A grounded theory study of information preference and coping styles following antenatal diagnosis of foetal abnormality

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Abstract

Title. A grounded theory study of information preference and coping styles following antenatal diagnosis of foetal abnormality.

Aim. This paper is a report of a study to explore the information-seeking behaviour of women following an antenatal diagnosis of foetal abnormality.

Background. The identification of a foetal abnormality on routine ultrasound in pregnancy is both shocking and distressing for women, and seeking information in this stressful situation is a common response. There is evidence that women's information needs are not always adequately met, and in some cases they recall little from the initial consultation.

Method. A longitudinal study involving 42 women was conducted using a classical grounded theory design. Data were collected in 2004–2006 through in-depth interviews at three time intervals: within 4–6 weeks of diagnosis, 4–6 weeks before the birth and 6–12 weeks postnatally.

Findings. Women described their main concern from diagnosis until the time to give birth in terms of regulating the information received in order to cope with the situation. Two main categories were identified: 'Getting my head around it' and 'I'll cross that bridge when I come to it'. These two differing information-seeking preferences are described as monitoring and blunting.

Conclusion. Matching of information preferences with coping styles may support individuals to cope with this stressful event. Women with high information needs (monitors) respond well to detail. However, those with information avoidance behaviours (blunters) should be facilitated to 'opt-in' to information when they are ready, in order to reduce the stress caused by perceived information overload.

Keywords: antenatal diagnosis, coping, foetal abnormality, grounded theory, information preferences, midwifery, obstetric ultrasound

Introduction

Over the last 20 years, second trimester ultrasound examinations have become an almost universal aspect of antenatal

care in western countries (Garcia *et al.* 2002) for women at low risk of complications in pregnancy and are consequently seen as benign. When normal findings are revealed, women's views of screening are extremely positive (Green

1994, Rapp 1999, Stephens 2000, Lalor & Devane 2007), viewing it as a social event, an opportunity to meet the baby. However, ultrasound is both a screening and diagnostic tool. Many routine programmes have been established with the express intent of detecting foetal anomalies [Royal College of Obstetricians and Gynaecologists (RCOG 2000)], resulting in termination of affected pregnancies. With such widespread availability, it is unavoidable that some women taking part in screening programmes will be faced with an ultrasound scan (USS) uncovering a foetal anomaly. Therefore an understanding of the way in which women need and use information about the anomaly is essential for clinical practice.

Background

Local context

Routine ultrasound has been a key component of antenatal care in Ireland since the 1990s, yet there is no consensus or professional guidelines on the type of ultrasound examination that should be offered routinely or selectively. Although many obstetric practices in Ireland follow guidelines developed in the United Kingdom (UK), such as those produced by the RCOG and the National Institute for Health and Clinical Excellence, when it comes to foetal anomaly screening the practice in Ireland differs significantly. This is influenced not least by the fact that termination of pregnancy is not legally available within the Republic of Ireland, and there appears to be little political or societal will to move from this position in the near future. The extent to which a traditional pro-life culture has influenced the development of prenatal screening programmes nationally is unknown, yet it is likely to have had a bearing to some extent. An Irish survey of antenatal ultrasound services (Lalor *et al.* 2007a) has shown that, although wide variations in practices exist, 95% ($n = 21$) of units offer a second trimester USS to some or all women. Given that 64,000 babies are born annually in Ireland, with a 2% rate of congenital anomalies, up to 1280 women annually may thus receive an adverse diagnosis.

Informing families of an adverse outcome

Many people when faced with the possibility of serious illness are overwhelmed by fear and a sense of loss of control, characterized by uncertainty about the future (Timmermans *et al.* 2007). Therefore, it is unsurprising to find that parents become psychologically distressed in response to

a diagnosis of foetal abnormality (Statham *et al.* 2000, Lalor & Begley 2006). In this context, the information received can be very threatening and, when the foetal prognosis is grave, the sense of distress experienced can be compounded by the negative information given. Previously in the literature, the focus has been predominantly on descriptive reports of women's feelings and reactions to the diagnosis, or attempts to measure the extent of the resultant psychological trauma. Confusion about the unpredictability of individual women's responses to particular adverse diagnoses remains, as published findings are limited to descriptions of a multitude of factors related to parental reactions and decision-making. The dearth of information on the experiences of women who continue the pregnancy is reflected in suboptimal care (Chitty *et al.* 1996, Finnemore 2000).

Theoretical framework

As our search for a suitable conceptual framework to guide the study continued, relational theories of loss and hope were reviewed to ascertain if connections existed between extant frameworks or parallel discussions in other fields. On initial review, it seemed that women included in many published studies shared some of the psychological responses associated with theories of grief such as denial and depression; however, others such as bargaining and eventual acceptance were not consistently reported. Many cognitive-processing models have been published, each concerned with understanding how individuals come to terms with a traumatic experience. However, Horowitz (1992, p. 92) has suggested that, when one experiences a traumatic event, there is a 'need to match new information with inner models based on older information and the revision of both until they agree'. At times this reconciliation can be so painful as to interrupt information processing temporarily (avoidance). Lazarus and Folkman (1984) in their transactional theory of coping suggest that there are two approaches – problem- and emotion-focussed, and individual preference for a particular strategy influences information-seeking behaviour. Miller (1980) has further explored the concept of information preference in the context of receiving threatening medical information, and suggests that in general two cognitive coping styles are common: monitoring, associated with problem-focussed coping, and blunting, associated with emotion-focussed coping. Monitoring is described in terms of seeking information about the threat in order to clarify the situation, to take appropriate action and regain control over uncertainty. Blunting is a tendency to avoid information about

the threat, even though uncertainty regarding the outcome may remain, preferring instead to distract oneself from the situation (Miller *et al.* 1988, van Zuuren & Wolfs 1991). Although these styles have been presented as conceptual opposites, Miller maintains that individuals can use either, depending on the situation (Miller *et al.* 1988). Relatively little is known about women's coping styles and information-seeking behaviour as they grapple with regulating the level of information needed to cope with continuing or terminating a pregnancy.

This study builds on previous work in the substantive area of antenatal screening and offers a theoretical perspective on the interacting effects of information preference in coping with an adverse prenatal diagnosis.

The study

Aim

The aim of the study was to explore the information-seeking behaviour of women following an antenatal diagnosis of foetal abnormality.

Design

A longitudinal grounded theory study of women's experiences from diagnosis of foetal abnormality and up to 3 months following birth was undertaken, designed to develop a theory of adaptation following foetal anomaly diagnosis. In this paper, we present data from one aspect of the analysis: the psychological processes of information-seeking behaviour following diagnosis.

Participants

The work was based at a tertiary referral maternity hospital in Dublin, Ireland, where foetal medicine specialists care for up to 200 women carrying a baby with foetal anomaly annually. Data were collected from April 2004 to August 2006 with women registered for care at the main centre, or referred from a number of regional centres. The consulting clinician identified and assessed women for eligibility and offered information about the study. All women with low risk of pregnancy complications receiving a diagnosis of foetal anomaly at ultrasound were eligible to participate. Women with a high risk of carrying a baby with an anomaly who were accessing detailed screening for previous history or electing for a non-routine invasive procedure such as amniocentesis were excluded. If an eligible woman was receptive, an information pack and consent form were

mailed to her by clinic staff. Women could then indicate their willingness to participate by phoning the researcher (JGL) or by returning a signed consent form. A reminder was mailed 2 weeks later, and non-responders at this stage were deemed to have chosen not to participate. To ensure they did not feel under any obligation to participate, women were informed that their referring clinician would not be made aware of their decision. Women were initially sampled according to the above factors, and were subsequently theoretically sampled on the basis of the type of anomaly/likely pregnancy outcome as conceptual gaps were exposed during analysis.

Data collection

Data were collected on three occasions: within 4–6 weeks of diagnosis, 4–6 weeks from the likely timing of birth and 6–12 weeks postnatally or after return from termination of pregnancy in the UK. Interviews were conducted in the woman's home at a time convenient to her, were digitally recorded, and lasted 1–2 hours or longer. The interviewer usually began by asking the woman how she had been since the initial diagnosis, which was sufficient to generate dialogue without further questioning. However, each successive interview became more focussed as theoretical sampling was implemented to clarify both interpretation of the data and to obtain accurate information about issues such as information preference, decision-making and emotional response. Twenty-two (71%, $n = 31$) women were interviewed pre-birth. Nine women (29%, $n = 31$) who had taken part in the initial interviews gave birth unexpectedly shortly after the diagnosis, and consequently were not interviewed again until 6–12 weeks after the birth. One woman developed a depressive illness and was receiving care from the psychiatric team. She was excluded from the study to ensure that she did not become increasingly vulnerable through taking part in the second interview.

Ethical considerations

The study was approved by university and health service ethics committees. Women gave written consent before and after each interview. On completion of the interview participants were offered the option of withholding or amending any of the information given. As protection of their emotional well-being was held to be paramount, all participants were offered the option of an exploratory session with a counselling psychologist external to the study site. None took up the offer. Access to the routine hospital-based support services, such as consultation with a social

worker or referral to a psychiatrist, was also available as necessary. All data were kept strictly confidential, referral centres were not identified, pseudonyms were assigned to participants and if staff names were mentioned they were replaced by their professional status (i.e. midwife, obstetrician etc.).

Data analysis

Data were analysed by the principal researcher (JGL) concurrently with data collection, using the constant comparative method (Glaser 1978). Diary entries were made after each interview, first to record thoughts or links to analysis already performed and, second, as the transcripts were being hand-coded to explore the interchangeability of indices as links between codes, categories and extant frameworks became apparent (Glaser 2001). The iterative process of developing codes into categories was subsequently mapped on an A1-sized paper. These links were tested for accuracy in future interviews. Use of the constant comparative method (Glaser 1978) allowed comparison of data between each participant, testing and refinement of emerging categories, and facilitated the development of relationships between concepts and categories as data saturation occurred. The researcher's interpretation was clarified with the women to ensure the rigour of the ongoing analysis and findings. Finally, we compared our findings to extant theoretical and scientific literature in the substantive area and the broader area of mood and cognition. The findings reported here are from data collected up to 12 weeks after termination

($n = 10$), and reflect information preferences related to decision-making. When the pregnancy was continued ($n = 31$), data from the prebirth interviews are presented and reflect information preferences for the pregnancy.

Findings

Participant characteristics

Sixty-five women with a range of foetal anomalies were invited to participate, of whom 41 (63%) women with 44 fetuses (42 anomalous) agreed to take part. Ten (24%) travelled to the UK for termination of pregnancy. Of the 31 who chose to continue the pregnancy (three of whom were expecting twins), 10 (32%) were primigravidae and 21 (68%) were multigravidae. There were no differences between the eight who delivered prematurely (six primigravidae, two multigravidae) and those whose pregnancies continued to term in relation to type of abnormality (see Table 1). Three babies died *in utero* and three in the immediate neonatal period, compared with one death *in utero* and six neonatal deaths in the 23 pregnancies that continued to term.

At varying times following diagnosis, women had diverse needs with regard to the nature and amount of information they required in order to cope and make decisions. For those who continued the pregnancy, ongoing antenatal visits and interactions with caregivers about the pregnancy were central topics of conversation. For women who opted for termination of pregnancy, access to information was critical in

Table 1 Classification of anomalies – pregnancies continued

Type	Description of anomaly in premature deliveries	Interviewed twice ($N = 22$) (25 fetuses)	Born prior to 2nd interview ($N = 9$)
1c	Lethal (e.g. anencephaly, renal agenesis, Trisomy 13 and 18)	6	5
2c	Non-lethal with normal karyotype		
	A: likely physical handicap only (e.g. limb abnormality, skeletal deformity)	1	1
	B: likely physical and mental handicap (e.g. neural tube defect, Dandy Walker malformation)	2	
3c	Non-lethal with abnormal karyotype (e.g. Trisomy 21, Turner's syndrome)	3	1
4c	Structural abnormality with an option to repair		
	A: with a significant risk of mortality (e.g. diaphragmatic hernia, abdominal wall defects, cardiac)	3	1
	B: without significant risk of mortality (e.g. talipes, some renal anomalies)	6	1
5c	Suspicious (e.g. multiple markers/anomalies with normal karyotype)	1	

Foetal $N = 34$, 32 anomalous and two normal. Five women were not interviewed postnatally. Two were excluded for reasons of psychological well-being, one could not be contacted and a convenient time could not be arranged for two others.

informing that decision. The relationship between women and their caregivers, which was essentially based on information-sharing, became influential in women's struggle to manage their daily lives, which had fundamentally changed since diagnosis. Information-seeking emerged as a key coping strategy, with two distinct styles observed – high or low preference for information. These observed behaviours were categorized using two *in vivo* codes 'Getting my head around it' and 'I'll cross that bridge when I come to it', which equated to the monitoring and blunting styles described previously. The data are presented chronologically, from diagnosis to birth, and are presented in terms of the information preference style exhibited.

Getting my head around it – monitoring

Initial diagnosis

After the shock of diagnosis, many women experienced autonomic disturbance (such as insomnia or loss of appetite). The threat of loss of an expected healthy child produced a high state of alarm. Some women described their need for high levels of information in order to cope in the period between discovery of the anomaly at routine screening and their next scheduled clinic visit. Commonly, these women accessed sources such as the internet, or asked others to search for them, to supplement what they had been told. Access to information seemed to reduce uncertainty about diagnosis or outcome, and being able to understand how specific changes in test results affected pregnancy outcome seemed to increase their sense of control over the situation:

I went home to do my research. The internet cleared up a lot of things for us – it helped us ask the right questions when we went back (Cliona, type 4cB).

Where the diagnosis was less clear-cut and the outcome was not definitive, information to clarify the situation was not available. Women with a high preference for information found it difficult to cope with uncertainty. Also, when information received was predominantly negative and did not contribute to finding ways to improve the outcome, this seemed to add to the stress and anxiety experienced:

I searched everywhere, but I had to put up barriers – there are so many unknowns, so many bad outcomes. I was so down today – it's so unclear – you don't know what to hope for (Eavan, type 4cA).

Decision-making

When ultrasound revealed structural anomalies associated with chromosomal disorders, amniocentesis was offered. For some women, their high need for additional information

influenced their decision as to whether or not to opt for amniocentesis:

I had the amnio to try to deal with it...I was delighted just to get a diagnosis...there was a great sense of relief just knowing...we had been getting no information week after week [until we got the amnio result] (Doireann, type 1c).

When amniocentesis confirmed that the foetus had a lethal anomaly, this information was used as a basis to continue or terminate the pregnancy:

I had to have the amnio. I was waiting for the test to come back. I wasn't particularly expecting it to be normal. It was so we could move on and make decisions [to terminate the pregnancy] (Muireann, type 1t).

For women whose ultrasound predicted that the foetus would inevitably die, some opted for amniocentesis to inform the planning of future pregnancies:

The more information we could find out the better, in terms of whether to try [and get pregnant] again (Tara, type 1c).

Some women expressed difficulty in coming to terms with the diagnosis; this was most often observed in those with a high preference for information and where the extent of disability of the infant could not be predicted. The only sense of control these women felt they had left was to decide when the baby would be born:

I said I wouldn't be able to cope with it [going to full term]. I think if they said to me. 'You have to go to 40 weeks' it would kill me, literally kill me. I couldn't do it. I want an induction date at 38–39 weeks (Niamh, type 2cB).

I just I feel I have been pregnant for the last 5 or 6 years. It's driving me mad...I need a date for the birth (Keeley, type 2cB).

Ongoing information needs

Women who continued their pregnancy required frequent monitoring in the foetal medicine unit and found the regular feedback about foetal well-being crucial to how well they managed to cope:

It felt really good that they were checking everything – there was a sort of comfort in it (Ciara, type 5c).

I need those visits for the scans...you're hoping everything is stable even though [you live in fear] of getting more bad news (Niamh, type 2cB).

Once a definitive diagnosis was obtained, the need for information diminished. If an additional variable or problem manifested itself, a high need for information about the new variable returned:

Once you hear something new, you go back searching again. I focussed my energies on treatment options (Maoliosa, type 4cB).

I'll cross that bridge when I come to it – blunting

Initial diagnosis

Although the case for giving all available information to parents is compelling, some women felt that they were receiving information at a level exceeding their needs. Behaviours that reflected a woman's attempt to avoid information were categorized with the *in vivo* code 'I'll cross that bridge when I come to it'. Most of these women avoided engaging with the issue until confirmation was received from a foetal medicine consultant:

She [radiographer] just said she could see abnormalities and could I come in and get them to check again. I just wanted to get out. At the time you are not thinking of anything and you are not really listening – I think it's because you are so upset. You don't want to hear (Lori, type 3c).

When women with low preference for information received more information than they needed, the consequence was increased anxiety:

The condition is not going to get any better...I'm a little bit more down than I was. I haven't asked any more about the problems. I don't ask too many questions – it's just my way. It's just too much...(Emma, type 1c).

I wanted information, but not so much that it would freak me out. It's great to be prepared, but you can get information overload (Aisling, type 4cB).

Decision-making

When amniocentesis was offered to women with low preference for information, they often refused, preferring to hope for positive outcomes. Refusing the test kept the hope of a healthy baby alive, a hope they needed in order to cope. Sian had been given a 1:3 risk that her baby had Down Syndrome:

It [a positive amniocentesis result] could put a totally different outlook on the last few months of your pregnancy; we prefer to think that the baby will be normal (Sian, type 3c).

However, pregnancy is unique in that there are two (or more) people to care for. One woman expecting twins (one of whom was normal) was offered repeated invasive procedures to provide information about the affected foetus's condition, but on the balance of risk rather than avoidance of information, refused the offer:

We didn't keep having tests done because we didn't want to miscarry both babies (Orla, type 1c).

Ongoing informational needs

Women with a low preference for information said that, even when foetal well-being could deteriorate but neonatal intervention was possible, they could not cope with the emotional demands of assimilating additional information:

I felt I couldn't cope with any more information, I didn't want any more – I thought my head would explode. But my husband was full of questions (Emer, type 4cA).

For some women for whom neonatal survival was predicted to be low, hearing something positive at the foetal medicine visit was important:

The fluid hasn't built up any more [hydrocephalous] – that was good. But then the fetal medicine consultant said it can change again. I didn't need to hear that, not unless it happened (Keeley, type 2cB).

It is the custom in many units to arrange visits to the neonatal unit for parents whose infants may require neonatal support. Whilst this may be helpful for information-seekers, for information-avoiders this visit became an additional stressor:

I thought it was totally unnecessary. I didn't want to go to the unit at all...I went in with blinkers on and wasn't even listening to what the woman was saying...I just couldn't face it (Maeve, type 3c).

Providing an information booklet about the unit may be a helpful alternative, as women can choose to read the information at their own pace:

We got a booklet about SCBU (special care baby unit). It was helpful to kind of get your head around the amount of equipment that was going to be involved (Emer, type 4cA).

Informational needs – key issues for all women

Irrespective of information preferences, there were key issues that the majority of women thought needed to be addressed by healthcare professionals. Women travelling to the UK felt particularly vulnerable, as they were not only coping with a diagnosis of foetal abnormality but also trying to arrange services without any guidance:

I called to my GP to tell her I had a baby with anencephaly and I was planning on going to England and I just didn't like her reaction...I understand that they can't give any information, they can't give their opinion, but they can't just expect you to manage in a vacuum (Regan, type 1t).

Many were concerned about whether they could approach medical practitioners for care on their return, should any

complications arise. The data suggested that few general practitioners responded to this anxiety. Foetal medicine consultants were, in general, explicit that their door was always open for care at any time in the future.

For women who chose to continue the pregnancy, almost all mentioned their concern about labour or mode of birth, in particular the need for caesarean because of foetal complications:

I'm hoping it will be a normal delivery – a caesarean is a major operation and I want to be able to leave the hospital [to visit baby in SCBU] (Ciara, type 5c).

Although women knew that they would be separated from their babies, they also needed to know if the infant would be transferred to another hospital as this additional separation came as a blow to some. For women referred from regional centres, arranging the place of birth was essential, as many were fearful that knowledge about infant support would not be communicated to the booking hospital. Irrespective of information preference, once women were informed that the anomaly was lethal, one of their main concerns was whether the baby would die antenatally, intrapartum or postnatally, and if there were any resulting risks to themselves:

It's a horrible situation; we are waiting for the baby to die inside me...I think at the very outside it will go to term and die at birth...you need someone to tell you what happens when the heartbeat stops (Tara, type 1c).

I wanted to know was my life at risk? Would I miscarry? What would I feel before the miscarriage (Kasey, type 2cB).

Women were concerned about their possible reactions to seeing the baby, and needed reassurance that an experienced midwife would support them. The information preference exhibited in pregnancy, in general, remained consistent up to the birth. Consequently, information-seekers required information on the baby's likely appearance: fear of not knowing what to expect was greater than knowing, whereas information-avoiders preferred to wait and see. All women expressed the need for specific guidance on what to bring to hospital, and an opportunity to speak to the bereavement counsellor to assist in funeral planning was welcomed. Follow-up written information was necessary to remind women of choices available to them, as this helped women with low information needs, in particular, to access this information as and when they were ready. Planning the birth can a very positive experience for some women, as when the anomaly is lethal their greatest hope is to have the baby born alive.

Discussion

In this paper, we begin to explore the contribution of the personal information-seeking styles of monitoring (Getting my head around it) and blunting (I'll cross that bridge when I come to it) and information-seeking behaviours in women following an antenatal diagnosis of foetal anomaly. According to information-seeking theory (Berlyne 1960) people seek information to re-create a sense of control and predictability about the future. Women who exhibited monitoring behaviour in this study had high informational needs (even if the information was negative) in order to regain control of the situation and to make decisions regarding the remainder of pregnancy. Information preference as a coping strategy appeared to have a critical role in stress management. This behaviour was repeated when a new variable was introduced into the situation, such as a change in the foetal condition or the discovery of an additional anomaly or variant, regardless of the impact this new variable would have on predicted outcome. Regaining control in a stressful situation has been described as a problem-focussed approach to coping, where the focus is to manage the problem causing the distress and is common when the situation is perceived as changeable (Lazarus & Launier 1978, Lazarus 1990). In our study, women who responded initially with high need for information also focussed on emotional aspects of coping with an uncertain diagnosis/outcome, and they exhibited physical signs of stress, such as sleeplessness, which has previously been noted in conjunction with a monitoring style (Voss *et al.* 2006). At times women adopted distraction strategies to protect themselves. However, when choosing whether to accept the offer of amniocentesis, these women were more likely to accept than refuse. Our study supports other findings (Shiloh *et al.* 2001) that the motivational basis of information-seeking is complex and women with monitoring styles are interested in threat-relevant information for both problem and emotion-focussed coping purposes (Figure 1).

Women who adopted blunting strategies continued to avoid taking information on board about the foetal condition, particularly when it was negative. Folkman and Lazarus (1980) suggest that this manifests itself more often in unchangeable circumstances. Women exhibiting this preference required more positive information about the foetus, avoided confirmation by amniocentesis of a chromosomal abnormality and hoped for a positive outcome. These women preferred clinicians to highlight what was normal about the baby, such as positive foetal growth, even when foetal condition and prognosis remained grave.

Some women commented on a discrepancy in information-seeking preferences between themselves and their husbands,

Figure 1 Balancing information following diagnosis.

which on occasion caused tension between them. Locock and Alexander (2006) have suggested that men are more likely to adopt monitoring strategies and women to exhibit blunting strategies, but have suggested that further work is needed to confirm this. Whilst ours was an analytical, not statistical, study and preferences were based on observed behaviours not empirical measurement, it is interesting that two-thirds of the participants used 'blunting' strategies frequently. Our findings concur with those of others who suggest that information-seeking is a coping style, related to both problem and emotion-focussed coping, to regain control of the situation and/or help in regulating emotional response to the threat (Shiloh *et al.* 2001). The information level required did not seem to be related to the severity of abnormality, as both preferences were manifested throughout the range of diagnoses, indicating that individual differences exist among people in the perceived function of information seeking.

Limited data suggest that women in pregnancy are, in general, high information-seekers (Redlinger-Grosse *et al.* 2002). Whilst women in our study wanted to be informed about the foetal condition, the desired level of information varied. 'Monitors' required ease of access to information,

whilst 'blunters' needed to be allowed the freedom to 'opt-in' to detail as and when they wished. Women exhibiting monitoring strategies became increasingly distressed when insufficient information was not available; conversely, women using blunting strategies became distressed by information overload. Although the cognitive coping styles of monitoring and blunting are conceptually different, practically they remain linked. Ameliorating stress for women requires healthcare professionals to observe the strategies used by individuals and to respond appropriately. Healthcare professionals should reflect on the inappropriateness of 'one size fits all' policies, such as giving the worst-case scenario. Similarly, arranging a routine visit to the neonatal intensive care unit can be problematic, as it may be an additional stressor for many. However, data show that specific aspects of preparation for labour and birth should be raised by healthcare professionals, irrespective of coping strategies manifested, as they are welcomed by all.

This complexity of responses to traumatic situations has been highlighted in other areas of health care (Steptoe & O'Sullivan 1986, van Zuuren & Wolfs 1991, Alderson *et al.* 2006, Locock & Alexander 2006). We have previously urged

What is already known about this topic

- Provision of information for women taking part in antenatal screening programmes is fraught with difficulty.
- Giving explicit information on possible anomalies to a population where the majority will not be affected may cause needless worry.
- Providing information when people are experiencing stressful events can assist them to cope.

What this paper adds

- Women adopted one of two distinct processes of information-seeking behaviour following antenatal foetal anomaly diagnosis – ‘monitoring’ and ‘blunting’.
- Women regulate the level of information received in order to cope, and although this varies between women, all welcomed information to prepare for labour and birth.
- The majority of women wish to avoid receiving too much information but a sizeable minority have high information needs that are not always met.

caution about presentation of information about prenatal screening tests to large numbers of women without assessing its suitability (Lalor & Begley 2006). It is hoped that this study will contribute to theory development in this area and stimulate future investigation of the role of information seeking following adverse prenatal diagnosis.

Study limitations

The context in which this study was undertaken is very specific, in that termination of pregnancy is not an option available in Ireland following the diagnosis of foetal abnormality. This was an analytical study to develop deeper understanding of how women use information to cope in the aftermath of a foetal anomaly diagnosis; consequently, the findings may not be generalizable to all situations and contexts. However, the strategies of monitoring and blunting observed in this study have been validated in other areas of healthcare and health-related literature. Although information preferences in this study were not estimated empirically, we remain sufficiently concerned that pressures of service delivery and provision of standardized forms of information may result in a formulaic approach to consultations with a detrimental effect on clinician/patient relationships (Lalor *et al.* 2007b).

Conclusion

Our findings largely support existing theory regarding monitoring and blunting strategies and have expanded our understanding of women's responses to foetal anomaly diagnoses. We urge healthcare professionals to be sensitive to individual differences in information needs as, in general, women benefit from communication tailored to their styles. Although this will not always guarantee high levels of satisfaction with the information received, it may reduce levels of dissatisfaction and improve clinician/client relationships. We suggest that practitioners should explicitly discuss with women their information preferences by posing questions such as, “you generally think ‘Tell me everything, no matter how bad the news might be’ or do you tend to say, ‘I’ll cross that bridge when I come to it’?” as a way to explore cognitive style. Such emphasis on planning information-giving depending on observation of women's coping strategies and resulting information needs should assist in realizing our shared goal of more woman-centred care.

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Author contributions

JL was responsible for the study conception and design. JL performed the data collection. JL performed the data analysis. JL, CB and EG were responsible for the drafting of the manuscript. JL, CB and EG made critical revisions to the paper for important intellectual content. JL and CB obtained funding. CB and EG supervised the study.

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