

Non-directive counselling for fetal anomalies

Introduction

A 17-year-old woman at 20 weeks gestation is referred for a detailed anomaly scan. The fetus is diagnosed with anencephaly.

How should this woman be counselled?

The reflex answer is that it should be **non-directive counselling**. She should be provided with enough information about the condition and the management options in order to make a decision. But is this really enough? By not taking into account the psychosocial, religious, cultural, political, and historical factors of our local health-care setting into account, are we doing enough for our patients?^{1,2} Non-directive counselling may have led health care professionals into providing patients with information and then backing away from supporting them in their decision-making as this may be perceived as influencing their decision.³

The diagnosis of a fetal anomaly forces the health care provider and expectant patient to face the daunting task of breaking bad news. The expectant mother goes through a multitude of complex emotions when the diagnosis of a fetal anomaly is disclosed. At the same time the health care provider is faced with a stressful event that most may feel ill-prepared to deal with.

There is general consensus on the components of counselling a patient with a fetal anomaly.⁴ Counselling should include information on:

1. Diagnosis: What is the diagnosis? How certain is the practitioner?
2. Neonatal survival: What is the chance of survival beyond the newborn period? What treatment modalities are available?
3. Long-term survival: How long is the child likely to survive if all available therapeutic modalities are utilised?
4. Long-term impairment and illness: If the child survives what is the range of possible outcomes?
5. Burden of treatment: What treatments will be required for the child's survival? How burdensome is this to the family and the child?
6. What about future pregnancies: What is the implication for future pregnancies in the family?

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Adequate counselling may require multiple consultations with various health care professional including maternal and fetal specialists, geneticists, and neonatologists. The consultation process should include the patient's partner or family that may assist with the decision-making process as well as emotional support. However, the ideal way to deliver this bad news still remains controversial.

What is non-directive counselling?

In counselling about a fetal anomaly the health care worker's role is to provide information about the relevant condition so that the patient can understand its meaning and make a choice regarding the course of action most appropriate to them in relation to the problem. This non-directive approach is preferred as it provides information in a non-biased and neutral manner. The counsellor should not influence or advise on a specific course of action. This approach enhances patient autonomy, which is the dominant principle in medical ethics.

Non-directive counselling protects the health care worker from over-involvement with the client. The human rights of the disabled are already diminished by discriminatory attitudes, and the promotion of the expectation of the perfect baby. A non-directive approach to counselling protects from confusion, and moral contamination from eugenic ideals by providing adequate information but allowing the patient to make her own informed decision.^{3,5,6}

However, approaches vary in different circumstances. Furthermore, there is little standardisation on the definition of non-directive counselling. The ideal of non-directive counselling is not always attainable as whatever the health care professional does may influence the interaction. The counsellor is expected to provide objective information, avoid being directive, and to encourage independent decision-making. However, the counsellor is advised to tailor the information to the individual patient's needs and circumstances. Thus, the counsellor has to select the appropriate information for each case and base counselling on each patient's needs. Hence, the information is no longer objective, and the counselling may now be directive in some way.⁵

Challenges of non-directive counselling

Health care workers working in perinatal medicine often have to convey bad news to parents' expectant of a perfect baby. This is emotionally charged for both the health care worker and the parents. Furthermore, the health care worker needs to deliver this information in an empathetic manner whilst offering adequate information

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about the condition, but maintaining non-directiveness in order to allow the patient to make an independent decision. This process is faced with further obstacles.

South Africa is a country with much cultural diversity and eleven national languages. Many disparities in access to health care exist. The current models of genetic counselling draw on Western concepts which may not be appropriate to our population. Often pregnant women are integrated into the referral system with little influence on their health-care behaviour. They are probably more familiar with a more directive form of communication. In a non-directive counselling session regarding fetal anomalies the patient is now invited to make decisions after weighing up choices, often without the support of family. This may, instead of enhancing a patients' autonomy, further highlight the asymmetry between health care worker and patient. In addition, language barriers, cultural incompatibility and the relative lack of experienced counsellors in South Africa may compromise effective counselling.¹

How should we counsel patients?

Although non-directive counselling and autonomous decision-making is recommended, this may not always be acceptable to the patient. They may perceive this as sheer indifference by the health care worker. The health care worker is often asked to become the facilitator in the decision-making process. In this instance the health care worker's values may influence decision-making. Thus, the non-directive approach to counselling does not always effectively serve the needs of the patient.⁶

In the shared-decision making model the health care worker and patient share information in order to reach a decision that incorporates the emotional and personal values of the patient. This model offers a midway between the two extreme models of directive paternalistic approach and the non-directive information-providing counselling. The psychosocial component needs to be incorporated into decision making as it helps the patient to use the information provided to make an appropriate informed decision in a difficult situation.^{5,6}

The pregnant woman expects to deliver a perfect baby. In perinatal medicine we have to dispense bad, often unexpected, news regarding a fetal anomaly. Counselling in these difficult situations should be provided by an appropriately trained individual who understands the condition, can provide accurate, relevant, objective information, whilst ensuring the understanding of the patient, psychological support, informed consent, confidentiality, and ensuring autonomous decision-making by the patient.

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