

# The experiences of pregnant women diagnosed with a fetal abnormality

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## Abstract

### Purpose

This paper first focuses on outlining currently available knowledge throughout the world regarding women who decide to continue with their pregnancy knowing that there will be something abnormal about their child. Secondly, it discusses making information applicable to the existing issues available to midwives who deal with those women. Finally, the paper looks at coming up with a future agenda for improving the care environment for those women, to be worked on in clinical practice.

### Methods

Published literature concerning those women who choose to carry on a pregnancy after having been informed of a fetal abnormality was searched for using the following sources: PubMed, PsycINFO, CINAHL, and Ichu-shi WEB. A search was made for English language articles published in any country between 1998 and 2009, using the keywords “prenatal diagnosis” and “fetal abnormality”. We considered each article’s targets, research method and results in order to analyze how fetal diagnoses and mothers’ experiences influence the framing of psychological experiences.

### Result

In reviewing twelve domestic and international journal articles, five themes were highlighted that constitute pregnant women’s experiences carrying a child with a congenital abnormality, namely: grief, attachment, dilemma, uncertainty and isolation. These themes became clear that the experiences of those women carrying a child with a known congenital abnormality cannot be described in any one way, as there are so many constituent factors to take into account.

### Conclusion

These themes can be helpful in understanding mothers’ experiences. However, more studies need to be done in order to explore how they influence mothers’ relationship with, and involvement in society. Understanding mothers’ experiences from both psychological and social perspectives can help nurses improve their clinical practice, both in delivering the child and in caring for the mother. Future studies will yield further useful information, to help health-care professionals assist mothers, children, and families cope with any challenge they may face.

**Key words:** prenatal diagnosis, fetal abnormality, pregnant women, experiences

## I. Introduction

Recently, the number of pregnant women who choose to undergo prenatal diagnosis has continued to increase. This means more pregnant women today are in a position to receive diagnosis of fetal abnormalities.

While some make the decision to terminate their pregnancy, many women choose to continue, and carry their pregnancy to term.

Assisting pregnant women who have been diagnosed with a prenatal abnormality is an important clinical practice. Pregnancy and delivery are crucial events

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in women's developmental growth. Thus, it is fair to say that receiving diagnosis of prenatal abnormality can be a challenging experience, as women are faced with not only carrying their pregnancy to term, but doing so in the knowledge that their child will not be as healthy as they would hope or expect.

Hotta et al. (Hotta, Suzumori, Tanemura, 2005) state that the strongest grief reaction from mothers comes soon after they have received a prenatal diagnosis. Historically, Drotar's hypothetical model (1975, as cited in Akahoshi, Ogawa, Ikeda, et al. 2004), which presented five stages of parental reactions - shock, denial, sadness and anger, adaptation and reorganization - has been used to deepen understanding of mothers' post-diagnosis experience. However, Fukaya et al. (Fukaya, Yokoo, Nkagome, et al. 2006) present a contrasting view, stating that there is more to the women's experiences than Drotar can account for, such as a sense of attachment to their child that increases and develops over time. Despite the fetal abnormality, mothers still validate the experience of being pregnant (Fukaya, Yokoo, Nkagome, 2007). They experience more than just grief because, despite being torn between a 'hope for survival' and a 'hope for a peaceful death' for their child, mothers still develop a strong sense of attachment.

Pregnancy is also the time at which women start viewing society from the position of a parent. This can be an especially big change in perspective when they know that their child will have some form of disability. Those mothers who deliver their child after a fetal abnormality diagnosis can experience a negative relationship with their surroundings, which can lead to their feeling isolated and alone (Ichise, 2007).

It is fair to predict that as the average age of expectant mothers continues to rise, the number of women wishing to receive prenatal diagnosis will also continue to increase. This requires new prenatal diagnostic technologies, which are currently emerging. These factors in turn imply that there will also be more women carrying on their pregnancy after having been diagnosed with a fetal abnormality (Fang, Benn, Campbell, et al., 2009).

This paper first focuses on outlining currently available knowledge throughout the world regarding women who decide to continue with their pregnancy

knowing that there will be something abnormal about their child. Secondly, it discusses making information applicable to the existing issues available to midwives who deal with those women. Finally, the paper looks at coming up with a future agenda for improving the care environment for those women, to be worked on in clinical practice.

## II. Method

The purpose of this study is to discover what has been discussed by previous research into the experience of women who have received diagnosis of a fetal abnormality.

Published literature concerning those women who choose to carry on a pregnancy after having been informed of a fetal abnormality was searched for using the following sources: PubMed, PsycINFO, CINAHL, and Ichu-shi WEB. A search was made for English language articles published in any country between 1998 and 2009, using the keywords "prenatal diagnosis" and "fetal abnormality". We then excluded literature that was not regarding pregnant women, for example that which related to clinical diagnosis or treatment. Of the remaining articles, 65 were Japanese and 100 were from overseas. From those 165 articles, 12 were selected (4 domestic to Japan and 8 foreign) which examined women's experiences through qualitative methodology, and which analyzed the psychological aspects of pregnancies in which fetal abnormalities were diagnosed. (Table 1)

Our methodology was to first clearly organize the documents by subject and research method. We then focussed on the psychological framework of pregnant women, as discussed in each article, and aggregated the content into a similar framework of our own.

## III. Result

Based on the analysis, five themes were chosen to form a psychological framework that reflects mothers' experiences.

### 1. Grief

The experience of mothers who have received the news of a prenatal abnormality is similar to that of those

**Table 1 List of selected articles**

No.	Author (Year)	Participant	Ethnicity	Theory	Method	Result
1	Lator, J. et al. (2009)	Those who received a diagnosis of fetal abnormality: 26 women in the process of diagnosis and 36 post-birth received interview.	Irish	Grounded theory	Semi-structured interview	Women experienced the following reactions: assuming that the child is normal; shock at the diagnosis; gaining meaning in the experience of choosing whether or not to continue pregnancy; accepting a life-changing event, and rebuilding life for the future.
2	Nakagome, S. (2000)	1 woman who continued her pregnancy after fetal abnormality diagnosis.	Japanese	Phenomenology	Interviewing method	Mothers experience both "hope for life" and "thoughts of death" for a child with fetal abnormality. Many feel pressured to raise a child with a disability, and think about the role their child could play in their life. Over time, mothers start putting this child into their picture so that they can have a life together.
3	Okubo, N. (2003)	1 woman who terminated her pregnancy after learning her fetal abnormality was due to a genetic reason.	Japanese	Hermeneutic phenomenology	Interviewing method	News of a fetal abnormality brought both a sense of destruction in human relationships and a sense of denial for a woman deciding to terminate her own baby with an abnormality. This woman continued to seek human connections throughout the process.
4	Abe, I. (2003)	1 woman who delivered a child after receiving a fetal abnormality diagnosis seven years ago.	Japanese	N/A	Interviewing method	The woman experienced the following process: happy to be pregnant, thinking the baby should be healthy, disbelief that her child is abnormal, if I get depressed this nightmare is going to be real, I don't want to lose hope, constant fear, I need to see myself how abnormal my child will be, I will love my baby regardless of its health situation.
5	Chaplin, J. et al. (2005)	Parents from 13 families who received a prenatal diagnosis of spina bifida, hydrocephalus or both.	Australian	McLeod & Hill	Interviewing method	Common experiences/considerations were: disbelief when learning about a child's abnormality; the influence of professionals' involvement; information seeking in deciding whether or not to continue pregnancy; valuing of human life; reactions of significant others.
6	Jones, S. et al. (2005)	7 pregnant women who chose to continue pregnancy after baby's diagnosis.	British	N/A	Interviewing method	Common themes behind sense of confusion involved ambivalence, uncertainty and loss.
7	Ekelin, M. et al. (2008)	9 mothers who received the diagnosis of a nonviable fetus and 6 partners of those women.	Swedish	Grounded theory	Semi-structured interview	The core category was Unexpected change in life. 4 categories encompassed by the core category emerged: (a) Deceived by a false sense of security; (b) Confronting reality; (c) Grieving; and (d) Re-orientation.
8	Kamijo, Y. (2003)	5 pregnant women who received a fetal abnormality diagnosis.	Japanese	N/A	Observation and interview	Reactions such as "shock at sudden news of fetal abnormality", "wishing the diagnosis were wrong", "establishing realistic goals", "shock at diagnosis confirmation", "experiencing conflicting emotions", "worry about delivery", "experiencing a sense of attachment to baby", and "learning lessons by carrying this baby" were noted.
9	Rempel, G.R. (2003)	Mothers and fathers of 19 babies with antenatally diagnosed CHD.	Canadian	Symbolic Interactionism	Interviewing method	Not all pregnant mothers with a fetal disability choose to terminate their pregnancy. They want to view themselves as "a good person" and "a good mother" in making decisions. It seems that mothers' ideas, values as well as health professionals' advice play a significant role in the decision-making process.
10	Hedrick, J. (2005)	15 pregnant women carrying a child with a nonlethal, congenital abnormality.	American	Phenomenology	Interviewing method	The pregnancy experience was of a paradoxical nature. Knowledge of the fetal diagnosis resulted in both positive and negative consequences. Three major themes were common to the women's experience: time is good, but it is also the enemy; you grieve, but you do not grieve; my baby's not perfect, but (s)he's still mine.
11	Lator, J. et al. (2007)	38 women, at low risk of fetal abnormality.	Irish	Symbolic Interactionism	Interview method	Six categories relating to women's encounters with caregivers emerged: information sharing, timing of referral, getting to see the expert, describing the anomaly, availability of written information, and continuity of caregiver.
12	McCoyd, J. (2007)	30 women who terminated their pregnancy due to abnormality diagnosis.	American	Grounded theory	Interviewing method	There were inaccurate expectations based on denial that an anomaly could occur, misconceptions about the nature of prenatal testing, and erroneous expectations about the experience and duration of grief. The contradictory norms in society are identified as creating additional dilemmas for women as they attempt to gain support and understanding following their loss.

who have lost a child. Lator, Begley and Galavan (2009) state that mothers come to find hope as they accept the reality of their situation over a period of time. This process is presented as follows: normal shock, gaining meaning, and rebuilding. Abe (2003) cites that, though mothers may initially have doubts about the diagnosis,

and subsequently enter a period of shock, they later come to find hope - while still struggling over whether to accept or deny reality. Both studies show that while the time of the diagnosis is the beginning of mothers' grief, it is also the beginning of a period in which they can reconstruct and find new meaning in their lives.

## 2. Dilemma

While trying to accept the diagnosis of a fetal abnormality, many women deal with dilemmas that arise between their own values and social norms. During the period in which induced abortion is still amongst the available choices, mothers often experience conflicting feelings as they are forced to consider their own values on issues like disability and abortion (Okubo, Tamai, Asahara, et al., 2003). Chaplin, Schweitzer and Perkoulidis (2005) mention that mothers find it helpful to receive appropriate information and support from health professionals when dealing with such challenges, because they need to feel validated, as ideas of guilt and justice are often involved in their conflicts. Mothers feel like they both want to protect their child, and reject them. While maintaining hope, they also experience periods of despair and hopelessness. Ambivalent reactions such as these were cited in past studies (Jones, Statham & Solomou, 2005; Nakagome, 2000).

While experiencing such ambivalence however, women were also likely to find meaningful experiences in fighting against those values, social norms, ideologies and ethics that they thought were normal. In other words, the dilemma arises from changes to existing attitudes, that mothers may be forced to face during pregnancy.

## 3. Uncertainty

Abnormality is usually confirmed by postpartum screening, which means that at first there is still much uncertainty regarding the future, and the various choices mothers face. They wonder what life will be like once their child is born, how long any treatment will be needed (if treatment is even available), whether or not they will be able to communicate with their child, and ultimately whether or not their child will be alive (Jones, Statham & Solomou, et al., 2005; Ekelin, Crang-Svalenius, Nordstrom, et al., 2008). Thus uncertainty can also lead many parents to have continued faith in their child's health and normality during their pregnancy. Because they can feel their baby's heartbeat they choose to believe that their baby may be born as normal as possible, even after being notified of an abnormality (Abe, 2003; Chaplin, Schweitzer, Perkoulidis, 2005; Kamijo,

2003; Ekelin, Crang-Svalenius, Nordstrom, et al., 2008). Parental uncertainty, it should be noted, does not mean that the accuracy of prenatal screening is questionable.

## 4. Attachment

Having their child diagnosed with an abnormality is the most crucial crisis that many women will face. However, it has been suggested that a mother can never lose her attachment and love for her own baby. Even after diagnosis, those who choose to continue their pregnancy experience feelings such as unconditional love (Abe, 2003), a strong sense of attachment regardless of birth defects (Hedrick, 2000), and a growing sense of closeness to their baby (Kamijo, 2003). Although they also felt some pressure at the prospect of raising a child with a birth defect, the idea of living together with that child helped women see how to reconstruct their lives (Nakagome, 2000).

## 5. Isolation

After the diagnosis of a fetal defect, many women become anxious about how they are being perceived by their family, health professionals, and society in general. A sense that they are being rejected by someone that they feel close to can cause them to feel isolated. The greater the mother's expectations that people understand their situation, the greater sense of rejection they experience (Chaplin, Schweitzer, Perkoulidis, 2005; Okubo, Tamai, Asahara, et al., 2003). Also, the more a mother puts pressure on herself to become 'a good mother', the more she restricts herself from talking about any thoughts of abortion and rejection that she may have regarding her disabled child. This, in turn, eventually isolates them from their support system (Rempel, Cender, Lynam, et al., 2004). That said mothers look to health professionals expecting them to understand such struggles, and expecting continuous support from them (Lalor, Devane & Begley, 2007). Some mothers however, keep from seeking out professional assistance because they already feel guilty about having such negative thoughts about their own child (McCoyd, 2007).

#### IV. Discussion

While reviewing the twelve articles used in this study, it became clear that the experiences of those women carrying a child with a known congenital abnormality cannot be described in any one way, as there are so many constituent factors to take into account.

First, women experience a growing sense of attachment to their unborn child, at the same time as displaying a grief reaction to the diagnosis. Receiving the diagnosis of a congenital abnormality initially causes them feelings of shock and depression, but their experiences are different from those of someone who has had a stillborn child, or lost another loved one to death (Jones, Statham & Solomou, 2005). Choosing to continue their pregnancy after such a diagnosis means that the mother will continue to share time with their child, and thus their attachment will grow as time passes. After the diagnosis, many women struggle to accept the reality of their situation, but their attachment and love for their child never diminishes. Prenatal attachment to one's child is the basis of motherhood, and it has a large influence on the future process of relationship building between mother and child. Very few studies have looked at how the nature and strength of this attachment change for mothers after receiving a congenital abnormality diagnosis, and this can be something to explore further in a future study.

Secondly, many women feel uncertainty about their experiences. Many issues arise after the diagnosis, such as whether the child is actually alive or not, whether the mother wishes to deliver the baby naturally or by caesarean section, how they will take care of the child's disability, and how they will manage financially once the child has been born. How those issues are confronted differs from woman to woman depending on their background. Also, while some women feel anxious about issues such as those mentioned, others continue to feel hopeful because their ambivalence makes the issues seem unreal. Abe (2003) mentions that while a mother does not know what will happen to her child and is still uncertain about the congenital abnormality, the very fact that she can feel her baby inside her can cause her to feel hope. Ekeline et al. (Ekelin, Crang-

Svalenius, Nordstrom, 2008) noted that uncertainty can also be an additional factor in a mother's anxiety; thus it is important for health professionals to provide appropriate information regarding treatment, prognosis and social resources at appropriate times. At the same time, health professionals also experience uncertainty regarding congenital abnormalities, thus the matter of how much information they can give to mothers is often problematic. Many past studies regarding mothers' experiences, particularly those focussing on ambivalence, have recommended improving clinical practice in order to develop an environment that better supports women.

Thirdly, many women found it difficult to see their ambivalence as an acceptable reaction to their situation. Conflicting values were a major challenge for many women as they accepted the fact that their child might be disabled. A struggle developed between their existing values and ethics, and the new ones they were forced to establish based on their child's possible congenital abnormality (Jones, Statham & Solomou, 2005). With regard to personal relationships and social networks, those women who experienced a high sense of loneliness were those who had families and friends with opposing ideas on issues such as carrying a child with an abnormality, induced abortion, and raising a child with a disability (McCoyd, 2007). The same applied to health professionals, in that mothers were very sensitive to what was said regarding issues they were struggling to deal with (Rempel, Cender, Lynam, et al., 2004). The fact that women find it challenging to accept the reality of a fetal abnormality diagnosis, implies that issues of fetal abnormality and raising a child with a disability are considered taboo in society. This isolates women, as they experience a lack of external support in addition to their internal conflicts. Few studies, however, have focused on these feelings of isolation and their negative impact on women's experience of their pregnancy, and their daily lives.

Many past studies largely focused on how the experience of carrying a child with a congenital abnormality affected women psychologically. Studies revealed both a grief reaction and a growing sense of attachment during the pregnancy, which indicated that mothers did not experience only sorrow and sadness, but also

the positive feelings associated with being a pregnant woman. However, more studies are needed in order to understand how the challenges that mothers face influence their societal relationships, because they still need to live within society, surrounded by conflicting ethics and values relating to their situation. They also have to deal with feelings of uncertainty, ambivalence and isolation throughout their day-to-day lives. Future studies need to take a step forward and look beyond the exploration of individual experience following the diagnosis of a fetal abnormality. In addition, clarification is needed regarding whether diagnosis of a fetal abnormality affects the mental and physical health of pregnant women.

Clinicians need to pay closer attention to affected mothers in order to see how their experiences impact upon their life as a whole. In this way they can help lead mothers through the challenging process of struggling to find a peaceful way to deal with their reality.

## V. Limitation

This study focused on qualitative study and reviewed no published meta-synthesis papers on the issues surrounding pregnant women's experiences carrying a child with a congenital abnormality. Cultural and linguistic barriers cannot be denied as limitations of this study.

## VI. Conclusion

In reviewing twelve domestic and international journal articles, five themes were highlighted that constitute pregnant women's experiences carrying a child with a congenital abnormality, namely: grief, attachment, dilemma, uncertainty and isolation. These themes can be helpful in understanding mothers' experiences. However, more studies need to be done in order to explore how they influence mothers' relationship with, and involvement in society. Understanding mothers' experiences from both psychological and social perspectives can help nurses improve their clinical practice, both in delivering the child and in caring for the mother. Future studies will yield further useful information, to help healthcare professionals assist mothers, children, and

families cope with any challenge they may face.

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# 胎児異常を診断された妊婦の経験に関する文献レビュー

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## 抄 録

### 目 的

本研究の目的は、胎児異常を診断され妊娠を継続している妊婦の妊娠中の経験に関する国内国外の文献とその知見を整理し、妊婦支援に向けて今後取り組むべき課題について分析することである。

### 方 法

PubMed, PsycINFO, CINAHL, 医学中央雑誌刊行会「医中誌WEB」をデータベースとし(掲載: 1998年~2009年), キーワード, prenatal diagnosis (出生前診断), fetal abnormality (胎児異常)をとともに含む国内・国外の原著論文を検索した。この中から, 胎児異常を診断された妊婦の妊娠期の心理・経験の本質を質的に探究・分析した12文献(国内文献4件・国外文献8件)を分析対象とし, 各々の文献について対象, 研究方法, 結果を整理し, これまでに明らかにされている胎児異常を診断された妊婦の経験がどのような心理的枠組みから明らかにされているかを検討した。

### 結 果

12文献の分析の結果, 胎児異常を診断された妊婦の経験には, 1) 悲嘆, 2) ジレンマ, 3) 不確かさ, 4) 愛着, 5) 孤立の5つの枠組みが存在した。胎児異常を診断された妊婦の経験は1つの枠組みでは説明することは難しく, 複雑に融合していることが明らかとなった。また, 妊婦の経験を個人にとっての意味から探求する研究が中心であるが, 経験の構造を社会との関係性から明らかにすることも試みられていた。

### 結 論

胎児異常を診断された妊婦の経験は5つの枠組みの融合であることが示され, 「悲しみの中にある人」にとどまらないという経験の本質が描き出された。しかし, これらの経験の何が生活者である妊婦にとって解決すべき問題となるのか, その問題の解決のために看護は何ができるのかについては十分に明らかにされていない。今後は, その経験が妊婦の人生や社会・生活の中の何に起因して起こっているのか, 妊婦にとって解決すべき事柄は何であるのかという視点から理解し検討することが必要である。

キーワード: 出生前診断, 胎児異常, 妊婦, 経験