



What parents say about disclosing the end of their pregnancy due to fetal abnormality

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ABSTRACT

Objective: to describe men's and women's experiences of deciding whether to tell people in their social network, including their children, about their pregnancy loss following a termination for fetal abnormality.

Design: secondary analysis of qualitative narrative interview data informed by a critical realist approach.

Setting: respondents were recruited throughout the United Kingdom and interviewed at home between 2004 and 2005.

Participants: twenty-eight women and nine men who had ended a pregnancy diagnosed with a fetal abnormality and who talked about disclosing or not disclosing the termination to others.

Findings: few respondents reported having any advice or information about whether or how to disclose their termination. None said they completely concealed their decision from adults in their social network; most said they disclosed selectively, telling close friends and family they had terminated and acquaintances they had miscarried. Most respondents reported telling their young children that the baby had died but did not reveal that they had chosen to end the pregnancy. A minority had not told their existing offspring about the pregnancy loss. Common reasons given for (partially) concealing a termination were: guilt over the decision; to avoid being judged; and to protect other people's feelings. Common reasons for disclosure were: others knew of the pregnancy; needing time off work; needing practical help and/or emotional support during diagnosis and termination; and wanting recognition of their loss. Positive consequences of disclosure were said to be getting more support and less criticism than expected; negative consequences included not getting the anticipated support and empathy; and encountering disapproval. Some respondents felt that concealing their pregnancy loss from their children had resulted in their confusion over the cause of their parents' distress. Some men said they found it hard to access emotional support from their social networks because of expectations about how men 'should' deal with emotions.

Key conclusions and implications for practice: midwives have to make difficult judgements about what, how and when to provide information when trying to support and advise parents who have ended a pregnancy due to fetal abnormality. Further education and training in this area could be of benefit. Midwives could signpost parents to existing sources of advice around disclosure, taking into account parents' individual preferences, help parents to consider the potential implications of disclosure and concealment and different ways of disclosing. They could also recommend alternative sources of emotional support, bearing in mind that men in particular may find it harder to access support from their social networks.

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Introduction

The diagnosis of fetal abnormality is a distressing time for parents. They have many decisions to face, not least the decision

of whether to end the pregnancy. Some decisions are time-limited to the hours and days immediately following a termination including whether to: see and hold the baby; have a funeral or cremation; or have photographs, handprints or footprints of the baby (Hunt et al., 2009). Other decisions can be taken over a longer time period, but can be equally distressing; one of these is whether to tell other people about a termination for fetal abnormality.

Despite the routine availability of antenatal screening and the legal availability of pregnancy termination due to fetal abnormality (up to 24 weeks gestation and beyond this in certain circumstances in the UK (Statham et al., 2006; Fisher, 2008) and in some states in the USA), termination of pregnancy remains stigmatised. In this context Thachuk (2007) points out, 'open discussions surrounding genetic terminations remain taboo and silenced. Women are socially isolated, their experiences kept secret, and their grief disenfranchised.' (p. 511).

Because termination for fetal abnormality is relatively uncommon and rarely discussed, few parents will be prepared for the decisions that they will face having ended their pregnancy. Guidance for health professionals on how to support parents is also lacking; although the National Institute for Health and Clinical Excellence's guidelines on antenatal and postnatal mental health (National Collaborating Centre for Mental Health, 2007) include protocols for supporting women following stillbirth, they do not offer advice on supporting parents following termination for fetal abnormality.

A literature search identified a few studies of termination due to fetal abnormality, which included some limited data on women's experiences of disclosing their termination (Statham, 1994; Bryar, 1997; Geerinck-Vercammen and Kanhai, 2003; Sandelowski and Barroso, 2005; McCoyd, 2007), but none focusing solely on disclosure. These studies have not included men's experiences, or disclosure to one's existing children. Only one study (Sandelowski and Barroso, 2005) included data on experiences of first trimester termination. The studies indicate that some women say they conceal having had a termination for fetal abnormality to: protect themselves from possible condemnation (Bryar, 1997; McCoyd, 2007); protect others' feelings; maintain social support; or to try to reconcile themselves with their decision (Sandelowski and Barroso, 2005). However, they report other consequences of concealment including feelings of guilt at 'betraying themselves and their babies' (Sandelowski and Barroso, 2005, p. 313); isolation; and having no emotional support or outlet (McCoyd, 2007), which might make it more difficult for women to come to terms with their decision (Statham, 1994). Those who do disclose their decision to their social network might encounter less disapproval than expected; be able to cope with any disapproval (McCoyd, 2007); and might gain support that helps with grieving (Geerinck-Vercammen and Kanhai, 2003; Sandelowski and Barroso, 2005). Bryar (1997) suggests that selective disclosure, for example, where women tell some people they have terminated but tell others they have had a miscarriage, might lead to stress in managing two versions of events.

In summary, both negative and positive consequences of disclosure and concealment of a termination for fetal abnormality are apparent. However, studies provide only limited data on women's experiences and existing studies tell us nothing about men's experiences or about whether and how parents disclose to children. In the absence of professional guidance, further research could help inform current practice in advising and supporting parents to manage this sensitive decision at a distressing time. This paper describes men's and women's experiences of deciding whether to tell people in their social network, including their children, about their pregnancy loss following a termination for fetal abnormality in the first, second or third trimester.

Methods

This study employed secondary analysis (Heaton, 2004) of narrative interviews to investigate parents' accounts of whether to disclose they have ended a pregnancy because of fetal abnormality; it forms part of a wider study on information use in health-related decisions (Wyke et al., 2011). Forty interviews were originally collected for a national, qualitative study of the experience of ending a pregnancy for fetal abnormality. A diverse purposive sample (Coynne, 1997) captured variation in experiences of termination for fetal abnormality and socio-demographic variables. General practitioners, midwives, hospital consultants, staff in antenatal clinics, support group leaders and existing interviewees distributed study information to potential participants. Those interested in participating contacted the researcher directly or gave permission for the researcher to be given their contact details. Most interviews were conducted in participants' homes during 2004–2005. The 1–3 hour interviews initially used a narrative style that allowed respondents to tell their own stories, with subsequent prompting on certain topics. Respondents were given contact details of support organisations following interviews. With respondent consent, interviews were audio and video recorded and transcribed, then checked by the respondent who could edit the transcript. Counselling support was available to the research team but not used. Emotional support was also provided to the researchers through debrief sessions with the wider project team and a 'buddy' researcher who understood the complexities of undertaking narrative research interviews on distressing topics. The research methods were approved by the Multi-centre Research Ethics Committee and National Health Service (NHS) governance permissions were granted.

The analysis presented here draws on 33 full interview transcripts from 37 people—28 women and nine men, seven of whom were the male partners of the women (four women and their partners were interviewed individually, three were interviewed jointly according to their preference). Table 1 provides respondents' biographical and pregnancy details. These interviews were selected because they discussed during the interview the decision about whether to tell others about the termination due to fetal abnormality. In order to include parents with recent and more distant experiences of termination interviews took place 1–11 years after a termination although most were 2 years after a termination. Women/couples had experienced one or more terminations for fetal abnormality, most by induced labour during the second ($N=25$) or third ($N=2$) trimester; four women had had a surgical termination. Pseudonyms are used throughout.

Our conceptual approach was influenced by Bury's (2001) framework for analysing illness narratives, which distinguishes between contingent narratives (what respondents said about events and what happened to them), moral narratives (accounts of relations between the person, their decision and social identity), and core narratives (deeper cultural meanings). We focused on contingent narratives to analyse people's perceptions of their experiences while recognising that the interviews are 'factions' (Bury, 2001, p. 282), i.e. accounts combining fact and 'fiction' as people retrospectively reconstruct events. In taking this approach we were informed by critical realism, which uses a critical stance to 'factual truth' while maintaining that a reality exists; as such it challenges both constructionism and positivism (Bhaskar, 1989; Bergin et al., 2008).

Our initial interest was in the types of information people used in reaching decisions related to their termination, including decisions about whether to tell others about having ended a pregnancy. Using an adapted framework analysis (Ritchie and Spencer, 1994), for each interview EFF recorded in a framework data relating to every decision discussed including: the type and

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