest and then employ a method of enquiry that enables the researcher to measure the quantity of these behaviours.

One such research method is systematic observation. This enables a trained observer or observers to record in some detail how often a particular behaviour is demonstrated. The method can be employed with a researcher present to observe behaviours in a room with those engaging in the interaction, observing an interaction as it occurs through a one way mirror or live video feed, or through listening to audio recordings or watching video recordings of interactions after the interaction has concluded. This paper uses the example of intrapartum support to discuss the potential of this method in midwifery or maternal health research.

Background

Observational methodology to measure the quantity of key behaviours

Choice of research method is driven by the central research questions. Where these centre around seeking to understand

the behaviours of health professionals in a particular setting, in order to more fully understand the impact of those behaviours on the recipients of health care, it can be argued that some form of observational research is required. 'Many questions about behaviour are most appropriately answered by observational research' (Martin and Bateson, 1986: 16). Observational research can be defined as 'the collection of data that are visible to visual sensors, whether that consists of the researcher's eyes or the use of video' (Rees, 2003: 140). Observational research seeks to observe behaviour in its natural setting, rather than in an experimental or laboratory setting, in order to provide an accurate picture of what actually happens: 'Virtually no other data collection method can provide the depth and variety of information as observation. With this approach, humans, the observers, are used as measuring instruments and provide a uniquely sensitive and intelligent tool' (Polit et al, 2001: 286).

Historically, there have been two key approaches to observational methods of enquiry. The first, ethnographic participant observation, is an essentially qualitative style, while the second, structured or systematic observation, produces quantitative data. Traditionally, advocates of qualitative or quantitative approaches to research have maintained that these methods reflect incompatible paradigms, though this mutual exclusivity of methodologies has more recently been questioned by researchers. It is possible for creative researchers to use elements of both approaches in an observational study, either in separate phases of the research

or by developing quantitative indicators that seek to capture richer more qualitative information (Hall et al, 1996).

Qualitative observational approaches were first developed by anthropologists and sociologists to examine the actions and interactions of animals and people in their natural social world. Many influential ethnographic studies have been undertaken in midwifery settings (Walsh, 2007; McCrea et al, 1998; Hunt and Symonds, 1995; Kirkham, 1989). These studies have contributed valuable insights into midwifery culture in the UK and midwife behaviours in childbirth settings. In this approach, a narrative account of events observed is written in detailed field-notes and, generally, a 'grounded theory' approach is taken to the development of hypotheses (Glaser and Strauss, 1966). Hypotheses are developed as a result of the findings, rather than before the research begins. This requires the observer to 'perform difficult tasks of synthesis, abstraction and organisation of data. The observer is the instrument' (Robson, 2000: 320).

The systematic observational approach seeks to reduce the impact of the personal judgements of the observer by developing a clear coded schedule of observations, where pre-determined categories of behaviour and interaction are noted. The coding scheme is developed to incorporate the behaviours and distinctions which the observer feels are important in providing answers to the research questions. A number of observers are trained to use the coding scheme. The coding system and training should be devised so that the same results are derived when different observers are observing an interaction ('inter-observer reliability') and when the same observer reviews an interaction at two different times ('intra-observer validity'). This reliability can be tested using an 'index of concordance' (Bakeman and Gottman, 1997: 80).

Systematic observation can be used when hypotheses have already developed from earlier research. The approach can then be employed to confirm or refute the hypothesis by testing whether any relationship exists between the behaviours of interest and particular outcomes. An example is the Flanders Interaction Analysis System (Flanders, 1976); a systematic observation instrument that enables an observer in a classroom to note down the key elements of interactions between teachers and pupils. The system has been widely used to identify the relationship between teacher-pupil interactions and a range of outcomes, such as student learning and satisfaction. A further example is the development and use of the Brazelton newborn behavioural assessment scale which enables an observer to record details of parent-infant interactions. The data gathered through such studies have led to a huge growth in understanding of human development, parent-infant interactions and ongoing infant mental health and cognitive development (Cohn and Tronick, 1987; Brazelton, 1974).

Systematic observation methodology to measure the quality of interactions

It is clear from a large body of research that systematic observation can contribute significantly to knowledge about how the frequency and quantity of behaviours can be related

to outcomes, but can it contribute to understanding the impact of the quality of interactions on health outcomes?

The international definition of quality in health care is that it is 'safe, effective, efficient, timely, equitable and person-centred' (Institute of Medicine, 2001: 3). If clear parameters defining safe and effective care for any particular care episode have been established, these can be easily included in a systematic observation instrument as key behaviours to be recorded. For example, in intrapartum care, systematic observation could be used to record whether midwives used electronic fetal monitoring according to evidence-based guidance or employed infection control procedures. By recording timing and frequency of care behaviours of interest, we are also able to measure how equitable and timely care has been using the systematic observation approach by comparing care provided to different patients or service users.

When exploring the potential of the method to measure 'person-centredness', it is necessary to look at research beyond the maternity care setting. A considerable body of research with health professionals outside the maternity care setting has succeeded in recording and measuring the quality of interactions using a systematic observation method (Caris-Verhallen, 2004; Roter and Larson, 2002; Booth, 1995; Jarrett and Payne, 1995). This begins by seeking to define the key behaviours in a particular care episode that are considered to demonstrate elements of person-centredness, such as positive communication skills. The approach has been used to observe and record quantities of behaviours that express elements of quality in an interaction: some studies define and then record positive and negative behaviours (Sala et al, 2002; Caris-Verhallen et al, 2000; Reynolds, 2000; Beck, 1997) and some seek to record non-verbal and paralinguistic behaviours, as well as verbal and physical behaviours (Philippot, 2003; Russell, 1997; Booth et al, 1996).

One of the most widely used and validated observation instruments is the Roter Interaction Analysis System (RIAS) (Roter and Larson, 2002), devised to code video or audio recordings of doctor-patient interactions. The tool has been used in more than 75 studies and substantially tested for validity and reliability. The RIAS has 34 mutually-exclusive verbal categories and allows the observer to also record a general assessment of the atmosphere of the interaction. Some studies have added further non-verbal categories, such as patient directed eye gaze and affirmative head nodding (Kruijver et al, 2001; Caris-Verhallen et al, 2000).

Some observational instruments have been developed and validated to record and measure one particular aspect of quality in a healthcare interaction. The Euro-Communication rating scale was developed to rate a doctor's patient-centred behaviour from 0 (poor) to 5 (excellent) across five dimensions: involving the patient in problem definition, involving the patient in decision-making about management, picking up cues about hidden aspects, exploring issues of patient ambivalence and the doctor's overall 'responsiveness' (Mead and Bower, 2000: 74). The importance of humour has been explored in one study examining videotapes of 92 doctor-patient visits (Sala et al, 2002). It was found that humour had more of an impact on satisfaction than the

length of the visit, demographics of the patient or doctor and health of the patient (Sala et al, 2002). Several approaches to measuring quality within interactions are identified in the literature. These include categorisation of particular elements of interaction as either positive, neutral or negative. Other studies have used a Likert scale to enable observers to rate a behaviour from 'poor' to 'excellent'. A potential problem with the use of ratings scales in observational studies is the danger that they are open to error and bias; observers may have a tendency to rate everything according to a general impression, which may lead to an 'error of central tendency', 'error of severity' or 'error of leniency' (Kerlinger, 1995: 495).

Several studies have used systematic observation as a method to identify the extent to which key concepts of quality in nursing are demonstrated in practice. In a study on a psycho-geriatric ward, this was done by identifying observable behaviours that exhibited key concepts in practice: 'The measurement of the quality of care requires a descent of the "ladder of abstraction" from concepts, such as autonomy and dignity through dimensions of these concepts, such as choice and independence, to indicators, such as whether patients are given the opportunity to choose where they sit for a meal' (Gilloran et al, 1993: 273).

Further examples of systematic observation measuring the expression of abstract concepts in clinical practice come from a considerable amount of research that has sought to assess and measure empathy in clinical interactions. Such research begins by seeking to define the concept of empathy as a specific set of behaviours. For example, clinical empathy has been defined as the ability to 'understand the patient's situation, perspective and feelings; to communicate that understanding and check its accuracy; to act on the understanding with the patient in a helpful way' (Mercer and Reynolds, 2002: 9). A widely used instrument to measure empathy in nurse-patient interactions was developed drawing on clients' descriptions of behaviours that they found helpful or unhelpful in establishing a feeling of empathy, resulting in 12 categories of behaviour, which were recorded as present or absent (Reynolds and Scott, 2000).

The targeted review of studies undertaken to measure the quality of healthcare interactions identified that a considerable body of research has been undertaken which appears to successfully define particular dimensions of healthcare quality and which enable an observer to reliably measure the behaviours that demonstrate these dimensions (Pelander et al, 2009; Mercer and Reynolds, 2002; Razavi et al, 2002; Sala et al, 2002; Kruijver et al, 2001; Caris-Verhallen et al, 2000; Reynolds, 2000).

Intrapartum support: the potential of systematic observation
The literature review also sought research that had employed systematic observation in the maternity setting, to identify if there is potential for the method to be used to answer key questions about intrapartum care and labour support.

The review found that there has been some limited use of systematic observational techniques in the labour setting. A handful of studies were identified using systematic observation of second stage care and behaviours (Thomson, 1995;

Mackay and Smith, 1993; Beaton, 1990). In one study, 33 women and 39 care providers in labour were observed, using a schedule to categorise the 'verbal response modes'. This identified the way in which nurses used communication and language to maintain professional control (Beaton, 1990). In a 1995 pilot study for a randomised controlled trial (RCT) to compare spontaneous and directed pushing in the second stage of labour, 32 women were observed by a researcher once the second stage of labour had been diagnosed. The women were randomised at the point of diagnosis of second stage to either spontaneous pushing or directed pushing. A proforma coding sheet was completed by the researcher, which recorded the time of contractions, number of pushes made in each contraction, instructions given by the midwife, the woman's actions and the positions adopted by the woman (Thomson, 1995). The focus of this research was the woman's 'natural' pushing behaviour, if left undirected, which identified that women will naturally use shorter 'open glottis' pushes than those prescribed by many midwives in 'directed pushing' (Thomson, 1995: 1027). These studies have provided important additional information to inform practice change in second stage labour care. None specifically focused on observing or recording the support behaviours of

Table 1. Intrapartum observation schedule (Gagnon and Waghorn, 1996: 5)

Supportive direct care activities	All other activities
Category 1: Physical comfort measures	Category 1: Direct care activities with woman
<ul style="list-style-type: none"> • Use cool cloths, warm compresses • Bathing, assisting with shower • Linen and under pad changes • Offer ice chips, fluids • Position (for comfort) • Massage back or other body parts • Assist with ambulation • Give reassuring touch. 	<ul style="list-style-type: none"> • Includes all other activities in the presence of the patient, for example physical assessments and performing procedures.
Category 2: Emotional support	Category 2: Indirect care activities in room
<ul style="list-style-type: none"> • Reassurance, encouragement, praise • Be with the patient to keep her company • Laughter, joking, social chitchat. 	<ul style="list-style-type: none"> • Assisting with procedures • Washing hands • Talking to partner • Charting.
	Category 3: Postpartum
	<ul style="list-style-type: none"> • Care of mother and baby.
Category 3: Instruction and information	Category 4: Indirect – not in room
<ul style="list-style-type: none"> • Instruct or coach, such as with breathing or pushing techniques • Give advice • Explain, provide information about progress, for example fetal wellbeing • Interpret physician's findings to woman • Instruction to partner. 	<ul style="list-style-type: none"> • Preparing medications • Washing hands • Preparing equipment • Teaching other than with patients • Charting, documenting care (not in presence of patient) • Discussing care with other members of the team • Attending CS • Social discussions.
	Category 5: Other non-care activities off unit
	<ul style="list-style-type: none"> • Meetings • In general operating suite • Meal breaks • In other units.

the midwives. The targeted literature review identified one study which used systematic observation to compare the professional intrapartum supportive behaviours of midwives in public and private hospital settings in Africa. This study employed an adaptation of the Bryant adaptation of the nursing support in labor questionnaire (BANSILQ) (Bryanton et al, 1994) to record 37 midwife-woman interactions in labour alongside interviews and focus groups (Eustace and Lugina, 2007). The BANSILQ is a questionnaire validated for the description of labour support received by women as a postnatal questionnaire. This study adapted the questionnaire to serve as an observation instrument with the observer identifying each behaviour on a scale from 1, 'not done', to 5, 'done very well'. This study has a number of methodological limitations. Reliability testing of this adapted instrument was not described, the observers were described as 'concealed participant observers' without fully describing how the observation was carried out, other than saying that the observers were members of unit staff, and no details were given of the duration of each observation period. This study suggested marked differences in approach between the public and private setting, with more information-giving, listening and back massages observed in the private setting than the public hospital setting (Eustace and Lugina, 2007).

An electronic search for observational studies of intrapartum support identified five previous studies focusing on the description and recording of professional support in labour (Barnett, 2008; Miltner, 2002; Gale et al, 2001; Gagnon and Waghorn, 1996; McNiven et al, 1992). All five studies were undertaken in North America and focus on the behaviours of obstetric nurses. The role of obstetric nurses and the systems in which they work differ significantly from midwives, thus the results of the studies are likely to differ significantly from a comparable study of midwife care. While the results may not be transferable, the methods employed were of interest in demonstrating the potential of the systematic observation approach to provide new knowledge about professional intrapartum support.

Three studies (Gale et al, 2001; Gagnon and Waghorn, 1996; McNiven et al, 1992) took place in Canada, employing a random work sampling design to record the activities of all obstetric nurses working on the observation labour wards at particular times. All three used an observation schedule developed for an RCT by Hodnett and Osborn (Hodnett and Osborn, 1989). The schedule is reproduced in Table 1.

The systematic observation study undertaken by Miltner used a different design to the three Canadian studies. The observation schedule for this study is presented in Table 2.

The most recent study was undertaken by Barnett in the US in 2008. Barnett's computer-based observation schedule was the simplest, with the inclusion of just seven categories (time in room, time out of room, professional activities,

Table 2. Intrapartum observation tool (Miltner, 2002: 755)

Surveillance	Indirect care	Informational support	Emotional support	Physical support
History/admission	Documentation	Relaxation techniques	Remaining with mother if anxious/fearful	Comfort positions
Maternal vital signs	Procedure preparation	Pain relief measures	Coaching	Urine output
EFM interpretation	Assisting other health professionals	Fetal status	Praise	Pelvic rock/tilts
Administration of analgesic medication	Discuss with other health professionals	Procedures	Encourage/reassure	Ambulation
Post-epidural care	Other care management	Pushing	Other emotional support	Other physical support
Fetal resuscitation	-	Other Information	-	-
Other assess/technical	In any patient room. Care of other patient	Non-productive time	Other RN with patient	-

emotional support, physical support, instructional support and advocacy support). Barnett's study used timers on the computer programme to record the amount of time spent undertaking an activity, rather than the frequency a behaviour was observed. The researcher stayed in the room with the woman and recorded the care received by the woman rather than following the nurse and recording care given. Interesting comparisons of the quantities of different support and non-support behaviours found in the North American studies can be undertaken. Significant methodological differences between the studies make direct comparison of the descriptive data difficult. However, it is possible to examine the proportions that the different categories of support were observed in relation to each other (see Table 3).

Discussion and implications

The five existing studies employing the systematic observation methodology to measure professional intrapartum support were reviewed in depth. These studies resulted in important new information about the quantity of particular categories of support behaviours demonstrated by intrapartum nurses in North America in the 1990s and early 2000s. The observation schedules developed for these studies enable a trained observer to record data about the frequency or length of time that supportive behaviours are seen, providing some information about the quality of the support provided. A nurse who is outside the labour room for the majority of active labour, providing supportive care for the minority of time she is in the labour room, is not meeting the definition of high-quality intrapartum support suggested by the literature.

However, the focus of the observation instruments is on what behaviours are demonstrated, rather than how. It is clear from the literature, in both maternity and non-maternity settings, that the way in which behaviours are demonstrated is of central importance in the assessment of quality: the use

Table 3. Comparison of nurse behaviours in systematic observational studies

Author and year	Nurse in room	Supportive behaviours	Emotional support	Informational support	Physical support	Advocacy
McNiven et al (1992)	Not calculated	9.9%	25%	70%	3%	3%
Gagnon and Waghorn (1996)	21.4%	6.1%	17%	50.5%	26.7%	5.8%
Gale et al (2001)	27.8%	12.4%	-	70%	-	-
Miltner (2002)	58.9%	66.2%	35.3%	18.2%	12.8%	-
Barnett (2008)	31%	40%	37%	40%	20%	3%

of positive non-verbal and paralinguistic elements, such as smiling, eye contact and verbal tone, have a considerable impact on patients' perceptions of an interaction and other health outcomes (Halldorsdottir and Karlsdottir, 1996a; 1996b). These elements of an interaction are not included in any of the intrapartum observation instruments. Further, the instruments employed in the existing studies do not record or measure the frequency of negative behaviours by the care providers. Research with women identifies that negative behaviours have a significant impact on their feelings about the birth experience (Elmir et al, 2010; Davies et al, 2008; Leeds and Hargreaves, 2008; Halldorsdottir and Karlsdottir, 1996a; 1996b). To build a complete picture of the quality of intrapartum support, it is necessary to record the presence of any negative behaviours, such as belittling humour, physical restraint or instigating interventions without consent.

The review of these studies suggests systematic observation may be helpful to explore key research questions about the relationship between the quality and quantity of intrapartum support and outcomes, but that a new systematic observational instrument is required. These studies also suggest that such an approach to measure supportive behaviours in the intrapartum setting could be acceptable to women and staff and feasible from a researcher's perspective.

The literature from non-maternity settings demonstrated the use of observational instruments that were able to reliably record behaviours that illustrated key aspects of quality and person-centredness in a healthcare interaction, such as the expression of empathy and appropriate use of humour. Potential benefits of using a structured systematic approach have also been identified. It can reduce the time-consuming labour-intensive nature of observational studies, as the

observational fieldwork can and should be divided between a number of observers. The development of a systematic tool allows replication of the study in different settings and at different times. A systematic observation reduces the impact of the individual judgements of the observer. It also produces quantitative data, which has the potential to identify correlations between the quantities of particular supportive behaviours and clinical outcomes.

Conclusion

A large body of research in non-maternity settings has established the efficacy of the systematic observational method of enquiry as a means of describing and recording human interactions quantitatively, thus enabling statistical correlations between behaviours and outcomes of the interaction to be explored. Systematic observational instruments from education, behavioural psychology and health research provide evidence that it is possible to reliably measure the quantity of behaviours that operationalise concepts of quality, such as empathy, respect and patient-centredness and the quality of interactions through the recording of non-verbal and paralinguistic behaviours, negative behaviours and humour. When seeking to answer key research questions that relate to the relationship between the actions and behaviours of the maternity care provider and clinical outcomes, the methodology of systematic observation should be considered.

The review of systematic observation instruments developed to measure professional intrapartum support suggests that the methodology has the potential to provide new information about the quantity of professional support provided during labour and birth. The review highlighted that the existing instruments developed to measure intrapartum support did not adequately address elements of quality as well as quantity. If the research questions posed relate to the relationship between outcomes and quality, as well as the quantity of intrapartum support, a new systematic observation instrument will be required. A robust systematic observation instrument is required that enables observers to accurately record all key aspects of the quantity and quality of intrapartum support.

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Nepalese mothers' experiences of care in labour

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Abstract

Background. The government of Nepal aims to reach millennium development goals 4 and 5 by focusing on the provision of skilled birth attendants (SBAs). This is undertaken by providing two months' additional training on complicated childbirth to physicians, certified nurses, auxiliary nurse-midwives and degree-trained nurses. However, SBAs are under-utilised, as only 36% of all births are supported by SBAs, while 72% of births take place at home. For the women in Nepal that do access main hospitals with the highest level of maternity care, there are limited descriptions of their experiences of being cared for during birth.

Aim. To explore mothers' experiences of the care received while giving birth in hospital settings in Nepal.

Method. An interview study with 10 first-time mothers voluntarily recruited from maternity units in two tertiary-level hospitals was conducted over a four-month period. Ethical approval was obtained from the Nepal Health Research Council. Data were analysed using content analysis.

Results. The main category 'trust in care providers, both relatives and professionals, was fundamental for mothers to feel cared for' captured the essence of the two categories 'accountable caring' and 'the act of communication' with, in total, nine sub-categories.

Conclusion. For women to experience 'being cared for' in birth, they need to be accompanied by relatives and they need to trust those relatives and healthcare providers. This study concludes by arguing that relatives are a valued addition to healthcare providers' provision of clinical care during birth. Delivery of preparation for birth sessions for both mother and relatives are recommended. Mothers highlighted that more information and some preparation for birth might have reduced their fear.

Key words: Respectful care, Nepal health facilities, skilled birth attendants, midwifery, evidence-based midwifery

Introduction

In Nepal, policy is medically driven by the concept of 'risk', which requires women to give 'supported birth' in the formal health system where services are increasingly technological and instrumental (Regmi and Madison, 2009). In order to increase the numbers of supported births in health facilities, Nepal's government has been providing free maternity care services, focusing on skilled birth attendant (SBA) training. The government of Nepal aimed to reach millennium development goals 4 and 5 by 2015 (Bhutta et al, 2010; Hogan et al, 2010) by providing two months of SBA additional training on complicated childbirth to physicians, certified nurses, auxiliary nurse-midwives, or degree-trained nurses (Family Health Division, 2006). However, data from the *Nepal Demographic and Health Survey 2011* (2012) shows that the percentage of potentially safer ways of birthing for women is not increasing, as only 36% of all births are supported and 72% of births take place at home. There are several possible reasons why the numbers of SBA-supported deliveries have not increased in Nepal. A total of 88% of the population reside in remote areas, with insufficient transport to access health facilities (Peters et al, 2008). Relatives are needed to escort the women and the costs associated with loss of income influence the decision about whether or not to seek care (Simkhada et al, 2008). Other barriers to utilising health care include poor attitude of staff and inadequate nursing care (Spleen et al, 2013). Socio-economic, cultural and religious factors in a

patriarchal family structure also impact on the woman's ability to access care (Regmi et al, 2010). Against the policy direction of maximising the numbers of women in Nepal giving birth in healthcare centres and hospitals (Regmi and Madison, 2009; Family Health Division, 2006), the families may value traditional knowledge more than medical knowledge, and the woman will not seek care in the formal health system. Women adhere to the traditional culture and belief system and this means that women do not speak up and leave that to other family members (Kaphle et al, 2013; Spleen et al, 2013; Bajracharya, 2012; Regmi et al, 2010).

Nepal does not have midwives who meet global standards, however healthcare workers providing midwifery care strive to achieve the competencies for a midwife or other healthcare workers providing maternity care (see Table 1) (International Confederation of Midwives (ICM), 2010). Knoblauch et al (2010) have measured the quality of healthcare workers in Nepal and found there is a need for well-trained providers; also, according to the patients, improvement in how staff treat their patients is needed (Paudel et al, 2012). In a recent focus group enquiry with SBAs, (Erlandsson et al, 2014) the authors identified that women giving birth in central hospitals can only have respectful care if it is facilitated by relatives. For the women in Nepal that do access main hospitals with the highest level of maternity care, however, there are limited descriptions of their experiences of being cared for during birth (Bowser and Hill, 2010). Therefore, this study aims to explore mothers' experiences

Table 1. Competencies for a midwife or other healthcare workers providing midwifery care (ICM, 2010)

1. Midwives have the requisite knowledge and skills from obstetrics, neonatology, the social sciences, public health and ethics that form the basis of high-quality, culturally relevant, appropriate care for women, newborns, and childbearing families
2. Midwives provide high-quality, culturally sensitive health education and services to all in the community in order to promote healthy family life, planned pregnancies and positive parenting
3. Midwives provide high-quality antenatal care to maximise health during pregnancy and that includes early detection and treatment or referral of selected complications
4. Midwives provide high-quality, culturally sensitive care during labour, conduct a clean and safe birth and handle selected emergency situations to maximise the health of women and their newborns
5. Midwives provide comprehensive, high-quality, culturally sensitive postpartum care for women
6. Midwives provide high-quality, comprehensive care for the essentially healthy infant from birth to two months of age
7. Midwives provide a range of individualised, culturally sensitive abortion-related care services for women requiring or experiencing pregnancy termination or loss that are congruent with applicable laws and regulations and in accord with national protocols.

of the care received while giving birth in hospital settings in Nepal. It is hoped that by sharing the mothers' experiences, the quality of care will be improved. In this study the term 'at birth' covers admission to discharge. Physicians, certified nurses, auxiliary nurse-midwives or degree-trained nurses are referred to as SBAs or healthcare providers.

Method

Qualitative open interviews and content analysis were chosen as the method for gathering and analysing data, as this approach would allow for a comprehensive description of the mothers' experiences (Polit and Beck, 2012). Ethical approval for the study was sought and obtained from the Nepal Health Research Council (reference 1434).

Setting

This study was conducted in two tertiary-level hospitals where maternal and neonatal care was available. Both have teaching/learning and research sites in reproductive health, one facilitating more than 25,000 births annually and the other, 4000 births. Antenatal care was provided by doctors.

Study participants

To ensure a diverse group (Polit and Beck, 2012), the women represented different experiences, ages, education and ethnicity. The criteria for inclusion were first-time mothers with a healthy baby, vaginal birth, normal birth and/or assisted (intervention) birth, with a minimum of six hours spent in the hospital prior to giving birth and 24 hours after. The mothers had attended at least three appointments with doctors during their pregnancy, and gave birth between 38 and 41 weeks' gestation.

New mothers who met the inclusion criteria were invited to participate by the principal investigator (SS). The study was explained and potential participants left to decide whether to volunteer. Their decision to participate in the study was communicated to the study team through the ward in-charge or directly to the researcher who had approached them. In total 12 new mothers were approached to achieve 10 participants. Two could not participate in the interview due to earlier than expected discharge and 10 participants gave verbal and written consent prior to the study. All data remained confidential within the group of researchers. Participants details are included in Table 2.

Data collection

One-to-one, open interviews were conducted between July and November 2013. The aim of the study and method for data collection was communicated through the information sheet. When a woman had expressed her interest, a time and place was agreed. In order to secure a comfortable and confidential setting (Polit and Beck, 2012), the interviews took place in a private room on the postnatal ward with the native Nepali interviewer on the day of hospital discharge. The participants received written information explaining the aim of the study and the purpose of audio-recording,

Table 2. Details of mothers

ID	Age	Education	Duration in hospital	Ethnicity	Occupation	Sex of baby
M1	21	5th grade	Seven hours before and 24 hours after birth	Dalit	Homemaker	Boy
M2	20	11th grade	One day before and one day after birth	Chhetri	Homemaker	Girl
M3	19	8th grade	Seven hours before and three days after birth	Newar	Handicraft maker	Boy
M4	18	8th grade	30 hours before and 30 hours after birth	Janajati	Student	Girl
M5	24	10th grade	Seven hours before and two days after birth	Brahman	Homemaker	Girl
M6	23	Bachelor level	15 hours before and two days after birth	Chhetri	Homemaker	Boy
M7	23	10th grade	Six hours before and 24 hours after birth	Newar	Homemaker	Boy
M8	27	10th grade	14 hours before and three days after birth	Janajati	Service	Girl
M9	27	Bachelor level	One day before and three days after birth	Brahman	Government officer	Girl
M10	23	10th grade	10 hours before and two days after birth	Janajati	Homemaker	Boy

and were assured confidentiality. Identifiable data, such as names, were stored separately from interview transcripts, in computers only accessible to the researchers. Nepali was the language used throughout the interviews. The opening question was: 'I would like to know about your experience in the hospital. Please start by telling me what it was like when you were admitted?' The mothers talked about their experiences.

Where necessary the interviewer asked follow-up questions, such as: 'Tell me more about...?' or: 'Can you give an example?' The interviews lasted between 32 and 72 minutes, were audio-recorded, transcribed verbatim and then translated into English, according to Abujelban et al (2012). Cross-checking of transcripts, comparing the native Nepali transcriptions with the translated English version, was done by the translator and the principal investigator (SS). By placing interpreted text in its cultural context and by parallel cross-checking with the Nepali transcripts, the translated version was ensured not to be misinterpreted.

Data analysis

The process for data analysis was informed by Elo and Kyngäs' (2008) method for inductive content analysis (see Table 3). The phases of analysis were carried out between all authors to ensure credibility. The first step of the analysis was familiarisation. To make sense of the content and become immersed in the data, the transcripts were read several times. In step two, all text referring to experiences of being cared for was extracted and condensed. In step three, the condensed texts were given individual headings (codes). In total, 204 codes were identified. In step four, similar codes were shaped into nine sub-categories. The sub-categories were sub-divided based on their different contents. Five with similar content were grouped together under the category 'accountable caring'. The other four formed the category 'the act of communication'. The main category, 'trust in care providers, both relatives and professionals, was fundamental for mothers to feel cared for', captured the main themes identified within the text as a whole. To verify the interpretation of data, the findings were discussed with an 'expert panel' – a group of mothers who had given birth to

their babies in similar settings (Abujelban et al, 2012). To complete the analysis, the research group read and compared all translated transcripts to validate the accuracy of the result descriptions in this study (Polit and Beck, 2012).

Findings

Accountable caring

Accountable caring comprises five sub-categories: 'being cared for with others in the same situation', 'relatives' care complemented healthcare providers', 'relatives as guardians and source of information', 'gratitude for routine clinical care', and 'concerns about hygiene'.

Being cared for with others in the same situation

The mothers described how there was no privacy in the hospital but the women appeared comfortable with this arrangement because it created a sense of equality. The beds were in rows without partitions. Labouring women in first stage were on the bed with a relative next to them. Other women and relatives heard and saw them when in pain and compared their situation with others. Conversations between staff took place in the same room as other labouring women in the second and third stage of labour. The beds were in rows with partitions. Other women heard them giving birth and they compared their situation with others:

"The contractions kept coming – coming, going, coming, going – and many other women had already been taken out of the delivery room after delivery, some 45 had already given birth but it was me who still could not deliver the baby" (Mother 10).

In postnatal care, the mothers appreciated sleeping in the same room as other women and babies. With this arrangement, the mothers never felt alone. For many Nepali women, co-sleeping with family is the norm, so being alone in a room might be isolating.

Relatives' care complemented healthcare providers

The mothers found that relatives' care complemented the care provided by SBAs. Relatives acted as care-providers and supporters during the first stage of birth until the woman was moved into the delivery ward where relatives were not

Table 3. Sub-categories, categories and main category

Main category									
Trust in care providers, both relatives and professionals, was fundamental for mothers to feel cared for									
Category					Category				
Accountable caring					The act of communication				
Sub-categories					Sub-categories				
Being cared for with others in the same situation (30 codes)	Relatives' care complemented healthcare providers (20 codes)	Relatives as guardians and source of information (19 codes)	Concerns about hygiene (9 codes)	Gratitude for routine medical care (65 codes)	Healthcare providers and relatives giving advice (38 codes)	Mothers' need for antenatal education (12 codes)	Shared decision-making (6 codes)	Concerns and conflicts (5 codes)	
204 codes									
For example, no privacy, support from relatives, birth preparedness, decision-making									

permitted, only staff and other women giving birth. The women felt that they could not have managed the first stage of birth without support from their relative. Close relatives consoled the mother, provided basic care and gave massages:

"My elder sister massaged my back and I felt something happened, I had some relief" (Mother 3).

Relatives as guardians and source of information

Relatives took responsibility for bringing the women to hospital and would either accompany them or wait separately to be updated by staff. Relatives were part of all decisions made regarding mother and baby. Although the mothers could not choose their birth companion, they described feeling reassured that their relatives were nearby to offer support. The mothers had heard birth stories from relatives and friends about delivering at a health facility or hospital. Some mothers had female relatives who taught them about tolerance to birth pain and how to refrain from taking pain relief medication. The women had been advised that whatever the nurses told them was in their best interests. Some mothers were reluctant to have a hospital birth, but took relatives' advice:

"After my waters broke, my husband brought me here. So everything here is ok. All the things here are good for me" (Mother 4).

Gratitude for routine clinical care

The mothers felt reassured that the SBAs were continuously present and assisted them and their relatives during birth. They felt gratitude towards healthcare providers who routinely updated them and their relatives about the progress of the birth, provided paracetamol and offered advice such as how to massage and change position, what to eat or drink, how to push and breathe and why an episiotomy or stitches were necessary. The mothers talked about being consoled by SBAs during routine checks and recordings:

"They told me not to shout and cry because that would make it difficult for the baby and me at the time of delivery. They told me not to be afraid and consoled me by saying these words" (Mother 7).

After the delivery, the mothers felt gratitude towards the staff when they got to hold their baby skin-to-skin, and when the baby was given time to 'seek and suckle'. When a baby was going to be transferred to the neonatal unit, the women and her relatives were told the reason. Before discharge from the postnatal ward, mothers received information about self-care, for example, how to clean the wound after the routine episiotomy and the importance of future vaccinations.

The women all agreed that the hospital birth was better than they expected. They had found consistency in information and support offered:

"The nurses were very good. The nurses were like us, same like us. They were good, warm-hearted. They did well. The work was going on slowly, properly and in a careful way" (Mother 5).

Concerns about hygiene

Some mothers noted that their childbirth experience would have been more pleasant in a cleaner environment, with less

risk of infection:

"The hospital was not clean. After giving birth they took me to the floor where everyone was kept... it was not clean and they just pretended to wipe the floor" (Mother 6).

The act of communication

The act of communication comprised four sub-categories: 'healthcare providers and relatives giving advice', 'mothers' need for antenatal education', 'shared decision-making' and 'concerns and conflicts'.

Healthcare providers and relatives giving advice

At the onset of birth, the women and her relatives were advised about the birth process, but not necessarily in a way which empowered them:

"The doctors had already told me that it is difficult to give birth and a human is born out of a human so tolerance is needed and all will be fine" (Mother 1).

The women also described how the SBAs constantly advised and encouraged the relatives and the women towards a vaginal birth. The SBAs tried to convince relatives and women who wanted a CS of the benefits of a vaginal birth. Together, they encouraged the women to withstand the pain and were constantly offering advice:

"I felt I wouldn't be able to give birth... I was feeling a lot of pain. It was extremely unbearable. That is why I had been told that it was better to get the baby out with surgery. And then they told me you will give normal (vaginal) birth and it will be good. It cannot be surgery" (Mother 2).

Mothers' need for antenatal education

The mothers reported that they did not know enough about the hospital setting or about being pregnant and giving birth. During antenatal care, and from admission to discharge, the mothers indirectly gathered information by listening to staff conversations about other women and by listening to conversations between other women and their relatives. This was one of the ways they prepared themselves for birth.

In postnatal care, some described it as beneficial listening to other conversations as this helped them to better understand how to care for their baby. They expressed in wishful thinking how seeing the inside of the hospital wards and receiving more verbal or written information during pregnancy might have reduced their anxiety. The women talked about the importance of preparation for birth in order to fully understand what was behind the SBAs' advice and actions:

"I did not know anything about pregnancy, birth, child care or the hospital setting. I only came for check-ups during pregnancy. I never got the chance to see anything. What I saw was only during the birth" (Mother 4).

Shared decision-making

The mothers appreciated healthcare providers who involved the woman's relatives in decisions and choices that arose. Some very much appreciated the opportunity to make informed choices which involved them and their relatives:

"Then they counselled my husband and me and said that

"there was no clear reason for a caesarean section and asked our opinion giving us two options, birth by induction or caesarean section. We preferred this approach of giving us a choice and we chose birth by induction" (Mother 9).

Concerns and conflicts

Some women did not feel comfortable during birth with their accompanying female relative and would have preferred their husband to be present. Depending on the mother, some did not feel needful skills and positive experiences of giving birth had been communicated to them by female relatives during pregnancy:

"The sister and the mother-in-law who lives at my house, they told me 'it will be very difficult'" (Mother 4).

Some women felt the SBAs provided care during childbirth without considering a woman's individual needs and without attention to the newborn baby. Therefore, postnatally, female relatives took on the responsibility of caring for the baby.

Discussion

The findings of this study show how the trust of relatives and healthcare providers can pave the way for an experience perceived as 'being cared for' by woman giving birth in Nepal. With relatives playing such an important role in preparing for and supporting the woman, inviting them for some preparation sessions might improve maternity care in line with the ICM's (2010) competencies.

Relatives play a central role in decision-making as the guardians for the women and her baby (Erlandsson et al, 2014; Regmi et al, 2010). Mostly, female relatives accompany women in maternity units, as traditionally the partner is not present (Bajracharya, 2012; Sapkota et al, 2011; Acharya and Jimba, 2007). The SBAs had a common understanding of Nepali family structure and culture, which ensured that the mother's needs and expectations were met by cooperating with the relatives. In Nepal, as in other developing countries, cooperation with relatives in healthcare facilities and hospitals is important (Spleen et al, 2013; Paudel et al, 2012; Bowser and Hill, 2010; Peters et al, 2008; Simkhada et al, 2008) to bridge formal health systems and cultural care and maintain childbirth as being culturally safe (Kaphle et al, 2013).

In the present study, the women's experiences appear to have fulfilled their expectations overall, although some expressed less satisfaction when experiencing being neglected by SBAs and this is in line with other studies (Legare et al, 2012; Bowser and Hill, 2010; Swahnberg et al, 2007). The findings in this study point to a need for respectful care training for all types of healthcare workers providing maternity care (White Ribbon Alliance, 2011; ICM, 2010). Areas for change, in relation to the White Ribbon Alliance's (2011) and ICM's (2010) guidance, would be to ensure all women have the right to choose their birth companion. However, privacy does not appear to be so important to the mothers in this study. The lack of privacy and confidentiality was seen to be used by some women as an opportunity to learn and prepare themselves for a culturally sensitive birth

and baby care (Erlandsson et al, 2014; Kaphle et al, 2013; Abujelban et al, 2012).

This study indicates that birthing women in Nepal's national-level hospitals cannot rely solely on the care of SBAs for experiencing 'being cared for', as recommended by the ICM (2010). Instead, they rely heavily on relatives (Erlandsson et al, 2014). Mothers highlighted that more information and some preparation may have reduced their fear. This appears to be a valuable central issue in the findings and it seems appropriate to offer 'preparation for birth sessions' to both the woman and her relatives, in line with the WHO's position and previous research advocating SBAs empowering women to take care of themselves and their newborns (Paudel et al, 2012; Utz et al, 2012; Acharya, 2007; WHO, 2004).

Limitations

No review analysis, or analysis of the quality of the articles referred to, has been performed. The search strategy was to find and present Nepal-specific articles linked to the theme of this study. The main limitation is the small number of interviewees, which makes the transferability of the findings difficult. This study is unique because finding women who were prepared to speak honestly about what is considered a private subject is rare in Nepal. On the other hand, the women who did participate had an interest in sharing their experiences of giving birth in a main hospital with highest level of maternity care and the authors faced no difficulties in recruiting participants or tape-recording the interviews. This might have affected the findings of this study, as choosing women from different backgrounds within Nepal, other views might have been illuminated. In this study, there may be a threat to dependability (Polit and Beck, 2012), since the interviews took place just before discharge, when the mothers were still dependent on hospital healthcare providers. Notwithstanding these limitations, this study emphasises the importance of relatives' involvement to ensure women experiencing 'being cared for' in hospitals in Nepal.

To achieve trustworthiness (Polit and Beck, 2012), the interviews were held in a private room in the hospital where the women were free to express their feelings to an independent Nepali interviewer. The forward and back translation (Abujelban et al, 2012) was done by a native Nepali with a good understanding of both languages and the topic. Caution was taken and cultural issues considered while translating verbatim into English. This reduced the risk of the findings being distorted or misrepresented. To verify the interpretation of data, the authors discussed the findings with a group of mothers who had given birth in similar settings. In the final step, no external experts confirmed the interpretation made but the group of researchers. This might have been a threat to trustworthiness (Polit and Beck, 2012).

Conclusion and implications

'Trust in care providers, both relatives and professionals, was fundamental for mothers to feel cared for'
For women to experience 'being cared for', they need to be accompanied by relatives and trust those relatives and

healthcare providers. There must be clear communication between mothers, relatives and care-providers. Relatives should be prepared to take on basic caring tasks and work together with the SBAs. For practice, delivery of preparation-for-birth sessions for both the mother and relatives are recommended; because mothers highlighted that more information and some preparation for birth might have reduced fear and anxiety. Relatives are a valued

addition to healthcare providers' provision of clinical care during birth. Culturally sensitive delivery of respectful care could be improved and, therefore, appropriate training programmes to healthcare workers are also recommended. Further qualitative research could be undertaken with more women from different areas and healthcare levels in the same country to obtain a complete picture of culturally sensitive and respectful maternity care based on mothers' experiences.

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Early labour midwifery care in Italy: local and cross-cultural challenges

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Abstract

Introduction. The definition of early labour and its management are debatable issues at a local, national and international level. In Italy, this issue is also of concern.

Approach. This is a descriptive discussion paper designed to portray the cross-cultural issues and the comparisons between Italian and international early labour care.

Key issues. Many of the issues regarding early labour care in Italy resonate with what emerged from the international literature. These include the dilemmas of diagnosis and management of early labour, appropriate timing for women's admission to hospitals in the latent phase and the type of maternity service available to women in early labour. The lack of a mapping of the geographically variable services offered to women in the Italian peninsula makes the task of offering national data to international research on early labour care challenging as little is known about the availability, efficiency and effectiveness of triage systems for women in the latent phase of labour.

The way forward. The organisation of maternity services within the Italian national health system requires a review to consider how best to meet women's needs during early labour. Research in this field needs to be carried out in Italian birthing settings in order to be able to understand what would work best for women within the specific socio-cultural context and what is required to enhance midwifery knowledge and skill.

Key words: Early labour, latent phase, midwifery care, Italian national health system, Italy, evidence-based midwifery

Introduction

Early labour definition, knowledge and care appear to be quite contentious among healthcare professionals worldwide (Janssen et al, 2009). International debates on the topic are mainly related to diagnosis and management of early labour (Cheyne et al, 2006), maternity services available to women in the latent phase of labour (Spiby et al, 2013) and admission to hospital versus staying home in early labour (Janssen and Desmarais, 2013; Eri et al, 2011; Nolan and Smith, 2010; Cheyne et al, 2007). The Italian context seems to share many of the key issues highlighted internationally by authors, even though it is not clear where Italy is placed within these debates; an apparent dearth of publications concerning early labour care in Italy may be due to relevant material only be available in Italian language, making it inaccessible for many international readers. This discussion paper reflects on both internationally shared and local challenges around early labour, with the rationale that 'cross-cultural comparison can be expected to provide information for a better understanding that is not available from the inside point of view of any particular system' (Jordan, 1993: 6). By doing this, it aims to offer a picture of the Italian situation in light of the relevance of discussing the 'culture-specific shaping of the universal physiology of birth' highlighted by researchers and anthropologists (Jordan, 1993: xi).

Italian national health system and maternity services

In order to allow an understanding of the challenges related to early labour care in Italy, it is necessary to provide some

contextual elements regarding the Italian maternity system of care and culture. In Italy, maternity care is guaranteed as free and provided as part of the public services by the national health system, called 'Sistema Sanitario Nazionale'. Services are also supplied as part of the state-run healthcare programme, or independently by the private sector.

Although the available services and care provided are geographically heterogeneous, the medicalised and hospital-centred culture around pregnancy and childbirth appears as dominant in the country and emerges from the data of recent national reports on maternity care. Lauria et al (2012) found that only 3% of Italian women receive midwifery-led care in pregnancy while 86% are cared by a gynaecologist/obstetrician. The remaining percentage of pregnant women (11%) are assisted in community facilities with no indication of whether midwifery-led or consultant care is provided.

The majority of births take place in public services (88%), followed by births in non-public institutions (12%) and a very low rate of home births (0.04%) mainly assisted by independent midwives (Basili et al, 2013). Hospital represents the main place of birth, while midwife-led units and home births are very rare. Unsurprisingly, women can access midwives' care primarily in large hospitals and obstetric units, rather than in their own homes and communities. Although in the last decade attention has been placed on normal pregnancy and birth (Sistema nazionale per le linee guida, Istituto Superiore Sanità, Ministero della Salute, Centro per la valutazione dell'efficacia dell'assistenza sanitaria, 2014) and a slight increase of independent/

community midwives has occurred, these data show the controversial reality of maternity care in Italy, and stress the necessity of supporting more evidence-based and family-centred models of care. For example, midwife-led continuity models (Sandall et al, 2013) currently operational in the UK (Redshaw et al, 2011; de Vries et al, 2001), Netherlands (Borquez and Wiegers, 2006; de Vries et al, 2001), Australia (Homer et al, 2002) and New Zealand (Freeman et al, 2004; Guilliland and Pairman, 1995).

The power of terminology

The terminology regarding early labour in Italy seems to reflect the authoritative knowledge underpinning professionals' education and practice. The Italian term generally used to describe the latent phase is 'prodromi', plural of 'prodromo' – from the Greek πρὸδρομός – that means precursor, forerunner, a fact or event that precedes another. Interestingly, in the Italian language, 'prodromo' is commonly used to indicate a precursor of an adverse event, such as an economic crisis, a war or a disease (Gabrielli, 2013). Therefore, this term seems to identify a discrete phase of a process that appears not necessarily fortuitous for the individual involved.

Additional reflections can be made when this terminology is compared to the English definitions internationally adopted. In fact, while the English term 'early labour stage' seems to highlight this as a phase on a continuum with active labour, the Italian definition underlines it more as a separated, although linked, period of time that comes first, before the first stage.

The Italian traditional classification of labour stages seems to reinforce this view of early labour as a distinctive step, in a step-like pathway rather than as an early phase of a continuous process of labour/childbirth.

According to a popular Italian obstetric textbook, commonly known as 'Pescetto' after the name of one of the authors, labour is characterised by a sequence of four different phases. The first is the 'periodo prodromico' (early labour stage), followed by the 'periodo dilatante' (dilation period – first stage), the 'periodo espulsivo' (expulsive period – second stage) and finally the 'periodo del secondamento' (delivery of the placenta – third stage) (Pescetto et al, 2009).

Despite the importance given to 'prodromi' that deserves its own place in this classification, the phenomena characterising this phase occupies less than a page in the text, with a focus limited to characteristics of pain and expected changes of the cervix within a set time. Consequently, midwives and doctors have been taught for decades that a physiological early labour stage is supposed to last eight hours in nulliparas and five in multiparae, on average, under the influence of the authoritative knowledge of the 'Pescetto'. Given these parameters, it is of little surprise that the tendency of many Italian health professionals is to label and manage physiological early labours as pathological, even if different definitions included in international guidelines – such as NICE's Intrapartum care (2007) – are well known and adopted.

Italian early labour midwifery care: internationally shared and local challenges

The relevance that early labour care may have within maternity systems has been highlighted in a roundtable discussion engaged by Janssen et al (2009). The authors address the problem by stating 'in places where hospital birth is the norm, one of the major contemporary challenges to the organisation of intrapartum care is posed by women who are not in established labour' (Janssen et al, 2009: 332). This resonates strongly with the situation in Italy. Unsurprisingly, Italian midwives and obstetricians/gynaecologists seem to experience many of the clinical and organisational challenges reported in the international literature. These include, in particular, the dilemma of the appropriate timing for women's admission to hospital when in the latent phase, based on the increasing evidence concerning the negative outcomes related to early admission.

This appears to result in a higher likelihood of women being diagnosed with labour dystocia and undergoing intrapartum interventions, such as augmentation with oxytocin, instrumental delivery or caesarean section, when compared to women admitted to hospital in active labour (Cheyne et al, 2006; Bohra et al, 2003; Klein et al, 2003; Holmes et al, 2001; McNiven et al, 1998). Thus, in Italy, as elsewhere, early labour may represent a 'time of conflict between a woman's perceived need to be cared for and the perception of care-givers that best practice means keeping women out of hospital' (Janssen and Desmarais, 2013: 190).

Early labour had been described as a fundamental physical and psychosocial phase of transition for women potentially affecting birth at many levels from maternal and neonatal outcomes to women's satisfaction (Cheyne et al, 2007; Cheyne et al, 2006). Italian authors have contributed to the debates on the key role played by this phase raised in the last decade. In particular, Minocchi (2007) acknowledged that all the places where a 'technocratic model' (Davis-Floyd, 2001: s5) of labour care is dominant, the prevalence of a 'doing' culture in Italy necessarily leads to great interferences with the delicate physiological process of women's 'prodromi'. The overuse of drugs and medical interventions, as well as the adoption of an authoritative and 'asymmetric' communication style with the woman, resulting in her depersonalisation as an individual instead of her empowerment, are presented as a translation of that 'doing' culture into early labour care within Italian maternity services.

Bianco (2007) described the key role played by midwives in understanding women's individual needs during this sensitive phase of labour as often being underestimated in favour of hospital routine practices. According to Perazzola (2007), inappropriate care might originate in Italy from a misleading knowledge of early labour. The author stresses, for example, how the devaluation of the latent phase often originates from considering it for 'what it is not', as terminologies such as 'false labour' might express, than for 'what it is'. The powerful role played by what is (un)known and not valued yet of the latent phase on professionals and decision-making (Janssen et al, 2009;

Cheyne et al, 2006), together with the presence of non-homogenous/unclear criteria for its diagnosis and management (Spiby et al, 2013; Janssen et al, 2009; Minocchi, 2007; Cheyne et al, 2006), seem to equate the practice in Italy to many others in developed countries.

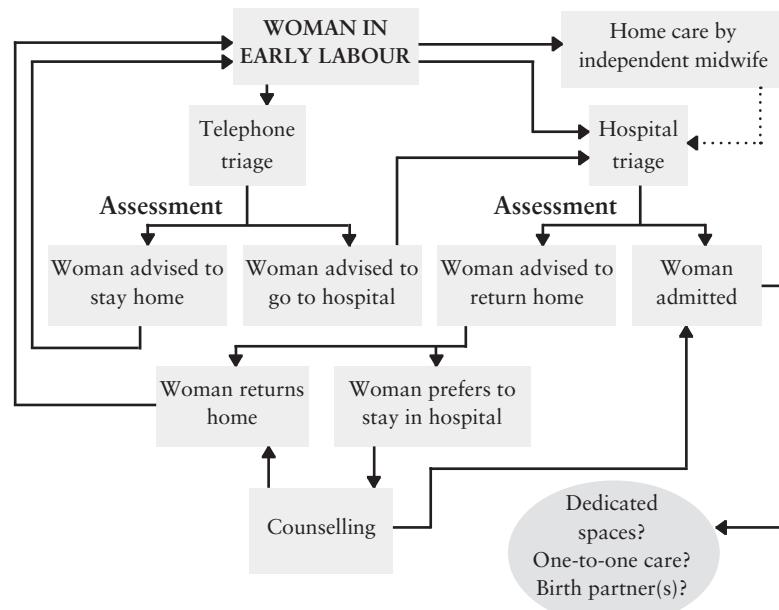
Women accessing services during the latent phase encounter the fragmentary nature of Italian maternity system and care. Given the absence of a shared national pathway, the options available are heterogeneous and may vary depending on local policies (see Figure 1). The types of access mostly offered to women in early labour in Italy are telephone triage and hospital triage. Home care in early labour appears as the most controversial option. In fact, community midwives are usually not involved in intrapartum care and the (few) independent midwives are not accessible nor affordable as costs for everyone. Doulas are emerging figures, but they are not always perceived as a resource and their role in women's care is still unclear and increasingly questioned (Guana, 2013; Cinotti, 2012).

However, much of what is illustrated above can only be supported anecdotally, given the dearth of research evidence in this area. The fact that midwives in Italy are still struggling to have academic and leadership roles and be protagonists in research is part of the problem. Moreover, the lack of mapping of the geographically variable services offered to women in the Italian peninsula makes the task of offering national data to international research on early labour care very hard. For instance, little is known about the availability, efficiency and effectiveness of triage systems (both hospital and telephone) for women in the latent phase of labour. Information on how Italian maternity services deal with the issue of inappropriate hospital admission, and subsequent inappropriate care, in early labour where alternatives such as a community or independent midwifery-care are not supported (Lauria et al, 2012) would assist both local stakeholders and women and their families, and contribute to the international debate. Information should also be obtained on who can provide the best possible care for women in Italy, given the alarming national shortage of midwives – estimated years ago to be around 1700 by the WHO (Büscher et al, 2010) – and the openly questioned possibility of integration with other practitioners, such as doulas (Guana, 2013; Cinotti, 2012). A medically dominated healthcare system and lack of financial resources are other obstacles for Italian midwives to work to their full potential (Büscher et al, 2010). Apparently, many interesting questions are waiting for answers; to include them in a national research agenda would be beneficial for both the Italian and the international scientific and professional communities.

Conclusion

This paper offers the first Italian contribution to current international debates and controversies around early labour

Figure 1. Main path of women's access to early labour care in Italy



midwifery care. Many of the issues related to early labour care in Italy resonate with what emerges from the international literature. Besides the possible differences in the provision of maternity services (for example, community services, home visiting during early labour and hospital admission) in various countries, similar struggles in finding a proper support in that sensitive phase of childbirth represented by the latent phase seem to make women and families in Italy close to many others in the world. Interestingly, by looking at local practices within international debates, some women's needs in early labour emerge rather strongly as universal, likewise the professionals' struggles in meeting these needs through their understanding and care of this phase. Feelings of uncertainty characterising women's experiences of early labour, especially in first-time mothers (Cheyne et al, 2007), may dominate birth places regardless of geographical boundaries. Midwives' reassurance appears to be crucial in helping women to cope with the early stages of labour (Cheyne et al, 2007), whether this occurs at home or 'in casa' (the Italian term for 'home').

The issues raised regarding early labour care in Italy appear to be only the tip of the iceberg in a system where midwifery-led approaches to care, recognised internationally as highly beneficial for women and families, are still struggling to find their place. The organisation of maternity services within the Italian national health system deserves important reconsideration in order to meet women's needs. Much has to be done to support a midwifery culture and its models, for example by re-discussing community midwifery systems, midwife-led units and caselocation. In the meantime, considering the available Italian maternity services, midwives are challenged to find original and alternative solutions for early labour care. Examples of these might be the provision of a home visiting service from existing community facilities, the implementation of telephone triage and the rearrangement

of current hospital spaces to create dedicated areas, in order to provide a better care during 'prodromi'.

Evidence related to Italian early labour care needs to be produced for the benefit of the national and international community. Research needs to be carried out in Italian settings to understand what would work best for early labour in the specific socio-cultural context and add elements to

the cross-cultural midwifery knowledge. An urgent first step in developing a research agenda might include the creation of a national map of maternity services available in Italy; this would be useful to women and healthcare professionals. Furthermore, both midwives' and women's perceptions, views and experiences of early labour should be explored in the context of Italian maternity services.

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Antenatal education in Jordan: a rapid appraisal abstract

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Abstract

Background. Antenatal education is a widely accepted primary care intervention that is implemented across most cultures. However, the standard of the education provided is variable and has not been widely evaluated in the Middle East.

Aim. To evaluate the provision of antenatal education in the Kingdom of Jordan.

Method. A rapid appraisal using triangulation of data. A convenience sample of 23 healthcare professionals in two public and five private maternal and child healthcare providers and 10 pregnant women were chosen as the key informants. Data were collected from semi-structured, face-to-face interviews, observations and written documents. Approval was obtained from the University of Ulster and the research ethics committees of the Hashemite University in Jordan.

Results. Analysis of the data demonstrated inadequate service provision and poor access to quality antenatal care.

Conclusion. This study provides important data about the provision and impact of antenatal education in Jordan and demonstrates that improvements can be made.

Key words: Antenatal care, antenatal education, Jordan, service provision, service evaluation, rapid appraisal, health promotion, evidence-based midwifery

Introduction

The Hashemite Kingdom of Jordan is a conservative, developing Arabic country with a population of 6.5 million (Department of Statistics, 2014), a fertility rate of 3.5 children per woman (Department of Statistics, 2014) and a maternal mortality rate of 0.19 per 1000 live births (Amarin et al, 2010; UNICEF, 2010); the latter rate reflecting half the number reported 10 years ago. The under-five mortality rate is 21 per 1000 live births (Department of Statistics, 2014) and the neonatal mortality rate is 13 per 1000 live births (UNICEF, 2010).

From these figures, it is clear that most deaths occur in the neonatal period, which means that better care for women during pregnancy could potentially reduce the neonatal mortality, as enhanced antenatal care and antenatal education (ANE) have been shown to have positive effects on neonatal morbidity and mortality (Singh et al, 2013).

The government of Jordan has given priority to the nation's health and has developed a national strategy, which has resulted in considerable progress in maternal and child health care. The largest agency providing primary health care is the Ministry of Health, with 6.3% of the total government budget (Ministry of Health, 2011). The Ministry of Health is committed to make health services available, accessible, and acceptable in all communities; it also seeks to ensure equitable distribution of these services.

One of the basic strategic roles of the Ministry of Health is providing preventive and primary health care. This includes vaccinations, educational services and awareness campaigns, mother and child services, school health services, food safety, environmental health, safe disposal of waste, occupational health services, prevention and treatment of infectious and non-infectious diseases and mental health services (Ministry of Health, 2002).

Recent developments include free, nationally available ANE programmes, which aim to prepare expectant mothers for labour, birth and their new lives as mothers, to decrease their fear and anxiety, and to increase women's confidence in their ability to give birth. The new programme is designed in order to educate women about health during pregnancy, birth, and the postnatal period. The key principles are adopted from the seminal work on ANE by Nolan (1998) where the purposes were identified to:

- Build a mother's confidence and self-esteem
- Increase awareness among women of their bodies, feelings and needs
- Enable women to achieve physical and mental health after childbirth
- Encourage critical thinking about medical interventions in order to protect the normality of birth and the right of women to receive evidence-based care.

The Jordanian government is currently offering all pregnant women support during their transition to motherhood. This is intended to complement the informal support already provided by parents and grandparents, and is free of charge.

Success in childbirth depends on the woman being fully engaged in the process, empowered to participate fully and having good professional support from a midwife. The enhancement of women's knowledge about labour is important for the next generation of parents and children as modern women expect individualised care during their labour and birth (Robertson, 2006).

However, establishing new ANE services requires change in local health services and adequate planning for an integrated service delivery, with in-built evaluation of service initiatives to assure quality, and guide further developments. Such evaluations help to ensure sensitivity

and responsiveness to local needs. While the Ministry of Health publishes annual statistics about the number of women who received ANE, the important part played by other agencies and their contribution to improving ANE is not recorded.

In order to identify and understand the current position of ANE in Jordan, a structured review of the literature was undertaken to search for studies combining: 'antenatal care', 'utilisation', 'antenatal education', 'Jordan', 'service provision', 'service evaluation', 'rapid appraisal and health promotion', and 'impact of antenatal education'. Common databases were accessed: Cochrane library, CINAHL, Medline and selected sites on the internet. In addition, the lead author hand-searched citation lists for relevant papers. Papers were selected if they included the key words above and were focused on health promotion and antenatal health in Jordanian settings.

Two studies found to be most relevant to the study were conducted in Jordan on maternal and child health utilisation and health promotion. The first was a survey conducted by Haddad and Umlauf (1998) to explore the attitudes of Jordanian midwives and nurses working in primary care settings regarding health promotion.

The study included all midwives and nurses (n=104) working in the Irbid Governorate primary health care and maternal and child healthcare centres. Half of the respondents considered 'lack of time' to be a barrier to carrying out health promotion effectively, however they all acknowledged their responsibility to encourage healthy activities.

Furthermore, the respondents believed that they were well suited to provide health education. The second study (Obermeyer and Potter, 1991) examined the uptake of maternal and child health services using data from the *Jordan Fertility & Family Health Survey* of 1983 (Department of Statistics and Division of Reproductive Health, 1983), which included 2949 women. The findings showed that over half the women (57%) went to the private sector, mainly physicians (42%), while the next most common provider of prenatal care was public maternal and child health centres (25%).

These two studies were descriptive and focused on primary healthcare provision and utilisation in general. Haddad and Umlauf (1998) explored attitudes regarding health promotion and Obermeyer and Potter's study (1991) was focused on service utilisation. None of the studies described the current Jordanian ANE provision from either women's or providers' perspectives.

A further overview was undertaken to understand the impact of ANE on birth outcomes, using systematic reviews published between 2001 and 2007. Four reviews were found in the *Cochrane Database of Systematic Reviews* and one in the *Journal of Human Lactation*. The reviews identified the effectiveness of ANE in general and specifically on breastfeeding, psychological adjustment, smoking cessation and information about caesarean section (CS).

The reviews included randomised controlled trials and other experimental designs. Three reviews demonstrated

the effectiveness of ANE on breastfeeding practices and smoking cessation (Dyson et al, 2005; Lumley et al, 2004; de Oliveira et al, 2001), while two reviews concluded that the effect of ANE on CS rates and fear remain largely unknown and inconclusive (Gagnon and Sandall, 2007; Horey et al, 2004). Overall, the methodological quality of the trials was uncertain and the power was inadequate to detect the difference between the comparative groups.

Hence, the effects of ANE remain unknown and it may or may not be the most effective way of improving maternal and neonatal outcomes. In Jordan, there is a lack of research regarding ANE provision and effect of this education on maternal and neonatal outcomes. Therefore, further studies are needed to determine the provision, implementation issues, and effectiveness of Jordanian ANE.

Rationale

Since 2002, ANE has been freely available to all Jordanian women, however, there are no available evaluation data about the uptake or perceived benefit. ANE is provided in different settings by people with different educational backgrounds. This led the authors of this paper to perform a rapid appraisal to provide a 'snapshot' of the current provision in the Kingdom of Jordan.

Aim

The aim of this study was to identify the range and extent of supports provided through ANE. This was in order to:

- Identify the views of users, provider organisations, midwives, and healthcare professionals about current arrangements of ANE and future service options
- Inform local policy-making and the commissioning of services
- Facilitate and inform interagency collaboration and development.

Method

Rapid appraisal was adopted to enable a district wide approach to review service provision (Murray, 1999; Murray et al, 1994).

Rapid appraisal is fast and economical in time and effort. It does not include randomisation, however, it can yield helpful data and acceptable levels of validity. It is a useful approach for measuring, monitoring and evaluating many types of health programmes (Beebe, 1995). The method included:

- Review of secondary data and re-analysis of statistics from household surveys and governmental documents
- Gathering of primary data, through key informant interviews and non-participant observation
- Mini-survey of service users to obtain factual quantitative data (UN ESCAP, 2005; Murray, 1999).

To enhance validity, triangulation was used: a short, tightly focused list of issues was made; for each of them, data were obtained from at least two sources. This was done using different techniques (for example, observations and key informant interviews).

Data sources

Over a five-month period, data were collected from written policies at national and local level, interviews with a range of key informants drawn from the local community, women and service providers, and observations made in the health centres where ANE was provided (this involved one clinical day in each health centre to observe and record the main key points in the practice of ANE). The sources of written information were census statistics, surveys, governmental and non-governmental agencies, ANE providers, reports of studies undertaken within local universities, internet search, regional health statistics and health centre records.

Procedures

A list of local health and ANE providers and community groups was compiled and visits planned. The agenda for meetings and preliminary discussions were agreed with key agencies and community representatives. Each organisation was asked to nominate a key informant who was provided with full details: background information, aims and objectives, proposed methods, draft time plan, and expected outcomes. Users and potential users of ANE services were identified. Public and private agencies organisational structures, links, and contexts were identified. A range of methods (interviews, telephone interviews, observations and document review) was used to collect and verify data.

Participants

A total of 33 participants took part in the data collection: 10 pregnant women and 10 midwives were included in non-participant observation; a further 13 professionals were interviewed, comprising: five health educators, three obstetricians, two general practitioners, one head of health promotion in the Ministry of Health, one head of educational materials at the Ministry of Health and one head of maternal child health centres.

Data collection

Interviews (n=13) were carried out with professional key informants including public and private agencies in order to understand the ANE services provided: the educational styles, content and practical issues with service delivery. The effect of personal biases and prejudices on the part of informants was kept in mind at all times and leading questions were avoided.

A semi-structured interview schedule was prepared and validated by the co-authors. The schedule took the form of a broad framework of issues. The goal was to elicit views and opinions through guided questioning, in order to understand the current practice and establish the priority given to health and social need issues during pregnancy. In addition, the participants were asked to consider ways to improve the uptake of existing services to meet gaps in the current provision of services.

Unstructured non-participant observations (n=10) were conducted to understand the midwives' educational activities as they occurred, in naturalistic settings. Observations were started by gaining entry into the health

centres after getting to know the gate-keepers, developing rapport and establishing trust with them by giving a brief, simple explanation about the study.

Observations were conducted with the lead author remaining seated in the same position without interacting with the participants to minimise observer's bias and observer's influence. Observations were recorded in descriptive and reflective notes.

Ethical considerations

Following a preliminary review at the University of Ulster (UK), ethical approval was gained from the research ethics committees of the Hashemite University. Permission to access the maternal and child health centres, women, and the information centres was obtained after writing to private and public agencies. Consent was gained from the participants after an overview of the study purposes and objectives were explained.

Participants were assured that their participation in the study was voluntary and they were able to withdraw from the study at any time or refuse to answer any question without giving any explanation and without affecting their care. To assure confidentiality, each interview was assigned a number, rather than a name. In keeping with data protection policy, all paper copies of data were stored in a locked filing cabinet and all electronic data were stored on a password-protected computer.

Data analysis

Semi-structured interviews were transcribed verbatim and word-processed on a personal computer. The interviews were analysed by two researchers independently, using a thematic content analysis (Berg, 2004). They were categorised and coded before the emergent themes and patterns were identified; these were validated and agreed by the authors.

Results

The mean age of pregnant women was 27 years (range: 18 to 35 years). Three of the women were employed outside the home. Most of them (n=9) were primiparous and they were from different socio-economical classes. Their education varied from elementary (n=2) to secondary (n=5) and university education level (n=3). All had a low-risk pregnancy. Seven were in the third trimester; three in their second trimester.

The mean age of the midwives was 38 years (range: 30 to 45 years), and the majority of them held a midwifery diploma (n=9), one had a master's degree in nursing education and was certified as an antenatal educator. Demographic details of other staff participants were not collected at interview.

Triangulation techniques were used in analysing qualitative data collected through face-to-face interviews, observations and written documents. This resulted in two major areas of concern emerging: poor service provision and problematic access to quality antenatal care in Jordan. These themes will now be discussed in detail.

Current service provision

Respondents spoke at length about the details of ANE in Jordan. Three sub-categories were identified: antenatal care, ANE types, and ANE contents.

Antenatal care

Jordanian antenatal care has been established along the lines of common approaches used in most developed countries, with adjustment for local conditions. The Ministry of Health has set out the provision of antenatal care and its components as consisting of: history-taking, physical examination, laboratory tests, and ANE. The examinations include measurement of blood pressure, testing of urine for bacteraemia and proteinuria, and blood tests to detect anaemia; routine weight measurement at each visit is recommended.

The schedule of antenatal visits is as follows: following booking visit at around 12 weeks, women are routinely seen every four weeks until they are 28 weeks; then every two weeks until they are 36 weeks and then weekly until birth (Ministry of Health, 2002).

ANE is part of antenatal care for all pregnant women, and the Ministry of Health has set out the provision of this education with standards that detail the guidelines and content of the ANE. The guidelines clarify that the information should be divided over the course of the antenatal visits; each visit should build on the previous visit, avoid too much information at one time, and focus on the most important issues (assuming the woman may not be seen again).

Interviews with women and observations indicated that the provision of the main clinical components of the antenatal care, of history-taking, physical examinations, and laboratory tests, were provided, in both public and private sectors.

However, a problem was identified in both the public and private sectors with the integration of education with clinical care. For example:

"In my first visit, they asked me to do urine and blood test, in my second visit they recorded my personal information, then took my blood pressure, and weight, then sent me to the doctor. Neither the midwife nor the doctor gave me information about my pregnancy" (W0:10).

Types of education

In Jordan, antenatal care and ANE is provided by both public and private sector organisations (Obermeyer and Potter, 1991). It is provided in two ways: either in group classes or as support to individual women. A mixture of approaches was found. In the public sector, group classes were rarely conducted, mostly brief individualised instructions were provided.

On the other hand, in the private sector, the private educators held group classes when attendees were available, while the private obstetricians were providing individualised information for pregnant women from time to time.

Content of education

The Ministry of Health sets the standard for ANE (Ministry of Health, 2002) as a right for each pregnant woman, regardless of her religion, ethnic group or parity. The standards detail the content to include: birth planning, common complaints and symptoms of pregnancy, nutrition advice, immunisation during pregnancy, bathing and personal hygiene, clothing, relaxation and sleep, danger signs during pregnancy, travel, drug education and classification of drugs, work during pregnancy, sexual relationships, care of teeth and gums, breast care, breastfeeding, counselling, bowel habits, birth spacing counselling, exercise, fetal movement, hazards in pregnancy and postnatal issues, such as: smoking and alcohol, childbirth education, warning signs of preterm labour, physiology of labour, postnatal care and psychological problems (Ministry of Health, 2002).

Access to antenatal care and ANE

Analysis of the data from observations and interviews with the care providers identified themes around limited resources, lack of interest, lack of awareness, unsuitable timing, and inequity. Each sub-theme is presented below:

Limited resources (manpower, time, venues, family finance)
Despite the clear detailed policy of ANE in governmental standards, there were no antenatal classes held for women in public settings; where the education took the form of individual instructions. The midwives who are responsible for providing the information were not qualified for such a role and were often busy with other aspects of care, which affected their educating role.

Sufficient places for provision of education were rarely available and educational materials were not always available either. Also, a shortage in health educators was noted, as educators were not present in each health centre, and when they were available, they shared responsibility for other patients in the centres leaving them little time for individualised care of the pregnant women. The following comments were made by educators and midwives in public health centres:

"I do not have time to educate women" (M0:01).

"We do not have appropriate resources for education" (M0:03).

"We have no certificates in ANE" (M0:04).

"I am trying to do my best in educating women, especially the primis, but I do not have enough time because of the crowd" (M0:06).

"I am educating all the patients not only the pregnant women in this comprehensive centre" (E0:03).

It was a different situation with the private educators and one of the non-governmental organisations, where the education was well organised, but the women did not think they should have to pay for it. Typical comments were:

"When the education was free of charge, many women attend my classes, but when there is a charge, the women stopped coming" (E0:01).

"The women do not like to pay, so our programme stopped after two months" (E0:02).

Lack of interest

Even when the ANE was well organised and free of charge, attendance was sometimes poor. The head of one institute commented:

"I announced in the newspaper and inform every single woman about the classes, but the number is decreasing over time."

Women's opinions differed from those of the providers' and they gave different reasons for not making use of the ANE services provided by the public and private agencies. Some possible reasons were uncovered.

Awareness of ANE

Some women did not know about the services provided or how to access them:

"I do not know about such service" (W0:01).

"Neither the midwife nor the GP gave me any information about my pregnancy and about what to expect in labour" (W0:09).

Unsuitable timing of ANE

Others had problems accessing services during working hours because of employment:

"Because I am working, the time of the classes does not suit me" (W0:05).

Inequity in service availability

Lastly, reference was made to the limited availability of well organised, free-of-charge classes, which were offered only in the private sector and only in the capital city:

"I do not have enough money to pay for something I can get it from relatives' experience" (W0:11).

"I heard about such classes in the capital, none are available in my city" (W0:08).

Discussion

In spite of a high level of agreement at policy level, ANE in Jordan varies. This study indicated that ANE, as in many parts of the world, varied from individual instruction in the one sector to group classes in another sector. Unfortunately, such instruction did not appear to have achieved the desired educational objectives.

This mirrored the findings of Okour et al (2012) who noted that 85% of pregnant women were not aware of the signs and symptoms of dangerous pregnancy complications. This situation is not specific to Jordan as similar findings have been reported in other Arab countries, such as Sudan (Ali et al, 2010) where low rates of awareness of pregnancy-related danger signs were identified.

Nevertheless, this study identified a range of specific issues in relation to ANE provision in Jordan, which were unique and not reported in previous literature. The issues identified were challenging, with different perspectives being presented by the users and by the providers. Providers' issues with ANE were limited resources, inappropriate implementation, and disinterested customers. Users' issues were not knowing about the availability of free ANE classes, inconvenient scheduling of sessions and inequity

in the service availability. Public sector issues were not completely different from private ones.

While the main concern for the public sector related to resources (midwives, time, places, educational materials and cost for women), the concern for the private sector was the lack of interested women in the service, especially if they had to pay (also a matter of resources). This finding highlighted the under-utilisation of the ANE services in both private and public sectors and is a clear indication of the need to undertake further research to understand the actual reasons for under-utilisation from the women's perspectives, specifically in the public sector, where the ANE is free of charge.

This study also identified some conflicting views between providers and women, for example, between women who did not know about the classes and educators who claimed that every woman was informed about ANE.

As a part of its health reform, Jordan's Ministry of Health is focusing on primary and preventive care. Their standards of care for health centres (2002) detail reproductive health care and serve as a reference point, a guide for service delivery, and a tool to support performance improvement. Lack of such standards in the private sector emerged as a policy issue.

In 1997, Nolan and Hicks discovered UK antenatal educators utilising a wide variety of techniques/programmes, indicating no clear or standardised criteria – a situation which appears to be similar today in Jordan.

If the standards could be achieved, in both private and public sectors, women's health care would be improved. There is a need to decrease maternal morbidity and mortality as well as neonatal morbidity and mortality, as they are still relatively high in Jordan in comparison to more developed countries (UNICEF, 2010). It is known that the maternal mortality rate showed a remarkable reduction of 54% achieved in the last 12 years, but avoidable factors were present in 54% of fatal cases and 53% of them had substandard care (Amarin et al, 2010).

All providers acknowledged their educating role, as part of their care for women, as also found by Haddad and Umlauf (1998), who noted that midwives acknowledged their role to provide information. Furthermore, in this study, the public midwives claimed lack of time as a main reason for not providing enough information to women about their pregnancy, the birth and the postnatal period. Many suggestions emerged for ANE developments, including interagency collaboration, more supportive relationships with women, and evaluation of the current programmes.

In particular, the private educators showed a desire to provide classes in public health centres in view of the inadequate preparation of public midwives. They claimed that funds are needed to support their classes, as the fee was cited as women's main obstacle to attending. Further study is needed to fully evaluate the ANE programme delivered in public health centres.

This study aimed to identify issues, rather than produce generalisable results. The use of rapid appraisal methods proved to be effective as a means of clarifying some issues and of deepening an understanding about ANE provision, identifying drawbacks and implications of potential

developments of the service in this region.

Moreover, it offered a quick, relatively reliable, and collaborative method of understanding women's and provider's perspectives without having to resort to more costly methods.

Establishing trust and rapport with women requires targeted effort and time. Healthcare providers fear reprisal for not meeting women's needs and this is an important consideration in this type of research. Anonymity can be guaranteed but this may not be enough.

Conclusion

Rapid appraisal can be used to develop a perspective on ANE service and facilitate the creation of a shared vision

for service developments.

This study has not only provided baseline information about the current provision and issues of ANE (for example, poor attendance), but also the importance of involvement of users in service development to accommodate their needs. Over the coming period, the impact of this appraisal on ANE development will become clear.

ANE in Jordan is embryonic and needs rigorous evaluative studies to ensure effective care for women is achieved. Furthermore, midwives should appreciate their role as educators and seek training courses to develop their education and counselling skills, as pregnant women, especially first-time mothers, need special attention and support from both family and care providers.

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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 Ratnaike, 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

Breastfeeding innovation grant deadline

Applications for the breastfeeding innovation grant must be submitted by 31 January 2015. The annual grant of £10,000, supported by RCM Alliance partner Philips Avent and administered by the RCM, has been provided to encourage the take-up and/or improved duration of breastfeeding. All practising UK midwives, who are RCM members wishing to fund a new initiative to support breastfeeding, or the roll-out of a pilot project, are eligible to apply. The scheme should focus on a defined population and have clear objectives and a process for evaluating outcomes. For more information, visit: rcm.org.uk/breastfeedinggrant

Awards to celebrate top research

Top evidence-based projects and innovative research are to be celebrated at the RCM Annual Midwifery Awards on 3 March. The awards shortlist was revealed in November and the judges commended the high calibre of entries. Louise Silverton, RCM director for midwifery, said: 'This year we have had the highest ever number of entries, which demonstrates how midwives are innovating to make things better for women, babies and families.' The ceremony will begin at 12.30 with a drinks and networking reception, followed by a three-course lunch and the announcement of the winners and handing out of awards. For more information, visit: rcmawards.com

Iolanthe awards – applications open

Applications for the 2015 annual awards held by the Iolanthe Midwifery Trust (IMT) are invited until 30 January 2015. The IMT awards offer a maximum of £1500 for midwives who have projects for further study, or enhancement of their practice, while the student awards are up to £1000 for those planning an elective placement or an additional study course. The Jean Davies Award, which is held in partnership with the RCM, carries an award of up to £5000 for midwives working to address the impact of social inequalities on the wellbeing of pregnant women, new mothers and their babies. For more information, visit: iolanthe.org

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