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The experience of pregnant women with a diagnosis of fetal lower urinary tract obstruction (LUTO)

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ABSTRACT

Objective: to gain insight into the experiences and perspectives of pregnant women diagnosed antenatally with fetal lower urinary tract obstruction (LUTO) participating in an interventional fetal medicine randomised controlled trial (RCT).

Design: a qualitative study using semi-structured interviews. Interviews were analysed using Riessman's narrative analysis.

Setting: fetal medicine clinics within the United Kingdom National Health Service (NHS).

Participants: five pregnant women who were recruited as part of an RCT and two additional women who were recruited after the trial was terminated before completion.

Findings: three themes were identified and form the basis of this article: the use of technology in pregnancy, the loss of a normal pregnancy, and decision making in uncertainty.

Implications and conclusions: undertaking qualitative research within an RCT can illuminate the experience of the condition being studied. Women's experience of a pregnancy where LUTO was diagnosed in the fetus entailed an emotional journey following the visualisation of the abnormality through the use of routine ultrasound screening. Women tried to make sense of the diagnosis in order to make the best, albeit less than ideal, decisions for themselves, their baby, and their family. Midwives are in a good position to support women through the emotional distress of diagnosis and to help them negotiate the uncertain terrain in which they make decisions.

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Introduction

Congenital obstructive uropathy, although rare, accounts for up to 60% of all paediatric renal transplants (Parkhouse and Woodhouse, 1990) and lower urinary tract obstruction (LUTO) is a particularly morbid condition (Morris et al., 2007). Severe obstruction is commonly associated with oligohydramnios and abnormal development of the fetal lungs and kidneys with pulmonary and renal dysplasia frequently leading to death after birth due to respiratory and/or renal failure in the most severe cases. Ventilatory support may be required for babies who survive following birth although the long term

prognosis for infants requiring renal dialysis or transplantation is poor (NICE, 2006).

When a diagnosis of fetal LUTO is made during pregnancy women are usually presented with three options. These are to observe the clinical features of the condition and not intervene in any medically invasive capacity; to place a vesico-amniotic shunt to bypass the bladder obstruction allowing the fetal urine to drain into the amniotic cavity thus reducing the potential for further damage occurring to the fetal kidneys; or to terminate the pregnancy on the grounds of severe fetal abnormality. Guidance on the management of fetal LUTO issued by the National Institute of Health and Care Excellence (NICE, 2006) recognised that the condition is usually managed conservatively, and highlighted the uncertainty that exists about the criteria for appropriate selection of fetuses for treatment with vesico-amniotic shunt. For this reason it was recommended that the procedure should only be performed in centres specialising in invasive fetal medicine and in the context of a multidisciplinary team.

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The PLUTO: Percutaneous Shunting for Lower Urinary Tract Obstruction Study was a randomised controlled trial (RCT) undertaken to evaluate the safety and efficacy of fetal vesico-amniotic bladder shunting in moderate to severe antenatally diagnosed cases of LUTO compared to conservative management. In total 31 women were recruited to the RCT, and randomised to either vesico-amniotic shunting or conservative management, and a further 46 women were entered on to a prospective registry to enable outcomes to be assessed and compared similarly across both study groups. However, as around half the women approached to participate in the trial opted for TOP it failed to recruit a large enough sample size to produce definitive outcome data from the randomised cohort. It was therefore terminated prematurely, and women recruited for the qualitative study were (with one exception) from those women who decided to continue with the pregnancy.

Antenatal diagnosis of LUTO is made during routine ultrasound scanning (Morris et al., 2007). Since its introduction in the 1980s antenatal screening has become a ubiquitous element of antenatal care. The support that specialist midwives can offer families undergoing antenatal screening and diagnosis has been considered by numerous researchers in recent years with many recognising the importance for midwives to advocate for services that enable pregnant women and their partners to make decisions that embody their values, beliefs and attitudes based on accurate and balanced information (Skirton and Barr, 2010). Midwives in a study by Ahmed et al. (2013) had diverse views on their role in discussing information on antenatal screening, varying from fact giving to in depth discussion of information. However, they all had a clear understanding of policy requirements for midwives to facilitate informed choice.

The idea of medical supervision and surveillance of pregnancy has become normalised and routinised (Rapp, 1999; Markens et al., 2010) and is taken for granted by parents and health professionals. Not to engage in antenatal screening has become a non-acceptable choice, with some women reporting that they feel unable to exercise choice freely in deciding whether or not to undergo antenatal screening (Pillnick and Zayts, 2012). Routine ultrasound scanning is often presented in a positive light, promoting bonding between mother and fetus, as the image allows for representation of the fetus as a child (Gray, 2002; Molander et al., 2010). It may be considered to provide visualisation and personification of the fetus therefore allowing women to develop a strong connection and relationship with the baby. 'Having a scan' has become a social ritual and a chance to see and meet the baby, and an abnormal result is unexpected and distressing (Bijma et al., 2008). A systematic review of ultrasound scanning in pregnancy concluded that women are often unprepared for adverse findings and having seen their baby makes it harder to cope with its loss from termination or fetal death (Garcia et al., 2002).

A diagnosis which is considered to be compatible with life, albeit associated with varying levels of impairment, presents a real dilemma for a woman's decision making (McCoyd, 2008), as does an unclear prognosis (Garrett and Margerison, 2003). In addition women undoubtedly feel an inherent responsibility for the child they carry to the extent that they often modify their habits and behaviours during pregnancy. As such pregnancy may affect their ability to make 'free' choices, making them feel bound on the one hand to accept any interventions that might benefit the unborn child, and on the other to decline treatment for themselves due to potential teratogenic fears (Smyth et al., 2009).

As part of the RCT a qualitative study was undertaken to explore and capture the experiences and perspectives of pregnant women with an antenatal diagnosis of LUTO.

The specific objective was to gain insight into the experience and decision making processes of women who were invited to take part in the PLUTO trial.

Method

Although recruitment to the PLUTO trial was low, the opportunity to capture the experience of women who continue with a pregnancy following a diagnosis of LUTO is rare, and the rich data obtained by the study were considered worth reporting.

The discovery of a fetal abnormality is a time of great anxiety, distress and uncertainty for mothers and their partners (Sommerseth and Sundby, 2010). In order to understand the experience of parents in this situation we considered that a qualitative research design was most appropriate. This allowed participants to discuss issues of importance and concern to them, revealing as much of themselves as they wished. Semi structured interviews were undertaken as the purpose of the research was to explore and understand the impact of a diagnosis of LUTO, and to gain insight into the sense parents made of it within the context of their lives. The goal was to generate detailed accounts, rather than general statements (Riessman, 2008).

Participants

All women approached to take part in the PLUTO trial were invited to participate in the qualitative study.

Six women were recruited by the time the trial was terminated. Two further women with a diagnosis of fetal LUTO were subsequently recruited from the fetal medicine clinic leading the RCT, making a total sample of eight. Written consent was obtained from all of the participants. One woman who decided on TOP after recruitment has been excluded from this paper, as it was considered by the authors that findings from a small sample would be more meaningful if participants were more homogeneous. As this was a convenience sample, and LUTO is a rare event, criteria for assessing data saturation were not identified and it is possible that saturation was not achieved. Ages of the women ranged from 23 to 41, and all but one described themselves as White British, the other identifying as Sub Saharan African. Gestation at the first scan where an abnormality was detected ranged from 12 to 29 weeks, with the most common time being the routine 20 week scan. Two women were in their first pregnancy, two women had one child, and the other three women had two, three and four children. Five women were interviewed alone, and two couples chose to be interviewed together.

Data collection

Six women were interviewed by author 2 (the research midwife for the RCT) and one by author 1 (the co-investigator responsible for the qualitative study). All interviews were conducted face to face, at a time and place chosen by the woman. Interviews were semi-focussed and began with an open ended question requesting the participant to relate how and when she was told about LUTO. Follow up questions were guided by the response to this first question, although a loose interview guide was formulated around relevant topics, and women were free to define and discuss their own concerns and issues of importance (see Table 1). This approach to interviewing was felt to be consistent with the narrative analysis of Catherine Kohler Riessman (Riessman, 2002) which was to be used to analyse the data. Each interview lasted approximately 45 minutes and all interviews were tape-recorded with permission. Interviews were transcribed verbatim and anonymised using study identifiers. Interviews took place prior to childbirth in all but two cases. Due to the poor prognosis associated with this particular fetal condition the research team believed that it would not be appropriate to approach women who may have recently suffered a neonatal loss. However, one interview was undertaken post-birth following intrauterine death ($n=1$) as this woman was recruited pre-childbirth and expressed a wish to continue in the research.

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