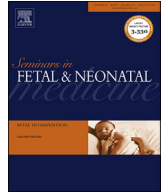




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Parental experiences after prenatal diagnosis of fetal abnormality

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For many pregnant women, prenatal testing is a routine component of contemporary pregnancy care. Receiving a prenatal diagnosis is frequently associated with intense feelings of shock and grief; the extent of which may be unrelated to the pregnancy gestation or the condition diagnosed. During this time of crisis, parents are often faced with important choices about their pregnancy. Levels of understanding and experiences of professional support throughout this time likely impact decisions that are made and how they are subsequently perceived. Despite considerable advances in prenatal testing technologies over the last 20 years there is a paucity of research examining parental experiences in-depth. Future advances such as prenatal exome sequencing will further increase the scope of prenatal testing and numbers of parents who receive a prenatal diagnosis. It is imperative that large-scale studies are performed to ensure that protocols are in place to adequately support couples at this time.

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1. Introduction

Until the twentieth century, pregnancy and childbirth were seen exclusively as “lay” and “female” domains and medical interventions were rare. Over time these “natural” processes have become increasingly medicalized with a corresponding welcome decline in maternal and fetal mortality [1,2]. As advances in technology have continually improved our ability to closely scrutinize a developing fetus, prenatal testing has evolved into a seemingly routine component of contemporary pregnancy care. A comprehensive audit of prenatal testing trends over 38 years in the State of Victoria, Australia, was recently reported [3]; the review period encompassed the initial availability of only invasive testing (amniocentesis or CVS), then the introduction of second trimester maternal serum screening followed by the availability of combined first trimester screening and more recently maternal plasma cell-free DNA. It clearly demonstrates that rates of invasive testing procedures have declined over time and, with the uptake of newer technologies, that diagnostic yield has greatly improved. However, it is only for a minority of situations that a prenatal diagnosis provides an opportunity for treatment or intervention to rectify the condition it identifies.

For most parents, receiving a prenatal diagnosis of a fetal abnormality is usually the beginning of a highly emotional and morally challenging process requiring assimilation of complex information and contemplation of possibly previously unconsidered concepts such as disability. Whereas knowledge gained from prenatal testing may provide an opportunity to prepare for the birth of a child with additional needs, depending on local laws parents may also choose whether they wish to continue the pregnancy or have an abortion.

This review investigates parents' experiences following a prenatal diagnosis, how they make decisions about continuing or ending their pregnancy, and how practitioners can best provide support throughout this time.

2. Receiving the diagnosis

Hearing about a suspected anomaly is acutely distressing, and emotional responses may have ongoing impact for the pregnant couple and their relationship as well as their perception of their pregnancy [4]. Receiving a prenatal diagnosis is often experienced as unexpected and shocking [5–10], regardless of the pregnancy gestation, length of time involved and perceived severity of the anomaly [11,12]. Parents frequently experience acute grief responses and strong emotions of guilt, anger, and loss [8,13–15]. In addition to these acute responses, prenatal diagnosis may trigger a shift over time from ‘hope’ to ‘despair’ [16] and a change in parental status and expectations, described as a ‘new life trajectory’ [6,9]. It

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is undoubtedly a time of great crisis that may be further compounded when there is uncertainty about the prognosis [9]; this is increasingly likely with advances in prenatal testing technologies that identify genomic variants of unknown or uncertain clinical significance [17]. Indeed, there is evidence that receiving a diagnosis of a fetal anomaly during pregnancy fulfills the criteria for trauma; being sudden, unexpected, and disrupting one's life beliefs [11]. Therefore, emotional and psychological impacts may be carried into subsequent pregnancies, making it important for health care professionals to ensure that any possible impacts are carefully and appropriately acknowledged and managed [18].

Unsurprisingly, studies have shown that parents appreciate timely access to relevant information and support [10,19], and benefit greatly from multidisciplinary care [20]. Although there may be some urgency to make decisions due to an advancing pregnancy, it is important to allow time to process new information, especially uncertain findings [9]. Several studies have highlighted how access to immediate, targeted support and information is aligned with improved coping and adaptation [8,10,21], with delays in accessing specialist support clearly impacting negatively upon parents' experiences [12].

The manner of communication as well as the perceived attitudes of the health professionals involved is also related to parents' later experiences [22] and adaptation. An integrative review of 33 studies demonstrated that parental coping was closely linked to the nature of health professional communication [21]. The review authors suggest that effective communication, comprising giving information in an honest, timely, personal, empathic, detailed, and straightforward way facilitated increased confidence by mothers in their treating health professionals: this confidence was fundamental to the development of a 'human connection' between clinician and patient and, ultimately, parental coping was a function of the strength of that human connection. The review recommends that to provide best practice care, there should be service-specific protocols developed to ensure timely delivery of accurate information to patients and that health professionals should be prepared to provide detailed verbal and written information.

3. Making decisions

The unexpected nature of a prenatal diagnosis means that decision-making about whether or not to continue a pregnancy usually takes place at a time of crisis and distress. Whereas for a minority of prospective parents this choice may be perceived as straightforward, many describe it as uniquely challenging and, frequently, the hardest they have ever faced [10,23]. Attempts have been made to outline determinants of decision-making at this time such as pregnancy gestation, nature, and perceived severity of the condition as well as individual background details such as age, parity and religious beliefs, but there is little consensus [24,25]. There is a range of conditions that may be detected prenatally increasingly early, and emerging genomic technologies will undoubtedly expand this list further. As such, parents will increasingly be making decisions about conditions with varying severities and outcomes. Whereas the term 'life-limiting' is often assigned to conditions such as trisomy 13 or trisomy 18, there are no certainties regarding prognosis and survival rates; although there is a higher chance of miscarriage or stillbirth during these pregnancies, studies have also suggested a variable survival period of 15–250 days for trisomy 18 [26].

Qualitative research has provided some insights into the complexity and the challenges faced by parents as they navigate decision-making after prenatal diagnosis. A meta-summary sheds some light upon how individuals and couples may construct the

choice they have to make; highlighted themes were concepts of 'chosen loss and lost choices' and how parents must consider their desire to become parents to any baby compared to the reality they now have to consider about becoming parents to a baby with an anomaly which may have uncertain severity and associated disability [27].

Although male partners are increasingly involved in all aspects of pregnancy care [28], it seems that when a prenatal diagnosis is made, fathers may sometimes feel excluded from the support being offered and the decision-making processes [29,30]; and may even choose to defer decision-making to their partners. Some studies have included fathers in their study design, though more usually participation is greater from women [15,30]. For example when Mckechnie et al. [30] recruited parents of 14 infants, only three fathers participated; two of these took part in an interview with their partner and only one was interviewed by himself. Participation bias such as this means that it is possible that reported experiences and support needs of fathers is an inaccurate representation of wider experience of male partners when a prenatal diagnosis is made.

3.1. The role of information in decision-making

One important component of decision-making after a prenatal diagnosis is an accurate understanding of the condition that has been diagnosed. Clearly this is also a time where parents need to consider the meaning of available choices (such as termination method or viewing ultrasound images [23,31]) as well as assistance with how to effectively deliberate. Accurate information is an important component of the deliberative process as well as an opportunity to reflect on individual values and beliefs. Ignoring the possible moral dimensions of the choice impacts negatively upon autonomy and may result in decisions being made that are unreflective and cause later regret.

Since a deficit model of disability continues to dominate popular discourse around prenatal testing it is likely that parents will receive an inadequate representation of the lives of children with disabilities on which to base their decisions. In Australia, following a prenatal diagnosis of Down syndrome, >90% of pregnancies are terminated and similar rates are noted in European countries [32]. This occurs despite an increase in life expectancy and quality of life; Raz [33] has described this as a paradox. It is important that couples receive accurate and current information about the condition that has been diagnosed, and it is especially important to avoid negative stereotypes and stigmatizing language [34,35]. Although the voices of individuals living with a disability such as Down syndrome are largely absent from dialogue about prenatal testing, there are a few exceptions [36,37]. These study participants stated that they personally felt valued, but they recognized that Down syndrome is a condition that is generally unwanted by society. Participants demonstrated overall support for the right of all individuals to have prenatal testing but were concerned that prospective parents may not receive enough 'balanced' information.

3.2. Talking about abortion

Despite an estimated 46 million procedures being performed worldwide every year, abortion is possibly one of the most contentious, ongoing debates in society. Many individuals hold strong and conflicting views, meaning that dialogue and decisions about abortion are often shrouded in secrecy. Access to abortion varies greatly according to location and healthcare setting. Abortion following a diagnosis of a fetal abnormality appears to be associated with greater negative psychological sequelae than abortions performed for other reasons [38] and there is increasing evidence of

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