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Pregnancy and postpartum following a prenatal diagnosis of fetal thoracoabdominal malformation: The parental perspective

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ABSTRACT

Purpose: The study's aim was to evaluate how information related to a prenatal diagnosis of fetal malformation could modify parenthood experience descriptions during pregnancy and after the child's birth.
Methods: A longitudinal case–control clinical study was conducted. Data on parenthood experience descriptions collected using a validated semantic differential technique during pregnancy and after the child's birth were compared between seven couples of parents receiving a prenatal diagnosis of fetal malformation and seven couples without any fetal diagnosis.
Results: Our results show that during pregnancy parents in the clinical group describe themselves as more fragile, passive, and timid [$p = 0.007$] than those in the control group. On the other hand, after the child's birth, there are no significant differences between groups.
Conclusions: Data are discussed with reference to better knowledge of the psychological dynamics involved in becoming a parent and to rational planning of support for parents receiving a diagnosis of fetal malformation.

Diagnosis of fetal abnormalities affects between 2% and 4% of parents who undergo ultrasound screening during pregnancy [1]. The discovery of a congenital anomaly has a significant emotional impact on both the woman and the couple as parents: relevant studies show that, in fact, such news is a highly critical event [2–4], to the extent that the couple is subjected to an experience which fits the definition of trauma given by the American Psychiatric Association (APA) [5], and which has the emotional impact of a major depressive episode [6].

Studies evaluating the psychological effects of prenatal diagnosis have described in detail the effect of receiving a diagnosis during pregnancy or after the birth [4], and the types of emotions experienced by women [7,8] as well as by both parents [9,10]. They have examined the ways in which the diagnosis is given by medical staff [11,12] and in turn received by the parents [13,14]. Further, they have evaluated the possible coping strategies [2] and the consequences over time of a pregnancy termination after the diagnosis [15].

Perhaps because of its cross-sectional nature compared to distinct medical disciplines such as gynecology, neonatology and pediatric surgery, a little researched aspect, but one which is highly relevant for the well-being of the family, is the possible effect that the diagnosis can have on the experience of the self-as-parent, and on the ways in which parents relate to first the fetus and then the baby. Clinical studies of the age range 0 to 3 years have highlighted how the images which parents, especially the mother, have of the fetus can produce long term consequences on their ability to interact with the child [16–18]. Given the known traumatic effect of prenatal diagnosis and the lack of literature which evaluates the effects of congenital malformations on the parent–child relationship after the birth, this study had the dual aim of 1) comparing a sample of parents who received a prenatal diagnosis with a sample of parents with typical pregnancies, through the responses given to a structured interview in which their experience of parenthood was described [19–23], and 2) evaluating whether the birth of the child changed the descriptions and opinions given previously [22,23]. In this study we chose to evaluate parents' representations relating to thoracoabdominal anomalies, because the Institute for Maternal and Child Health of the IRCSS "Burlo Garofolo" hospital (Trieste, Italy), where the research was conducted, carries out surgical operations specifically on this area of the body. We wanted to highlight this element because, to our knowledge, there are no comparative studies that evaluate parental representations of the fetus in relation to the different types of surgical intervention (e.g. brain, heart, thoracoabdominal surgery) needed.

This information appears to be of great clinical relevance for professionals who come into contact with the parents, providing them with medical assistance during prenatal counseling, during the diagnosis when the couple discovers the situation they are facing

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and the fears of the pregnant mother become real, and in the early postpartum period, when the birth and first contact permit the parents to deal with the actual baby.

1. Material and methods

1.1. Participants

Fourteen couples of parents, contacted through the Service for Prenatal Ultrasound and Gynecologic Diagnostics of the Institute for Maternal and Child Health, IRCSS "Burlo Garofolo" (Trieste, Italy), participated in the study. The seven couples of parents in the clinical group received a diagnosis of a thoracoabdominal congenital disorder (three cases of gastroschisis, one of hydronephrosis, one diaphragmatic hernia, one case of pyelectasis, and one congenital cystic adenomatoid malformation (CCAM)) during an ultrasound for morphological investigation of the fetus; the seven couples in the control group, after the same procedure of clinical examination, did not receive any diagnosis of anomaly in the fetus. The decision to include in the clinical sample different types of thoracoabdominal anomalies with varying degrees of seriousness was made for two reasons: 1) previous scientific works have shown that while an accurate explanation of the type of anomaly and the prognosis may reassure the parents, especially when it is easily curable, psychologically an underlying anxiety and uncertainty seem to characterize the remainder of the pregnancy [4]; 2) clinical experience, developed through the work of multidisciplinary teams over the years, has shown that during pregnancy parents, particularly mothers, imagine all sorts of things about the health of the fetus [24]; when an anomaly is diagnosed all these worries become real and concrete. Parents' reactions to the diagnosis of an anomaly do not always correspond to how serious it is, precisely because it is a reaction to the imagined fetus, rather than to the characteristics of a clearly visible anomaly.

The clinical group, but not the control one, was provided with prenatal counseling by a multidisciplinary team made up of a sonographer, a psychologist, a surgeon and, if necessary, a neonatologist during the counseling around the thirtieth week. These professionals met the couples periodically throughout the pregnancy, monitoring the development of the fetus. Multidisciplinary counseling was given on two consecutive occasions, of which the parents were informed in advance. Firstly, an ultrasound was carried out, while doctors discussed it in technical terms and the psychologist observed and noted the parents' emotional reactions to the image of the ultrasound, followed by the actual counseling. In a room next to the one in which the ultrasound was carried out, parents and professionals discussed the technical details of the anomaly, clarifying its nature, its possible consequences for the new-born and then the child, the need for intervention, and the short and long-term risks, concentrating on quality of life issues. The choice to provide the counseling afterwards was based on clinical practice and articles, which describe how the way in which a diagnosis is communicated is crucial for the parents [11,13].

Couples with socio-economic difficulties, or with known psychiatric or neurological disorders, were excluded from the study.

There was no significant difference between the participants in terms of age, education level and nationality, considering the mothers and fathers both together and separately (Table 1). Within the clinical group three males and four females were born, while in the control group two males and five females were born.

Written informed consent was obtained from all participants. The study was approved by the Independent Committee for Bioethics of the Institute for Maternal and Child Health, IRCCS "Burlo Garofolo", Trieste, Italy.

1.2. Materials

1.2.1. IRMAG, IRPAG, IRMAN and IRPAN

To evaluate maternal descriptions of experiences during pregnancy, the Interview of Maternal Representations During Pregnancy (IRMAG-R) [19–21] was used, and to evaluate paternal descriptions of experiences during pregnancy, the Interview of Paternal Representations During Pregnancy (IRPAG) [22] was used.

These are semi-structured interviews aimed at exploring the descriptions which parents give of their experience during pregnancy regarding their own female/male and maternal/paternal identity (in relation to themselves as parents and to their child), through an analysis of the narrative given by the parent of what she/he is experiencing. According to this approach, each partner collaborates to construct the new family dimension, activating anticipatory models of themselves as caregiver and developing mental representations of the child, specifically in terms of thoughts, feelings and expectations, which can be analyzed through such interviews [19].

To verify whether the parental representations remain stable over time or whether actually having the child changes them, the two interviews were followed up with the parents when the child was six months old, by giving the mother the Interview of Maternal Representations After the Birth, or IRMAN [20] and the father the Interview of Paternal Representations After the Birth, or IRPAN [22,23]. These instruments are well known in Italian clinical research and are also corroborated by their use in an international context [19–23,25,26].

IRMAG and IRPAG consist of 47 open questions, while IRMAN and IRPAN consist of 32 open questions, which enable the parents to recount their experience, both during pregnancy and after the birth of the child. The administration and coding of these instruments are rather complex and elaborate. When the interviews have been collected, recorded and transcribed in their entirety they are then evaluated in terms of the organization of the narrative, looking at

Table 1
Characteristics of parents included in the study.

	Clinical Group		Control Group	
	Mothers	Fathers	Mothers	Fathers
Age, Mean (SD)	28.4 (7.6)	28.4 (8.1)	31.5 (3.4)	36.4 (2.5)
Years of education, Mean (SD)	14.5 (3.1)	15.1 (4.0)	15.1 (1.3)	15.8 (3.4)
Nationality				
Italian	5	6	6	6
European	2	1	1	1
Other	0	0	0	0
Marital status				
Married	5		6	
Couple	2		1	
Single Mother	0		0	