

Lethal fetal anomalies: a case of bilateral renal agenesis

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ORIGINAL

This article explores the experience of a woman, who at 32 weeks' gestation was informed that her baby had a lethal fetal anomaly (LFA). Background information is provided about the condition in this case, and the key debates about how the news is shared, the interventions that are suggested, and most significantly the choices made by the mother in completing this inevitable journey. Midwives acting as advocates for the women they care for are often confronted with women's diverse cultural responses to grief that can challenge a medical model of care. However, in this case study, the midwife endeavoured to facilitate the experience of the woman and her partner from the point of breaking the news to the couple, to how decisions were made regarding any intervention culminating in the parturition, celebrating the birth, yet dealing with the grief at the loss of their baby and the life that might have been.

Case study

Natalie, a young woman of 27 experiencing her first pregnancy, had made the choice to engage an independent midwife to support her choices through pregnancy and birth. With her partner Matthew, they had read widely about pregnancy and birth, looking to midwifery guru Ina May Gaskin's *Spiritual midwifery* for guidance. Natalie desired a true 'with woman' approach to her care with no medical intervention unless really necessary, ensuring the power base of care sat with her, and with a like-minded midwife by her side. Natalie was fit and well, and the booking interview at 13 weeks was clinically very routine. The couple had organised and undertaken nuchal screening at a private scanning clinic with a normal result; they then made an informed decision that at this time they did not want further anomaly scans/screening. Natalie was happy to have routine blood screening and did this at 22 weeks. Natalie and her

midwife negotiated antenatal appointments, which included time away for both, meaning Natalie did not see the midwife between 26-32 weeks.

At the next visit, Natalie was in good health and relaxed, however, it was noted that on palpation the fundal height was 28cm. Natalie and the midwife discussed diet and general well-being, coming to the conclusion that she was in fact a well woman. It was agreed that the couple would return to the scan clinic to review the fetal well-being. It was at this appointment the couple were informed that, '*there's no fluid around the baby, it's measuring up at 30 weeks and I can't locate the bladder or kidneys*'. This statement was to change the course of the pregnancy and its outcome. It was the beginning of what, at times, seemed like insurmountable challenges for the midwife in her endeavour to provide woman-centred care.

Bilateral renal agenesis (BRA), also referred to as classic Potter's syndrome (Clarke 2003), has an incidence of 1:10,000 (Public Health England 2015). It is a lethal fetal anomaly (LFA) of absent kidneys, and little or no amniotic fluid, resulting in the poor development of the baby's lungs.

BRA has a detection rate of between 70-90% (NICE 2008) and has proved to be 100% lethal in all cases. It is referred to as 'not compatible with life', but no genetic mutation, disease, medical condition or anomaly has been linked to its cause. For pregnancies that go to term, infants typically survive for only a few minutes to a few hours and die from lung or renal failure (Clarke 2003).

Methods

A thematic content analysis of the case study was conducted to identify key themes to guide the search for literature. The key themes identified include, 'communicating bad news', 'supporting women's choices' and 'giving birth at home with a lethal fetal anomaly'.

A further electronic search for narratives from women who chose to carry their pregnancies to term after BRA fetal diagnosis was carried out. From the Potter's syndrome gateway (<http://www.potterssyndrome.org/>) – an online facility for mothers who choose to carry a pregnancy to term to share their stories – we selected seven cases for a further thematic analysis.

Search strategy

An electronic search was conducted for published literature that addressed women's experiences of carrying a pregnancy to term after an LFA diagnosis, in the context of the identified themes. Literature searches of databases MEDLINE, PUBMED and CINHALL were supplemented with Google and Google Scholar website searches for relevant evidence. Although studies about BRA started in the early 1940s (Potter 1946), there is limited evidence related to women's experiences of carrying a pregnancy to term. Sentiments expressed by mothers who carry a pregnancy to term with poor prognosis, related to other diagnoses, are similar. The literature review is presented according to the themes identified from the BRA case studies.

Communicating bad news

Almost all women give birth in hospital and the majority are subjected to a range of medical and technological interventions (Earle 2005). Most women undergo ultrasound screening as part of their prenatal care and it has become a test that does not require the woman to make any decisions (Smith *et al* 1995 cited in Mitchell 2004, Lalor & Begley 2006). The absence of informed consent and pre-scan discussions about ultrasound impedes the preparation for the possibility of fetal abnormality (Baillie *et al* 2000, Mitchel 2003). Encouraging informed choice leads to

reflection, engaged thinking, empowerment and active participation in life's decisions, which all contribute to improved outcomes for pregnancy care (Mitchel 2003, Sommerseth & Sundby 2010).

Some women, who go to what they believe is a routine screening, receive bad news at the time of the test (Lalor & Begley 2006) leading to a rapid shift in their emotional state (McCoyd 2009, Sommerseth & Sundby 2010). The way in which adverse diagnoses are communicated to parents needs to be reconsidered (Lalor *et al* 2007). Whilst the news has to be delivered, the interaction between parents and health care professionals is mostly characterised by imbalanced information, badly influenced decisions, with the unborn child discussed in terms of a diagnosis rather than an individual (Guon *et al* 2014). Literature shows that health professionals are generally not prepared for imparting such information (Simpson & Bor 2001, Fallowfield & Jenkins 2004) and that patients often carry bad memories of the moment they were given the news, not only because of the news itself, but because of the caregiver's inability, insensitivity, or both (Guerra 2011).

The patient's attention tends to 'scatter' when they receive bad news, decreasing their capacity to remember the information given (Hunt *et al* 2009, Guerra *et al* 2011). Natalie demonstrated this thought scattering process as she jumped from one unrelated question to the next in the days following the diagnosis. Effective communication is essential in achieving increased recovery rates, a sense of safety and protection, improved levels of patient satisfaction and greater adherence to treatment options (Wright 2012). Lalor *et al* 2007 recommend specific training for health professionals on how to break bad news sensitively to a vulnerable population (Lalor *et al* 2007).

Supporting women's choices

The term 'incompatible with life' can, unintentionally, take away the parents' right to make a decision concerning their unborn child. It implies a life judgment that should not be used as a label (Lathrop 2010, Mayer-Whittington 2012). In several cases the term conveys a message that there is no choice but to terminate the pregnancy. Indeed, in the case of Natalie and Matthew, a consultation with a fetal anomaly specialist on the same day as diagnosis, resulted in an appointment for the pregnancy to be terminated within a couple of days and the advice of '*it's the kindest thing you can do for your baby now*' given as parting words.

Woman-centred care means that midwives encourage self-efficacy by providing a range of unbiased information which takes into account women's beliefs and values. This includes a non-judgmental approach to understanding that some choices or decisions made by women may not fit into the Royal College of Midwives' (RCM) framework of institutional guidance and protocols. Nevertheless, the midwife's

role remains that of being the woman's advocate by enabling her to make decisions of her own (RCM 2001, Thewlis 2006). Natalie's midwife encouraged her not to rush into decisions, but to take time to process and accept the information she'd been given, before making any choices.

A woman's choice may be a meaningful experience for the family that is critical to the healing and bereavement process. Medical personnel, with their institutional knowledge about science and technology, are able to establish the medicalised model of childbirth as normative. This affects both the ways women approach pregnancy and the extent to which they are aware of their birthing options. Home birth activists advocate for a woman's right to experience childbirth in her own unique way and have the opportunity to determine the levels and kinds of interventions that are used during labour and birth (Cheyney 2008).

Qualitative findings by Cheyney (2008) revealed that for 'homebirthers', the body provides a sort of inner knowing that serves as a source of authoritative knowledge that can, in some cases, rival the discourse of medical knowledge. Midwives trust and rely on women's embodied knowledge, and to the same extent women trust and rely on the experience of midwives. This approach enhances feelings of intimacy and trust that women are less likely to experience when treated by physicians and surgeons (Cheyney 2008). Women feel that the most appropriate health professional to provide this aspect of care and the right expertise is a midwife (Lalor *et al* 2007). Their close relationship with a known, trusted, midwife of choice, providing continuity of care, enabled Natalie and Matthew to make informed choices at their own pace and according to their own particular needs.

Birth at home with a lethal fetal anomaly

Evidence shows that 98% of neonatal deaths occur in hospital settings, with few families spending time with their baby at home (Leuthner *et al* 2004, Craig & Mancini 2013). Parents benefit when offered the choice for their child to die outside the hospital (Simpson 2011), yet even where death is inevitable, health professionals are sometimes reluctant to consider offering this as an alternative. Inappropriate professional assumptions about what a family will want, or what a family can cope with, should not limit the choices made available to them (Craig & Mancini 2013).

A family may need, or want, 24-hour midwifery care in the home, which may not be feasible due to a lack of midwifery availability or financial resources. Families may be unable to address the possibility or inevitability of their child's death, leading to an inability to adequately consider their choices (Craig & Mancini 2013). There is no evidence available on experiences of home births for women who chose

to carry pregnancies to term after a LFA diagnosis (Leuthner *et al* 2004)

Discussion

The Francis report (Mid Staffordshire NHS Foundation Trust Public Inquiry 2013) found that practitioners had failed to act in a way that fostered a safe, caring, positive environment for patients, service users and carers. Thereafter, 'compassion in practice' (Department of Health, NHS Commissioning Board 2012) encouraged the realignment of health and social care workers' moral compasses in suggesting that the 6 Cs (compassion, competence, courage, care, communication and commitment) should be the guiding principles that underpin practice. The case study of Natalie and Matthew and the other electronic narratives not only raise questions about how health care professionals communicate bad news, and how women's choices are supported, particularly that of birth at home following a LFA diagnosis, but provides an opportunity to review how the 6 Cs can be seen in real time and truly embedded in practice.

Communicating bad news

For health care practitioners, breaking bad news can be one of the most difficult elements of their working life. Exploration of this challenge is difficult as the focus of the literature often relates to the reaction of the recipient and there is a limited amount of literature associated with this type of communication during pregnancy.

Understanding why practitioners find this a challenge is a complex interplay of emotions. Moss (2012) suggests that by consciously preparing for this situation there will be less of an overwhelming impact for the person receiving the news. The most helpful preparation at this level is to be able to treat the person with respect and seriousness, listen to their pain and be clear when responding. This should happen by giving answers that in effect keep the news breaker safe or make them feel comfortable. Certainly, in a diagnostic situation such as anomaly screening, development of the practitioner's skills in delivering bad news should be seen as an investment.

Another dimension to breaking bad news is the interprofessional interaction. In Natalie's case a midwife was present, acting as an advocate for the woman, and in order to make herself clear, she needed to gain an understanding of the condition. However, due to its low-prevalence, she was unable to add any further insight. This left Natalie, Matthew and the midwife with difficulties moving forward with the decision making process. For the couple, the process of decision making and understanding the condition rested on the information they could gain from the internet, creating the risk of finding unreliable non-evidence-based data. In this instance the midwife was able to contextualise the information; however this may not occur in every case.

Supporting women's choices

The literature recognises that the usual decision making process in the instance of LFA involves termination and a planned grieving process which fully supports choosing to end a pregnancy at whatever gestation. Yet allowing women alternative choices may sometimes be a needed experience for her and her family that is critical to the healing and bereavement process. The experiential lessons on life and the end of life are powerful. These emotion-based lessons far surpass those which are cognitive-based. It may be painful to accompany a child or sibling on his or her final journey, but the experience has the power to transform lives (Milstein 2003). A study by Guon *et al* (2014) found that after a poor prenatal diagnosis the majority of women carried to term for both child- and parent-centred reasons. This is in consensus with other studies where women expressed love and intrinsic value for their unborn baby and the desire to meet and spend time with their child, regardless of how long they believed their child would live (D'Almeida *et al* 2006, Breeze *et al* 2007, Simpson & Penrose 2011, Janvier *et al* 2012). For some women, the decision to continue their pregnancy after LFA diagnosis allows parents to avoid some feelings of guilt, regret, and doubt (D'Almeida *et al* 2006, Lathrop 2010). The number of women who elect to continue with their pregnancy, give birth and wait out events may be minimal. However, this fact alone complicates the issue because practitioners are often not skilled in facilitating a choice such as this and find it challenging to their perspective of 'the norm', complicated by their perspective of risk and the boundaries of professional guidance and policy.

For Natalie and Matthew the initial knee jerk decision was to accept the medical model advice to terminate the pregnancy. However, given time they came full circle back to the decision to continue and to meet their baby on the same day as saying goodbye in their home environment. It is clear that hospital births are more likely to fall prey to the overuse of such interventions due to the medicalised context in which they occur (Davis-Floyd 2003) but their choice was not to have medical intervention. The midwife's role was to facilitate this plan and she was confident in her pastoral support for the couple with guidance from her colleague and Supervisor of Midwives. However, there was increased pressure from the medical community to encourage Natalie to birth in an obstetric unit.

Birth at home with a lethal fetal anomaly

The planning for a home birth was crucial for Natalie and Matthew, and was balanced with the grieving process. The midwife reflected on how she observed that Natalie moved through stages of grief, facilitated

by conversation and active listening. The interaction between health professionals and bereaved parents, whatever the setting, plays an important role in families' ability to cope with their bereavement. It is absolutely critical to allow the family to complete certain tasks of grief involving: accepting the reality of the loss, expressing the pain of grief, adjusting to life without the deceased, and emotionally moving on with life to enable new relationships (Milstein 2003). In Natalie and Matthew's case this process was related to the impending death of their baby.

A birth plan outlining the couple's wishes and respected by all professionals, helps ensure the entire health team are well informed. This plan included having a Supervisor of Midwives on call to support the midwife, the coroner's agreement to the process and the availability of Sands' (Stillbirth & neonatal death charity) materials such as the memory box. The challenges in this case arose out of the general practitioner's (GP's) closed body language and perceived disapproval of the care plan during the multidisciplinary meeting; one can only associate this with a level of anxiety created by an uncommon experience. This behaviour continued, displayed in a conversation about the point of demise of the baby. The GP was not willing to attend the home under any circumstances or sign the death certificate, if the baby was to be born alive, and informed the midwife that an ambulance crew should be called at which point resuscitation would be commenced followed by a transfer into hospital. For Natalie this was devastating news. Part of her acceptance of the situation included a peaceful birth and death for her baby.

As Guon *et al* (2014) highlighted, midwives are privileged to accompany parents through the devastation of LFA diagnosis, the intense moments when they meet their baby and their journey through an altered or disrupted postpartum period, but they will need to take courage and not waiver when pressurised to intervene with a medicalised birth that is at odds with the woman's desired plans. The midwife stood fast, continued to liaise and negotiate with other professionals, particularly the coroner, and the agreement was finally made that Natalie would have the opportunity to achieve her desired plan.

At 43 weeks' gestation, after a short labour, Evan Gabriel was born at home, the natural empowering birth that Natalie and Matthew had planned. Although he was not born alive, Natalie was able to celebrate his birth, bathe him, cuddle him, spend much of the next week with him at home and say goodbye. This time and process is pivotal to the well-being of the family. Theoretical models of grief have changed over the past two decades with the traditional model focusing on 'letting go' and the

contemporary model placing emphasis on 'holding on' to the emotional relationship with the child that has been lost (Davies 2003). Parents are encouraged to write letters to their lost baby and to hold on to mementos like blankets, wrist bands and foot prints, all generating some of the most profound emotions in life (Woods & Rozovsky 2003, Guon *et al* 2014). The interaction between health professionals and bereaved parents plays an important role in families' ability to cope with their bereavement.

Recommendations for practice

The evidence and reflection presented in this article raise a variety of considerations for the way midwives and other health care professionals practise. When communicating bad news, such as in the case of rare anomalies, the emotional aspects can test the professional's being. In order to be successful there is a level of competence required; this should be accompanied by a level of emotional intelligence that allows the professional to reflect honestly, escalating to others without fear of criticism.

The medicalisation of birth is not a new concept; it is the attempt to manage the birth process of women who have medical or social reason to intervene. For some women it is about accepting responsibility and making an informed choice about their journey, although at times it can cause professional conflict and be emotive for the midwife, it is imperative that midwives act as the advocate for both women and their profession.

In similar situations to Natalie and Matthew's, it is important that inappropriate professional assumptions or haste about what a family will want or what a family can cope with, do not limit the choices made available to them (Craig & Mancini 2013). Whatever the local model of home care, care must be collaborative, community-based and family-centred. Care after death must be discussed with parents. They need to know who is responsible for confirmation and certification of death and the processes by which these are organised. If they want to move the baby to a different location after death, plans should be put in place to complete any necessary paperwork and transport arrangements should be considered in advance (Craig & Mancini 2013). Once the care pathway has been completed it is vital that there is not only debriefing between the woman and midwife, but between those involved with the woman's care, particularly in more unusual cases. The woman should be directed to other services which will help with the grieving process and to move forward in life, especially when considering further pregnancies.

Natalie and Matthew

Natalie has written a blog about her experiences which can be read here...

<http://missaniela.tumblr.com/post/73949075407/my-letter-to-evan-and-to-the-world>

Natalie says of her journey with Evan:

'The emotional reactions of fear at first made me feel as though home was the last place I wanted to give birth, but giving myself some time to think, I began to ask questions about the medical process being offered to me. At the same time, my feelings of love and bonding toward my baby were resurfacing above the fear, and making me realise this was still my baby and an important birth. It was going to be my first birth. If I could overcome the fear, anger, and bitterness, I realised that what does not change is love.'

Natalie and Matthew are currently expecting the birth of a healthy daughter.

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Useful websites

<http://www.potterssyndrome.org/>

<http://fetalanomaly.screening.nhs.uk/leafletsforparents>

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