



## The emotional process from diagnosis to birth following a prenatal diagnosis of fetal anomaly: A qualitative study of messages in online discussion boards

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### ABSTRACT

**Objective:** to explore written statements found in online discussion boards where parents currently expecting, or with previous experience of expecting, a child with a prenatally diagnosed congenital anomaly communicate about their emotional process from diagnosis to birth.

**Design:** cross-sectional qualitative study of messages in public online discussion boards.

**Setting:** Swedish public discussion boards about reproductive subjects.

**Sample:** ten pregnant women and eight parents (of children with prenatal diagnoses) who had written 852 messages in five threads in Swedish online discussion boards identified via systematic searches.

**Measurements and findings:** three phases were identified in the process of moving from the diagnosis to the birth: shock, existential crisis, and life remodeling. The people posting message ('posters') moved from initial shock to existential crisis and, lastly, a phase of remodeling life later in the pregnancy. During the pregnancy, considerable worries about both antenatal and postnatal aspects were expressed. To cope with their situation, the posters distanced themselves from the diagnoses, vented their feelings, sought control, and obtained practical support from friends and relatives.

**Key conclusions:** expectant parents faced with a prenatal diagnosis move from initial shock to a phase of life remodeling and acceptance. Burdened with considerable worries, expectant parents cope with their situation through informational, emotional, and instrumental support from health professionals, family, friends, and peers.

**Implications for practice:** health professionals should make sure that expectant parents feel involved in planning their children's postnatal care, that they are offered sufficient information, and that they have access to emotional and instrumental support structures.

### Introduction

Obstetric ultrasound examinations in the second trimester of pregnancy are procedures offered to pregnant women with several medical purposes: To calculate gestational age, assess the number of fetuses, locate the placenta, and screen for fetal anomalies. Many countries around the world, including Sweden, have implemented these procedures as part of routine maternity care. A large majority of pregnant women accept the examinations on offer and most find the choice to undergo these examinations easy to make (Crang-Svalenius et al., 1998).

A prenatal diagnosis of a fetal anomaly is a traumatic life event for

expectant parents (Garcia et al., 2002; Sandelowski and Barroso, 2005; Wool, 2011), resulting in intense grief and psychological distress (Wool, 2011). Following the diagnosis, women may be presented with the decision to continue or terminate the pregnancy. This emotionally difficult decision involves many considerations (Sandelowski and Barroso, 2005; Asplin et al., 2013; Kristjansdottir and Gottfredsdottir, 2014). In Sweden, pregnant women have the right to terminate their pregnancy before 18 completed weeks of gestation, and later after approval from the National Board of Health and Welfare. In clinical settings, pregnancy terminations are seldom performed after 21 completed weeks. When the pregnancy is continued, the diagnosis presents an opportunity to prepare for the birth of a child with

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disabilities (HoeHN et al., 2004; Hedrick, 2005; Askelsdóttir et al., 2008).

During the pregnancy, caregiving systems are activated that involve motivation to relate to the baby, handle practicalities, and manage the child's medical care (McKechnie and Pridham, 2012). After the diagnosis, expectant parents express a need for continued support and information during the remainder of the pregnancy and have concerns about the near future (Bratt et al., 2015). Nevertheless, expecting a child with a congenital abnormality involves conflicting feelings, with both optimistic and pessimistic thoughts about the future (Hedrick, 2005).

Individuals expecting a child with a fetal anomaly use online platforms, such as virtual communities, to find and communicate with others in similar situations (Hedrick, 2005; Bratt et al., 2015; Carlsson et al., 2016). Virtual communities, defined as 'groups of people with common interests and practices that communicate regularly and for some duration in an organized way over the Internet through a common location or mechanism' (Ridings et al., 2002), offer the possibility of anonymous communication among peers. Discussion boards are one type of virtual community, defined as websites where users commonly referred to as 'posters' read and write messages to one another in various threads. Threads comprise an initial message from a single poster and the subsequent sequence of reply messages.

Research has shown that people disclose more about themselves when they communicate online than in face-to-face settings (Joinson, 2001; Tidwell and Walther, 2002). Consequently, research that includes these kinds of materials have the potential to explore subjects that people may not discuss openly when interviewed by health professionals or researchers (Radin, 2006). Moreover, publicly available asynchronous communication makes it possible for researchers to unobtrusively explore, in a temporal perspective, written accounts of such experience as the emotional process from diagnosis to birth. Consequently, the aim of this study was to explore written statements found in online discussion boards where parents currently expecting, or with previous experience of expecting, a child with a prenatally diagnosed congenital anomaly communicate about their emotional process from diagnosis to birth.

## Methods

### Study design

This qualitative study of messages in public online discussion boards was based on grounded theory. This approach was chosen because we sought a deeper understanding of the processes that expectant parents experience when they are faced with a prenatal diagnosis of a congenital anomaly in their unborn child. Grounded theory is a fitting choice when researchers want to provide inductive descriptions of processes in a temporal perspective (Glaser, 2004), such as during the period between diagnosis and birth. Using an inductive approach, we set out to provide a conceptual model of the process from diagnosis to birth that was based on the data collected, rather than on preconceived models or theories.

### Sample

#### Search strategy

We set out to identify public Swedish virtual communities with discussion boards about reproductive issues, where posters could write messages anonymously. Three searches were performed during June 2014 in Google, the most commonly used search engine on the Internet (eeBizMBA, 2015), using the Swedish key terms for 'forum congenital defect', 'forum anomaly', and 'forum ultrasound pregnancy'. Total hits ranged from 54,100 to 345,000 and we decided to screen the first 100 hits. To be considered for inclusion, the discussion board had to (1) be in Swedish, (2) be public and freely accessible via the Web, (3) include

sections about reproductive issues, and (4) include the option to write anonymously. Eleven discussion boards were identified as eligible.

In the discussion boards identified, each subsection about reproductive subjects was screened manually by assessing the first 100 threads to appear. Additionally, key term searches were performed when applicable, using the Swedish words for 'anomaly' and 'congenital defect', and assessing the first 100 hits of each search. To be considered for inclusion, each thread needed to be initiated by a poster describing the experience of continuation of a pregnancy following prenatal diagnosis of a fetal anomaly. In total, 3233 threads were assessed for eligibility, and all six that met the inclusion criteria were included. The threads included were initiated between 2010 and 2013.

#### Characteristics of posters included

In the threads included, 18 posters described the experience of a prenatal diagnosis and continuation of pregnancy. Sixteen presented themselves as female and two did not disclose their sex. Ten were currently pregnant when they first posted to the thread and eight were parents of prenatally diagnosed children. Among the parents, the time since the diagnosis ranged from one to eleven years. The posters wrote a total of 852 messages. The prenatal diagnoses included anomalies in the kidney and urinary tract ( $n=7$ ), spina bifida ( $n=4$ ), heart defect ( $n=1$ ), brain anomaly ( $n=1$ ), cleft lip ( $n=1$ ), and club foot ( $n=1$ ). Three received prenatal diagnoses involving multiple anomalies.

### 2.3. Data analysis

The first author, a specialist nurse and PhD student, conducted the analysis inductively guided by the constant comparative method (Glaser, 1978). Nvivo for Mac was used to sort and code the data. Field notes, i.e. a personal journal containing preliminary observations and reflections, were written during the processes of data collection and analysis. Furthermore, memos, i.e. condensed reflections and summaries of the main findings related to the categories defined, were written during the analysis. The threads were collected in separate files and read several times to gain an overall perspective.

Each document from every poster included was subjected to open coding, which included fracturing the data into smaller parts referring to single subjects. These parts were then grouped into larger categories. The coding was a creative and flexible process, in which the author moved back and forth between the raw data and categories. Preliminary findings and categories were tested as more data from different posters were analyzed. As more data were analyzed, a core category was identified. The properties of this category were broken down into a smaller set of high-level concepts. The core category was then expanded further and, through reading of and reflection on the field notes and memos, various dimensions of the data were explored. Attention was paid to exploring and pondering potential differences and relationships among the categories identified, as dimensions of the core category.

In the later stages of the analysis, a conceptual model reflecting the core category and its dimensions was developed. In line with Glaser's description of grounded theory, the conceptual model was developed to convey a temporal perspective of the material (Glaser, 2004). This model is presented in the findings. During the later stages of the analytical process, the first author (who was engaged in the analysis between 2014 and 2016) concluded that saturation had been achieved. To further explore different perspectives on the data and analysis, joint discussions were held between the authors until consensus was reached.

#### Ethical considerations

The study was approved by the Regional Ethics Committee in Uppsala, Sweden. Only public online discussion boards where posters could write anonymously were included. Original pseudonyms are not

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