

Supporting women after a prenatal diagnosis

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Introduction

Between two and four per cent of pregnant women will receive a prenatal diagnosis that requires them to make a decision about a potential termination because of a poor or long-term prognosis [1]. Increasing routine care and technology have contributed to the rising number of women faced with this decision-making dilemma [2]. Following the routine availability of these tests on all women, including those who do not appear at risk, more prenatal diagnoses are revealed and more women are facing the difficulty of receiving a poor or fatal diagnosis and feel pressured by the decision-making process to choose their pregnancy option. This article will outline the recommended use of technical terms, the timing of information-giving, the influence of professionals at the time of receiving a prenatal diagnosis, and the role of psychosocial support and resources in coping with prenatal diagnosis issues.

Currently, it is assumed that prenatal testing has three purposes. The first purpose of testing is to inform and prepare women for the birth of a child with a disability. The second purpose is to allow treatment or delivery of the child in a tertiary maternity hospital, and third, to allow the termination of the pregnancy [3]. This testing process focuses on the physical state of the foetus. As a consequence of the testing, the physical wellbeing of the woman will be investigated, but little regard is attributed to her psychosocial wellbeing. While there has been some research about

the short- and long-term experiences of Australian women who have received a poor or fatal prenatal diagnosis, little is known about the psychosocial impact of such a diagnosis [4].

Recommended use of technical terms

The setting in which a large proportion of women receive the news that their baby has a poor or fatal diagnosis is a medical setting. Depending on what test was carried out, this may be a doctor's office, a counselling room or an ultrasound clinic. The environment is described by women as being unfamiliar and clinical. Most women are also unfamiliar with prenatal diagnosis tests, abnormalities and the conditions that may be diagnosed after a routine test. For the women who have had the tests and the conditions being investigated explained to them, they either do not receive counselling or receive a counselling session that lasts between five and fifteen minutes [5]. It appears that prior to undertaking the test and receiving the diagnosis, most of the women do not believe anything could be wrong with their child [5]. They describe feelings of extreme shock and lack of preparedness for the experience in which they have unwillingly engaged [6,7,2]. In some case studies, for example, women report that they had never heard of the condition their child has been diagnosed with [8]. Upon receiving the diagnosis, it appears that most women are in a state of shock, as they do not commonly receive counselling prior to engaging in routine prenatal testing.

The professionals involved in sharing the prenatal diagnosis and its implications with women play a sensitive role, and one which marks women's perceptions of the diagnosis, its implications and their decision making. In a study by Rempel in 2004, it was found that women did not understand the technical language used by the professionals giving them the difficult news [9]. Many had never heard the name of the diagnosis prior to them receiving it or did not know it could happen to them. Whilst case studies show that women may not understand the medical terminology used, they often do not feel able to interrupt the medical officer to ask for clarification. Some of the medical terms may appear cold and confronting and women describe some of the technical terms as biased and negatively tinted. For example, the term 'termination', often used by professionals to describe a pregnancy option after a poor or fatal prognosis, has been described as harsh and, at times, a poor reflection of the women's intention. Women may feel more comfortable with the phrasing of 'inducting early' rather than 'terminating' their pregnancy. Additionally, women may want to say goodbye to their 'baby' rather than dispose of a 'fetus', even through termination choices. Inherent to the belief that women are individuals with their own unique viewpoints and emotional needs, the opposite may also apply. Women may choose to terminate a 'non viable pregnancy' rather than verbalise it as rejecting their 'disabled child'. Women feel that they not only need to understand the condition of their unborn child but that they need

to understand it in an accessible and objective manner. Some of the women caution about an overly scientific language and 'hopeless' description of outcomes, which is confirmed in Rempel's study where women expressed a lack of understanding of the technical language used by professionals as well as a substantial bias towards discontinuing the pregnancy [9]. Women wished for the opportunity to decide for themselves based on consistent and honest feedback by professionals acknowledging the uncertainty of the outcomes given, if appropriate, and hope in their ability to make the 'right' choice for them and their family. The use of non-threatening verbal language has been found beneficial in the women's ability to understand and accept the information received in a way that appears consistent with how they feel about the pregnancy and the diagnosis received. Finally, women in case studies have described an element of shock from receiving a diagnosis and expressed their inability to retain the information shared by the professionals at the time of receiving the diagnosis. From the shock and trauma of receiving a poor or fatal diagnosis of their unborn baby, women's cognitive functions may be temporarily hindered and professionals should offer clarification of information as well as re-offer that information at a later stage.

Timing of information-giving

The timing of information-giving after a prenatal diagnosis has been found relevant to women's ability to understand and accept the information shared. The shock and distress felt by women when discovering that their baby has a poor, long-term or fatal diagnosis disables them from retaining the details shared by the person giving them the news. It would appear from case studies that when women find out about the diagnosis, they describe feeling overloaded with information, such as what the diagnosis is, what the baby's prognosis is, what their chances of having another affected pregnancy are, and the treatment options

[10]. Women report feeling pressured by too much information, provided too quickly. For example, women after finding out that their baby had a diagnosis may not want to know the likelihood of them having another baby with the same condition, yet the opposite may apply. Women may request answers at the time but will not understand their impact or remember them in the next pregnancy. Furthermore, women subjectively describe feeling an 'expectation' from their professionals to remember all the information given and it appeared from their recollection that the professionals did not always appreciate that they were in shock. It may be appropriate to give women the information about the prenatal diagnosis when they request it at the time of prognosis and additionally at a later stage when they are cognitively and emotionally able to take it in.

Impact of professionals

Research indicates that the manner in which clinicians communicate and support women makes a difference to their satisfaction with care and emotional wellbeing [11,12,13,16]. Many women feel isolated from their medical doctor because of the decision they make of either terminating or continuing their pregnancy. Some state 'discerning' a sense of acceptance or detachment from their clinician [13]. This perception may impact on their satisfaction and anxiety and on the decision to carry to term or terminate [12,16]. It is recommended that families be counselled together after a prenatal diagnosis and in a private and unhurried manner [14]. In various studies, women report feeling pressured to make a choice within a short time. This has exacerbated their sense of distress and many feel angry that they were not able to enjoy a last night of pregnancy or to reflect on the consequence of their choice for a length of time prior to their termination [8,14].

It appears that parental perception of trustworthiness and expertise of the professional are influenced by

the professional's ability to be task oriented, and his or her expressions of warmth and acceptance. Additionally, a professional's ability to validate a woman's experience and feelings was found to be highly beneficial to their grief recovery [2]. Hunfeld et al linked the woman's satisfaction with the professional's attitude and concluded that women appeared more satisfied with a professional with a trustworthy and knowledgeable attitude [12].

To support women to reach a well-informed and optimal decision for them, the professional needs to gain an understanding of what the prenatal diagnosis means to the woman and her partner, as well as what is needed for that woman to adjust to the shock, decision-making process and the consequences of their choice [15]. Women indicate that they feel better supported by professionals who communicate with them in a way that is clear, non judgemental and warm. Women who feel hurried, pressured or judged by their professional, report worse psychosocial outcomes. It is therefore recommended that professionals offer options to women and provide a platform for them to discuss the impact of both choices in a way that is warm and supportive. If possible, practitioners could ask women what a termination would mean for them, and in the same way, what a child with a disability would mean for them.

Role of psychosocial support

Women who have received a prenatal diagnosis find psychosocial support beneficial. This may include support groups, self-help groups, obstetric case management or counselling. Women state that some of their emotional needs have been met by making contact with organisations dealing with prenatal diagnosis issues or support groups for women with children with the same condition. A sense of belonging and common understanding has been described as positive and beneficial. Women also stated that support

networks were of significant importance. Women who felt supported by friends and family reported better outcomes, such as increased emotional coping abilities of the expectant woman and her partner. Reed stated in 1974 that the practical and medical support offered to women after a prenatal diagnosis were often prioritised over their emotional needs. It is important to remember that a prenatal diagnosis affects a woman's self-esteem, parenting, her relationship and her spirituality. Although 80% of women terminate, 20% of women will carry to term based on factors that include age, gestation, values, religion and education levels. Firstly, decision-making counselling and a referral to a supportive service are highly recommended. Secondly, the access to a hospital or clinic that provides terminations for women who would like to terminate their pregnancies should be facilitated. Similarly, a referral to a tertiary facility supporting women who wish to carry to term should also be organised. Thirdly, a referral to a support group or a supportive counselling service, as well as the provision of adequate supportive literature should be offered to women as soon as the diagnosis is made.

As the coordinator of 'Prenatal Diagnosis Support Australia' (PDSA), an online support group offering decision-making counselling, grief and loss support, resources, online chats and forums, as well as online parents stories, I am regularly approached by families who are searching for support after a prenatal diagnosis in their local community. I have also been approached by parents seeking a facility that will perform a termination. The experience described by parents as they desperately seek the 'right' support on their own is described as traumatic. It is vital for professionals involved with women receiving prenatal diagnoses to be aware of support groups, resources and tertiary facilities where women can be referred promptly, saving them the ordeal of searching on their own. Additionally, there are resources published specifically for women after a prenatal diagnosis, including the publication by SANDS and internally published tertiary hospital

brochures. As the author of *High-risk pregnancy and foetal diagnosis: your journey* [8], a pregnancy companion for women who have received a poor or fatal prognosis of their unborn baby, I have found that women benefit from accessible literature as soon as the diagnosis is provided to them. Professionals should be encouraged to review books that may provide guidance and support to women in this situation, and provide titles/lists to the families.

In summary, while research has allowed a faster and more accurate technology to diagnose conditions in utero, it appears that attention still needs to be given to the emotional, social and psychological aspects of receiving poor or fatal prenatal diagnosis. This article, based on case studies extracted from *High-risk pregnancy and foetal diagnosis: your journey* and women's testimonies from PDS Australia, serve to contribute to the existing body of knowledge as a means of describing women's experiences of support after a prenatal diagnosis. Additionally, it emphasises the importance of referring women to resources, literature and medical facilities that will support them in the decision they have made after a prenatal diagnosis.

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