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Care provision during termination of pregnancy following diagnosis of a severe congenital anomaly – a qualitative study of what is important to parents.

Highlights

- **This study provides insights into the specific needs of women and their partners who terminate a pregnancy affected by a severe congenital anomaly.**
- **Procedures often perceived as routine, such as signing a consent form or swallowing tablets, hold great symbolism to women and their partners.**
- **Parents felt a sense of being caught in 'no-man's land', of not belonging to either the antenatal or postnatal setting in which they were cared for.**

Key words

Congenital anomaly, decision-making, parental experience, termination of pregnancy, qualitative

Abstract

Objective: To understand the experiences of women and their partners following the decision to terminate a pregnancy affected by a severe congenital anomaly **Design**: Qualitative semi-structured interviews with a purposive sample of women and their partners who underwent a termination of pregnacy following diagnosis of a severe congenital anomaly. **Setting:** Women referred to four fetal medicine centres across two hospital trusts. **Analysis:** Data analysis was based on the constant comparative approach. **Findings:** The over-arching theme emerging from the data was that of 'falling through the gap', where the care received did not adequately meet the needs of women and their partners. This was particularly salient at three specific points in the care pathway: enacting the decision to have a termination of pregnancy and subsequent initiation of the process; care during labour and birth, where parents describe being caught in 'no-man's land' between the antenatal and postnatal settings; and post-birth, where parents made sense of and came to terms with their decision. **Conclusions:** The diagnosis of a severe congenital anomaly and the subsequent pathway that parents face is a

traumatic event. Responsibility for the decision to terminate the pregnancy intensifies emotions and adds to the complexity of caring for this group. These findings point to the need for a specific care pathway for parents undergoing this difficult experience. Recommendations include the need for a greater understanding of the views of midwives caring for these parents, review of specific training needs, and examination of processes to better support both parents.

Introduction

Pregnant women in England presenting before 20 weeks' gestation are offered antenatal screening tests for congenital anomalies through the NHS Fetal Anomaly Screening Program (FASP) (UK National Screening Committee 2009). The aim of the screening programme is to enable parents and clinicians to make appropriate plans for the pregnancy and any care required after birth or also to consider the option of termination, if a severe anomaly is identified (Lyus et al. 2014) Eleven congenital anomalies are screened for: serious cardiac anomalies, anencephaly, open spina bifida, exomphalos, bilateral renal agenesis, lethal skeletal dysplasia, congenital diaphragmatic hernia, trisomies 13 and 18, cleft lip and gastroschisis (NHS Fetal Anomaly Screening Programme 2010). The first nine anomalies (FASP9) are associated with high mortality or morbidity, whilst cleft lip and gastroschisis are amenable to early intervention. Around 2 to 3% of pregnancies in high-income countries will be affected by a severe congenital anomaly (Askelsdottir et al. 2008). Following diagnosis of a FASP9 anomaly, around 70% of pregnancies end in termination (Budd et al. 2015). This equates to around 2,700 such terminations in England and Wales annually (BPAS 2010). Caring for parents who terminate a pregnancy following diagnosis of a severe congenital anomaly is complex with dilemmas frequently encountered (Williams et al. 2002). However, the offer of screening for congenital anomalies is universal, and given the majority of pregnancies affected by FASP9 anomalies are terminated, care of this group of women and their partners is an important aspect of the midwife's role.

The diagnosis of a severe congenital anomaly and the subsequent decision that parents face is a traumatic event with potentially significant and lasting emotional impact (Benute, et al. 2012, Statham et al. 2001). The role of the mother as protector of the unborn is strongly embedded in our social and cultural context (Lupton 2011). As termination violates this norm, those who choose to terminate arguably take on a "*spoilt identity*" (Goffman 1963 pg.130) and may experience feelings of shame and guilt which complicate their grief (Bleek 1981, Lithur 2004, Lilford et al. 1994). Caring for this group of parents is complex (Lyus et al. 2014), made more so by the potential for conflicting personal convictions and professional responsibilities (Marek 2004). In turn, this risks the exacerbation of negative feelings parents experience. With little evidence examining the needs of parents who decide to terminate a pregnancy following diagnosis of a congenital anomaly (Bijma et al. 2008, Pryde et al. 1993,

Shaffer et al. 2006), their experiences, presented through their own narratives, provide a unique insight and transformative opportunity to improve care and healing (Landry 2015). Here we explore these experiences, employing a qualitative approach in order to identify themes that can be applied to improve provision of services.

Methods:

This paper draws on data from a larger study exploring parental decision-making following diagnosis of a severe congenital anomaly, with the aim here to provide an understanding of the experiences of parents who have made the decision to terminate the pregnancy. In order to appreciate the complex reality of decision-making within this context, a qualitative approach comprising interviews with clinicians and parents and recordings of consultations between them was employed. Recruitment took place in four fetal medicine centres across two hospital trusts. Sampling was purposive to represent women and their partners from a range of diagnoses of severe congenital anomaly, gestational ages at diagnosis, ethnicity and socioeconomic status. A total of 20 women and their partners were identified through fetal medicine clinic lists and invited to participate. All 20 women agreed to participate, but two separated from their partners shortly after diagnosis and so only 18 partners were recruited. Ten of the affected pregnancies were terminated and ten were continued.

The data generated in the wider study provided an in-depth, contextualized description of how parents and clinicians made sense of the situation and made decisions about whether to terminate the pregnancy. Here, we focus on the interview data generated from those who terminated the affected pregnancy. We interviewed the 10 women who had a termination of pregnancy, along with eight of their partners. The remaining two partners had participated in the recorded consultations for the wider study but were not interviewed due to practical and time constraints. Interviews were undertaken jointly with the women and their partners.

Patient and public involvement (PPI) was an integral part of the project, achieved through an advisory group comprising parents who had previously experienced a diagnosis of a severe congenital anomaly during pregnancy. A participant information sheet designed by the PPI group was provided to participants and written consent obtained. Semi-structured interviews (completed by RL) were digitally recorded, anonymised and transcribed verbatim. Interviews

lasted on average an hour, ranging between 20 minutes and two hours. Interviews were conducted outside the hospital, at a location chosen by the parents, around six to eight weeks following the termination of pregnancy.

Data analysis used a constant comparative based approach (Glaser, Strauss 2012), with NVivo software to assist organisation. Memos and a reflective diary, completed immediately after each interview, provided additional context and recorded insights and interpretations. Randomly selected interviews were coded separately by each member of the research team, and compared across the team for consistency. Consensus on emergent themes was reached through regular discussions. Permission was granted by the Nottingham Research Ethics Committee (REC reference 13/EM/0293).

Findings

Although there was much praise of and thanks to individuals for their support and care during the delivery period, women and their partners who terminated the affected pregnancy encountered many difficulties. Under the umbrella theme of 'falling through the gap', this paper identifies three specific points along the care pathway at which transition from one stage of care to the next is particularly complex: enacting the decision, where seemingly routine processes became hurdles for parents; during labour and birth, where women and their partners found themselves caught in 'no-man's land' between the antenatal and postnatal settings; and post delivery/birth, where women and their partners made sense of their decision.

Enacting the decision

After making the decision to terminate the affected pregnancy, parents expressed varying degrees of doubt and concern over enacting their decision, with great symbolism placed on procedures often perceived as routine by staff.

Consent

Prior to commencement of any medical treatment, a medical consent form is signed by clinician and patient; a formality undertaken to provide proof that discussions have taken place. Great significance was placed by parents on the formality of signing the consent form for the termination of pregnancy itself, and its integral part in the grieving process, with all the women discussing the emotional impact that signing the consent form had on them.

> *I struggled to sign it. Although you've made the decision, you're still signing your baby's life to be stopped … and that is really hard. (Mother 12)*

Whilst the legal responsibility for consent lies with the woman, several of the women requested that their partner also sign the consent form. They felt this was a way of ensuring future blame could not be apportioned individually, with the symbolic importance attached to the joint signing making it more of a shared decision.

> *I made [my husband] sign the consent form too…. I wanted to be sure that it was our decision, not just mine. I know that legally it had to be my signature … we both wanted to sign it…. That just felt right and it sort of shares out the guilt a bit. [Silence](Mother 15)*

When requested, parents reported that clinicians facilitated the signing of the consent form by partners to enable this sharing of responsibility, despite the lack of a legal requirement.

Taking the tablets

All of the women in this study underwent a medical termination of pregnancy. This was initiated in the fetal medicine clinic, where an initial dose of mifepristone was given. This was followed by administration of misoprostol 36 to 48 hours later following admission to the labour ward for completion of the induction of labour.

Parents indicated that the relationship with the clinicians became very formal and perfunctory once the termination process started.

> *… you just take that tablet and you're just sent away, that's pretty much how it felt. A very clinical process, so you come in and you take your tablet and then you are out (Mother 19)*

However, reactions of parents were divided when asked about the act of taking the tablets. Some women found taking the tablet "*a relief"* as it meant that the waiting was over and they could "*get on with it"* (Mother 20).

> *And I thought that the actual doing of you know the taking of the tablet, I thought I'd feel guilty, you know I was expecting all*

these other emotions but I did not at all, I think we just knew that the decision was the right decision. (Mother 09)

Although the emotional nature of the period between taking the first tablets and admission was discussed, this group conveyed a positive picture, recounting the various ways in which they had spent the time.

In the days between taking the tablets, we'd actually been to a funeral parlour to arrange everything, so we had already done it all in between. (Mother20)

All the women in this group responded by 'doing' and their activities focused, in different ways, on the pregnancy. These included arranging the funeral, washing nightdresses with the soap provided in commercial packs given to parents in preparation for the birth, packing up any baby things that had been bought or sorting scan pictures. Although their actions varied, they all represented symbolic as well as practical aspects to managing the process. They appeared to have come to terms with their decision and, although this did not lessen their grief, they suggested their strategy was that of 'moving on'.

Conversely, others required more 'direction' from healthcare professionals, including the need to be observed when swallowing the pills.

… if I went home and had to take them then I might not be able to. Just having someone there staring at me to make sure I took them was better. (Mother 12)

Medicalising the process, along with the desire to relinquish control to the healthcare professionals, appeared to be a mechanism employed by these parents in order to distance themselves from the process. Women in this second group recounted their experience of the waiting as anxiety filled and emotional.

We just didn't know what to expect. I was so scared … We just sat at home and cried. I couldn't do anything or think about anything. (Mother 02)

Labour and birth

Narratives about the transition of care from fetal medicine to maternity for labour and birth highlighted particular difficulties for the women and their partners as they found themselves caught between pregnancy and motherhood. One mother described this aspect of the process as being caught in "*no-man's land*" (Mother 15). Lack of preparation compounded parental feelings of isolation. This in turn was reinforced through the way in which facilities were laid out.

Isolation

A lack of understanding of the physical process of such a termination of pregnancy was highlighted by many of the parents. Whilst information was accessible and routinely provided, many suggested that they were still unprepared and the realities of the birth itself were often poorly understood.

> *… I didn't have a clue what I was doing… I didn't realise that I was going to have to do that [deliver the placenta following the arrival of the baby]. (Mother 09)*

> *We were really in the hands of the people at the hospital and all that, and we really did not know what was happening, what it would be like. Because obviously we had no antenatal [classes] or anything like that. (Mother 12)*

For many, their lack of preparation was compounded by feelings of isolation. This was further reflected in practical aspects of care such as access to pain control.

> *It wasn't just the pain relief it was somebody there, just having somebody there. Because we did not know what. At no point were we told this is what is going to happen. (Mother 20)*

Provision of care by an allocated midwife was highlighted by the parents as a key factor in supporting them. However, women frequently portrayed themselves as undeserving of care, universally expressing sympathy towards those caring for them during delivery.

> *I kept on thinking at the time that it must be really tough for you to be the person on duty who had to deal with that [termination]. (Mother 02)*

A number of the women delivered unassisted. When midwives were unable to attend to them, parents suggested that the needs of other women should rightly take priority over their own.

> *Then we didn't hear from her, but she was with another patient and obviously that is her assignment and her priority…. (Mother 10)*

Individual midwives and clinicians were frequently praised for the care provided. When problems were encountered, these were predominantly framed as systemic challenges of staffing numbers and provision.

> *The nurse was absolutely lovely but I think it was just provisions for it, I mean they were just too busy. I mean it's the provision side of it. It's a systems failure really. (Mother 20)*

The need for dedicated staff to care for women undergoing termination was discussed and the advantages of a dedicated midwife widely appreciated.

> *…it would be nice to have more support….I mean having a dedicated midwife… (Mother 02)*

Nonetheless, lack of resources repeatedly made these ideals unachievable and women frequently reported delivering alone.

> *And the midwife who was on, I guess she has quite a few patients at the same time, but she was actually on her break at the time, she had gone on her break when the baby arrived so my husband actually delivered the baby 'cause there was nobody there. (Mother 20)*

Subsequent justification for the midwife's absence was made by the parents in each case.

> *But maybe they weren't expecting it all to happen so quickly and you cannot just have someone sitting there for three hours while they are waiting for the tablets to work. But that was really tough. (Mother 16)*

For all, the physical process was incredibly distressing, and intensified the emotional turmoil they were already experiencing.

> *And you know it's just sort of it's just a bit degrading and horrifying to be in that situation really. (Mother 14)*

Specialised Facilities

Attempts by the centres to care for women who were giving birth following a termination of pregnancy and their partners separately from "normal" births appeared to compound the parents' sense of isolation. The facilities offered differed in each of the centres studied. Some had bereavement suites, whilst others offered separate facilities away from the main delivery suite. At the time of data collection, one of the centres cared for the parents on the delivery suite alongside other labouring women, although a separate bereavement suite has subsequently become available. Despite these intentions, the bereavement facilities had restrictions on the care that could be provided whilst using them. Where women opted for epidurals for pain relief, they were placed in a delivery room in the main facility. Following the birth, centres aimed wherever possible to continue to care for the women in the room where they had delivered. However, a number of the participants were transferred to the main postnatal or antenatal ward due to bed shortages in the delivery suite. This proved distressing for those involved.

> *When I was giving birth, it was … with all the other people giving birth and then afterwards I went onto a ward with other people and their babies. And obviously people see me and think, "Where's her baby? She's never with her baby." (Mother 12)*

Being neither an expectant woman, nor a mother heightened the sense of isolation. This evoked feelings of being judged and scrutinised by others around them. These feelings were reinforced by the physical space in which they received care.

> *There is nowhere to put people in that situation, you are in that sort of inbetween the place where yes you are a pregnant woman and you need to be treated like one but at the same time you are grieving. (Mother 14)*

For those who were placed away from other mothers, in general, the distance from the sights and sounds of newborns, was appreciated.

> *The only good thing was … we did not see a single baby, which was nice, especially when you know you are losing your baby. You're in a separate part…it was delivery but at completely the other end. (Mother 10)*

Despite acknowledging the benefit of being cared for away from the main delivery suite, some interpreted this as a strategy to protect the other women rather than themselves.

> *But it was as if it was like, "keep out the way" because these other women don't want to see you. (Father 10)*

Moving on

Ongoing fears were voiced by a number of parents as they searched for confirmation that they had made the right decision. Whilst concerns were frequently expressed about the potential physical appearance of the fetus following birth, the impact of visible defects provided some reassurance. Conversely, lack of visibility of the anomaly at birth compounded any pre-existing doubts. Delays in post-mortem results further increased the distress experienced.

Seeing the anomaly

Where a diagnosis of a visible anomaly had been made, parents frequently expressed a fear over what the baby would look like once delivered, and this led a number to avoid contact with the baby.

> *… we didn't know what he was going to look like. So that scared us even more. So we wanted them to take him away and then ask them what he did look like so we could prepare ourselves. (Mother 16)*

Midwives played an important role in preparing the parents and dressing or wrapping the baby. For some parents, viewing the anomaly was reassuring, as the visible deformities provided some comfort and reassurance that they had made the right decision.

> *… and I guess that as soon as we saw our little [baby] we knew that we'd, you know [made the right decision]. We could physically see the abnormalities you know she had a cleft lip even though [the] fingers and toes were all formed perfectly, [the] brain was not, and half [the] skull was missing. (Mother 20)*

For those delivering a baby with an asymptomatic anomaly (internal structural anomalies not visible externally), concerns about terminating what might have been a healthy baby were compounded by the normal appearance. Unlike parents delivering a baby with a visible anomaly, post-mortems were requested by all these parents, and played an essential role in confirming diagnosis.

> *I think once we've had the results and they say "Yes we were right on this, we were right on that" I mean I think just at the moment it's still not knowing 100%. Really we're just taking the doctors' word for it [the diagnosis] at the moment. (Mother 02)*

Staying Mum – Disclosure and Stigma

The stigmatisation associated with termination is well documented.(Kumar et al. 2009, Norris et al. 2011) For parents, this could result in social isolation where disclosure to peers was avoided, and hence support was not sought, due to fear of negative reactions. Analysis within this study highlighted a polarisation of views between women in their willingness to disclose. One group appeared confident in their decision, and expressed no anxiety over disclosure.

> *…there are going to be people who disagree with what we have done. But it was only us in that situation and so no that [disclosure] really didn't [concern me]. (Mother 09)*

This group also expressed an understanding that there was no right or wrong decision, and acknowledged that regret was likely for those who had continued as much as for those who terminated.

> *Whatever decision you make… there will be moments when you regret things. I'm sure people who carried on with their pregnancy sometimes regret that they did. (Mother 19)*

In contrast, at the other end of the spectrum, severe reservations over disclosing information about their decision was expressed, with fear of stigma and judgement widely felt.

> *I've had to tell the girl at work that we lost it rather than what we decided to do, to end the pregnancy. (Mother 02)*
> *Abortion has such strong, you know people have such strong views about it…I just don't want to have to justify my decision to other people. (Mother 12)*

The decision not to fully disclose came with additional guilt.

> *So I go between feeling guilty because they were being kind to me because they thought I'd lost my baby while actually I'd decided to abort her. I didn't really deserve their sympathy. (Mother 15)*

While the mothers in this study varied in their willingness to disclose, all the fathers found it difficult to do so.

> *[Talking of disclosure] I don't tend to tell anyone unless we know them really well. I mean you know some people have really strong views and I don't feel that it's any of their business what we did. (Father 12)*

Supporting the father

Organisational factors such as consent practices reinforced fathers' sense that their needs came second to that of the mother. This was reflected in many of their responses to taking part in the interview as many fathers initially assumed that their participation was not required.

> *…it's more about how my wife is, so that's all I've done really. I've not really thought about what I've needed… (Father 19)*

The sense of exclusion was reinforced throughout the termination process.

> *It does feel a bit like they forget the father sometimes you know. It was like the bed in the hospital and there was no bed for me. You know, not even a blanket, and [the midwife] said there wasn't enough pillows [for me to have one] … So I wrapped up my jumper. (Father 10)*

This was further reinforced through interactions with staff.

> *Yeah I know that I'm not actually carrying a baby but it is my baby as well. But she [midwife] didn't even ask my name. (Father 16)*

This raises the important issue of legitimating the father in the process, not only to avoid yet further grief should the relationship fail as a result of it, but also to optimise the support the parents are able to provide for each other.

Discussion

The findings from this study provide valuable insights into the unique needs of parents undergoing a termination of pregnancy for a severe congenital anomaly. The sensitivity of the issue has potentially contributed to the small volume of literature available (Bijma et al. 2008, Pryde et al. 1993, Shaffer et al. 2006). However, without an understanding of the needs of women and their partners who terminate a pregnancy affected by a congential anomaly, provision of 'best care' remains an illusion. The themes arising have been presented temporally: enacting the decision, where women and their partners move from decision to action and often place great symbolism on procedures perceived as routine by clinicians; labour and birth, where women and their partners fall through a gap in care provision, belonging neither to the antenatal nor postnatal care setting; and moving on, where women and their partners gradually come to terms with and make sense of their decision.

Assumptions that a 'chosen loss' involves a positive choice and enables those involved to move on quickly are gradually changing (McCoyd 2007). However, care pathways remain variable across the UK (Fisher 2008), with their focus predominantly directed towards ensuring timely diagnosis and referral to appropriate specialities (RCOG 2010). Whilst undoubtable important, this focus risks addressing the unique difficulties encountered by parents who have decided to terminate a pregnancy affected by a severe congenital anomaly.

A major influence throughout the process is the impact of responsibility and guilt and the subsequent need for tailored support, differing from that provided following other bereavement, such as stillbirth. Whilst some women 'internalised' or accepted responsibility for the decision, others 'externalised' it, offsetting responsibility onto the clinicians. This invariably affected the way in which they made sense of the process, and the level of support they required. This was invariably influenced by the parents' approach to the decision-making process. Whilst the women who 'internalised' the decision appeared to be able to move on more easily, those who 'externalised' the decision appeared to have greater difficulty. In particular, this was reflected in the decision to disclose or not, and the perceived stigma associated with terminating a pregnancy.

As highlighted by McCoyd, the parents in this study perceived themselves as undeserving due to the 'chosen' nature of their loss (McCoyd 2007). This may make traditional methods of evaluating care difficult. Whilst all the women openly praised the care they had received, the

in-depth interviews highlighted that many parents were unprepared for the physical process of delivery following termination for congenital anomaly. Despite access to written and verbal information, shock at the delivery process was widely expressed, suggesting that the provision of information is not sufficient to ensure parents are adequately prepared. Staffing levels and access to care from an allocated midwife were highlighted by the parents as key factors in providing 'good care', something previously highlighted in the literature.(Carlsson et al., Fisher, Lafarge 2015) Staffing levels are likely to have played an important part in the care received, with a recent parliamentary report into midwifery services in England describing a workforce that is overstretched (Public Accounts Committee 2014).

Little research into the experiences of men whose partners are undergoing fetal screening and diagnosis has been undertaken (Green et al. 2004). The role of the father in pregnancy and childbirth has primarily been characterised as that of 'supporter', with little emphasis on the feelings of the father himself (Barclay, Lupton 1999, Lupton 2012, Mander 2004). Findings from this study further support this, with the fathers universally seeing their role as being the strong one, the supporter. Assumption of this role subsequently reinforces their sense of exclusion (Locock, Alexander 2006). Yet previous studies have found evidence that the grieving process following termination in particular is dependent on the perceived support of a partner (Black 1989, Statham et al. 1999, Korenromp et al. 2009), thus highlighting the importance of informing and caring for men in their own right, and in order that they can be supportive to their partner (Statham et al. 2001). The differing needs and coping mechanisms employed by men and women have been highlighted as significant factors in the way parents manage their grief (Mourik et al. 1992), with a major contributor to relationship problems being lack of synchrony in the grieving process (Robson 2002) and poor communication (Mourik et al. 1992). Data from our interviews highlighted the sense of being a 'bystander', a role that resonates with studies of men's experience of pregnancy and childbirth more broadly (Locock, Alexander 2006).

Strengths and limitations

Whilst the sample size for this study was relatively small and intrinsic differences between centres are likely to exist, a significant volume of rich descriptive data was generated highlighting three themes concerning the difficulties faced by this particular group of parents.

The views and experiences of staff delivering care in this context have not been explored and care must be taken in attributing causality for the events discussed, particularly as there is little other literature exploring midwives' perspectives to provide additional insight (Vinggaard et al. 2013) However, within this study, women delivered in four different centres, suggesting the issues are unlikely to solely reflect local policy. Whilst centres may differ in terms of structure and facilities, and care pathways may reflect the recommendations made, to varying degrees, the recommendations are broad enough to have relevance to any service.

Implications and recommendations

Despite the limitations of this study, these findings provide valuable insights from which a series of recommendations may be drawn.

Lack of preparation and support during labour and birth intensified parents' sense of isolation, adding to their distress. Many parents framed episodes where midwives were not available to provide basic care as systemic challenges with staffing numbers and provision, rather than as a direct result of unsympathetic attitudes. New standards on minimum staffing levels currently being considered may assist in addressing these systemic challenges.

However, the universal perception of parents that they were underserving of care is likely to impact on expectations and the way in which their experience was subsequently framed. As highlighted, the views and experiences of staff were not sought and therefore causation cannot be attributed. Nonetheless, the influence of staff attitudes or ability to care for these women and their partners, requires consideration, in particular for midwives whose personal convictions may conflict with their professional responsibilities.

Whilst midwives can object to being involved in a termination, care of women during labour and birth remains an integral aspect of their role. Trusts should therefore seek to better assess their midwives' understanding and acceptance of termination practices, and facilitate discussions over whether 'professionalism' can overcome personal beliefs. Extending the role of fetal medicine midwives, who actively choose to work in an environment where women's 'choice' is supported, is perhaps one solution.

As demonstrated, termination of a pregnancy affected by a severe congenital anomaly creates a unique set of complex psychological needs, which need to be addressed. These findings highlight that these specific needs were not always met, or recognised. Whilst around

2700 such terminations are performed annually, many midwives will not have cared for parents during labour and birth following a termination of a pregnancy for a congenital anomaly. Bereavement counselling training should therefore be considered for all healthcare professionals caring for women undergoing a termination. At present these courses remain optional, and are often difficult to access in terms of time and funding requirements. A number of national courses are provided by charities including Antenatal Results and Choices (ARC) and The Stillbirth and Neonatal Death Charity (SANDS). However, support from employers would be required in order to access these.

The issue of fathers as 'bystanders' requires addressing. Consideration needs to be given to balancing the legal responsibilities of the mother with legitimising the role of the father within the process. The ultimate responsibility for the decision remains with the mother. However, providing opportunities for fathers to actively engage in the process, with the consent of their partner, should be considered. Adoption of practices such as a joint consent form for termination, although not a legal requirement, would provide the opportunity for parents to demonstrate their joint responsibilities whilst also caring for the parents as a unit. However, the final decision would rest with the woman, thus ensuring that a joint consent did not enable a partner to prevent a woman terminating their pregnancy. The psychological needs of the fathers frequently differed from those of the mothers and so provision of specific counselling services tailored to meet their needs may be required.

The distress caused to some parents in particular due to the delays in receiving post-mortem results was extensive where confirmation of the antenatal diagnosis was required for reassurance that the 'right' decision had been made. At the time of undertaking this study, a joint project was underway between the fetal medicine clinicians in one of the centres with the local coroner to investigate the possibility of creating a fast-track post-mortem process following termination for a severe congenital anomaly. This is an example of good practice that could be replicated.

Summary of Recommendations

- **Implementation of minimum staffing levels**
- **Support in accessing bereavement training for midwives**

- **Consideration to extending the fetal medicine midwife's role to supporting women through labour and delivery**
- **Increased understanding of midwives' attitudes to termination**
- **Legitimising the role of the fathers by creating opportunities for formal engagement in the decision-making process**
- **Implementation of the 'fast-track' post mortem service in all centres**

Conclusion

Understanding the needs of parents who terminate a pregnancy affected by a congenital anomaly is essential to improve the care provided. Traditional methods of evaluation are unlikely to produce valid findings, as many these women and their partners harbour a sense of guilt and responsibility and appear grateful for whatever care they receive. Awareness of the symbolism applied to aspects such as consent must be raised, to enable staff to effectively care for this group. Specific care pathways should be developed based on the unique needs of this group, along with interventions tailored to support partners, to ensure the long-term wellbeing of the couple as a unit.

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