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A Paradigm Mix or Shift? An Analysis of the UK Fetal Anomaly Screening Programme

Abstract

Objective: The aim of this paper is to examine the contradictions in the programme and propose an alternative model of care for use in fetal anomaly screening.

Methods: Non-directive informed choice is currently advocated, but it is well suited to protecting providers from the issues of eugenics. Although the concept of shared decision making has become an integral part of heath care programmes, a wholesome application has not occurred readily. Instead piecemeal practices are being applied to other models of care to promote informed consent.

Results: The current screening care model inhibits rather than support user-centered care. Authentic application of aspects of shared decision making into current practices involves a 'paradigm mix' that is often confusing and conflicting, because the conventional care model is embedded in frontline providers and orientate the offer of screening.

Conclusion: There are organisational issues influencing users' decision making process. Employing online decision support may not help users especially those with limited health literacy skills avoid falling into cognitive traps. A move to the proposed shared decision making process model (paradigm shift) would help inspire and support frontline providers to improve care.

Practice implications: Consistency about all aspects of the programme would be affirming and beneficial.

Keywords: Decision-Making; Informed Consent; Genetic Screening/Testing; Organisational Issues; Shared Decision Making; Guidelines/Policy

Review Article

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Introduction

Pregnant women in the UK are offered antenatal screening to detect fetal abnormalities as part of routine care. The most common fetal anomaly is Down's syndrome which is caused by the trisomy of chromosome 21. The other fetal anomalies routinely screened for are Trisomy 18 and 13. However, the development of online decision aid (Option Grid) by the UK Fetal Anomaly Screening Programme (FASP) to support service users through fetal anomaly screening decisions has thrown the programme's policy of objective informed choice under the spotlight [1-3]. The concept of objective informed choice is hinged on the biomedical paradigm of non-directiveness and autonomy to address the issue of eugenics, protect midwives from the emotional impact of screening and to guide against litigation [4-7]. The policy is underpinned by choice, autonomy and the right to self-determination. For consent to be valid, competent users must be offered quality and clear information, understand the information, and their decision making process free of any undue pressure or external influence. This entailed users are in control of the amount, speed and flow of information [8].

However, there is evidence [9] that even when service users are well educated and well informed about their treatment, many still find it difficult to engage meaningfully in decision making about their care. Recent work [10-12] has demonstrated that the fetal anomaly screening programme operates as a complex whole, involving factors such as contradictions and nuances in the translation of the national screening policy/ guidelines into organisational practices. The programme has also been less effective and in some instances failed to support users to achieve participation in screening with understanding and provide consent that is free of external influence or coercion.

The piecemeal application of shared decision making practices (online decision support) within a policy of objective informed choice would exacerbate the nuances within the programme and at best, confusing and conflicting to service provision. The reason is the training and socialization of frontline providers are entrenched in the current screening model of care. As a result, frontline providers will be caught betwixt and between two different philosophical approaches. The first approach is objective information giving and decision making completely left to users. The other is the collaborative approach where providers offer information, opinions and support users' decision making. Therefore, despite the potential immense benefits of an online decision aid to the programme, its operationalisation within the current policy may not help service users avoid falling into

cognitive traps. The purpose of this article is to better articulate the organisational issues affecting the concept of informed consent and advance a pragmatic proposal about how to adapt the Elwyn' shared decision making model to guide care that is personalisedin fetal anomaly screening.

Organisational Issues

The literature revealed frontline providers are supportive of ensuring service users have choices about antenatal screening, but there is inconsistency in such operationalisation [10,11,13-17]. A UK government White Paper [18] on the NHS expressed concerns that the organisational structure of the NHS is excessively bureaucratic and exerts top-down control. Users are expected to fit around services, rather than services around them.

Other work illuminates constraints in service delivery, and that of the wider organisational structures [12,13,15,17,19]. For example, they suggest time constraints, information overload, users' lack of understanding of information and power differential between providers and users. Additionally, users lacked adequate preparation and support for the physical and emotional burdens of fetal anomaly screening. Most users are expected to make a decision about screening at the first booking visit and undecided users usually have screening recommended and arranged by the midwives [11,12]. Undecided users are informed by service providers that they have an option to decline when they present for the screening test at the dating/Nuchal Translucency (NT) scan. The outcome of providers recommending and arranging for the screening test is the blurring of the line between non-directive informing and directiveness. It denotes a combination of paternalistic, informed and shared decision making models in a programme that has a stated policy of objective informed choice. This demonstrate inconsistencies and contradictions in the organization and offering of screening which have ethical implications for the programme. The connotation is that providers believed in the objective informed choice model, yet in the organization and offering of screening behave in ways that contradicts it, seemingly without being aware of the contradictions. Additionally, the first trimester combined DS screening test has the incidental side benefit of an ultrasound scan. Indeed, enthusiasm for ultrasound scan which is often seen by users as a routine procedure and a time to visualize and confirm the wellbeing of the baby may impair the exercise of choice.

Research [12,17,20] has shown time constraints, the differing knowledge bases adopted by service providers and users, and the prevailing policy of objective informed choice created interpersonal tensions and pressures in the antenatal context. These organizational constraints and pressures affect communication between service providers and users and have ethical and legal implications for the outcomes of consultations. For example, users may be wronged if their own values are ignored. Analysts [21-25] have demonstrated that most service users wanted advice from knowledgeable and trusted providers, but still wanted the freedom to make their own decisions. The recommendations were not viewed as directive, because the service users did not feel obliged to follow them.

A study that explored maternal decision-making concerning antenatal diagnosis suggests that women who were supported by their physicians and partners felt autonomous in decision-making. Women who reported the least support and autonomy were those, whose partners and providers left the decision-making entirely to them [26]. The account suggest the importance of the social context in decision making about fetal anomaly screening and provide clear evidence that the need for a social model of care that support users predominates over the need for objectivity, depicted in the current informed choice policy.

Unsurprisingly, the autonomous informed choice approach does not take into account providers' advice and support that users require for decision making. It also does not consider the trust and relationships formed between providers and users in the brief antenatal booking visit. However, promoting informed consent requires a combination of information and support. Pregnant women and their partners depend on the information received from midwives at booking to engage in dialogue about screening. Decisively, however, most users are able to address difficult choices if they are given support and service providers failing to provide such may be unhelpful. A wholesale adoption of shared decision making practices will be consistent with the programme's current intervention to facilitate and support users participation and involvement in decision making processes.

Why Shared Decision-Making Model?

Fetal anomaly screening is usually offered by community midwives in the UK. The tenets of the midwifery profession are relational, caring and women centred. Women are also relational and their decision making influenced by contextual factors. Therefore, the ideal provider-user interaction based on the principle of nondirectiveness and autonomous informed choice may be difficult to achieve in practice. Clearly, the organisational constraints to service provision demonstrate that the model of free, biomedical, individual informed choice does not adequately reflect the practicalities of implementing fetal anomaly screening on a nationwide scale.

As the programme enters into a new era of Non Invasive Prenatal Testing (NIPT) with a short window of opportunity and anticipated increase uptake rates, providers need to be supported and equipped to deal with these constraints to service provision. It is also essential that community midwives in England be aware of and positioned to meet these challenges and prepare service users to make informed decisions through relevant support, deliberation and advice. The shared decision making (SDM) model has been shown to enhance the autonomy of users by not making them feel abandoned by healthcare professionals [27]. Besides, evidence [28] demonstrates that SDM leads to reduced variation in practice, enhance users' autonomy and increase the sustainability of healthcare programmes. The following quote by James Lynch aptly described the future of healthcare decision making;

The social distance built into current ways of looking at the human body - the view of an objective scientist looking at another bodily object that is clearly separate and distinct – will be expanded to include a new type of social connectedness, where two human beings will be able to share their commonly felt experiences at their social membrane. In the new clinic, immunization from the emotional experiences of one's fellow man will no longer be seen as a vital necessity [29].

Lynch's views and ideas accurately described the philosophical shift that is needed in the traditional healthcare model to support users' participation in the decision making process. This view is consistent with the author's belief that providers in fetal anomaly screening ought to support and collaborate with users to help them become autonomous and achieve their screening goals, informed by an adequate understanding of the purpose of screening and an awareness of their beliefs, values and life circumstances that influence decision making. This philosophy is the antithesis of the current screening philosophy that pre-supposes that when information is communicated, pregnant women will received it well and remember it and are able and willing to take responsibility for their screening decisions. This premise is untrue and unhelpful as women are not all equal in their memory and cognitive capacity. Research [30] has shown that women are more vulnerable in pregnancy than when they are not pregnant. This is because previously memorized coping strategies are often not effective.

Adapting the Elwyn' Shared Decision Making Model

The shared decision-making model by Elwyn et al. [27] could be adapted to create a shared decision-process model (SDMP) for the fetal anomaly screening programme. In the shared decision-making process model the midwife and the pregnant woman exchange information on the basis of which a decision is to be made. The two-way exchange involves not only information, but the midwife assists the pregnant woman to identify personal values and beliefs relevant to participation in screening. A concept of autonomy which allows midwives to offer their opinions, and pregnant women the freedom to reject those opinions facilitates the process of shared decision-making. When women receive information about screening and are given time to assimilate, think of questions and discuss their concerns, the intervention enhances the dialogue whilst improving the quality of the decision-making process. Midwives should also provide users with additional information, if their values or questions suggest they are important to their participation in screening. The midwives, pregnant women and their partners' autonomy are maintained, if the focus is on the nature of the decision-making process rather than on the outcome of the decision.

At the end of the discussion, the midwife records in the handheld notes IT system that the woman has engaged in the shared decision-making process and all questions were sufficiently answered to permit informed decision-making. The proposed SDMP model is underpinned by a primary focus on the decision-making processes as opposed to SDM that focuses on both the process and the decision itself. The midwives work with pregnant women and their partners and encourage them to come to a mutual decision. The shared decision-making process model also allows pregnant women to delegate decision making. It is mandatory for the midwife to discuss the relevant information and to exchange opinions based on the woman's values, beliefs and circumstances. If at the end of that process, the woman has thought through the options and prefers to defer decision making to the midwife or significant others, that option is a perfect reflection of her informed preference. In all instances, the midwives must ensure that pregnant women understand they are responsible for the decisions made and the consequences of such decisions and this should be recorded.

Advantages of the SDMP Care Model in Fetal Anomaly Screening

Adopting the SDMP model will empower frontline service providers to clearly communicate information about screening to users including those with limited health literacy and check how well they understood the information using the 'chunking' and 'teach back' methods [31,32]. If providers employed decision aid as part of SDMP, the incidence of litigation would be reduced [33]. The reason is that it will be difficult for service users to complain that the information, use of decision support, and discussions were inadequate tone gate consent.

Unsatisfactory communication has often preceded patient's decision to pursue litigation. The SDMP model will enable midwives to dispel tensions, by presenting an environment where options can be discussed with pregnant women and their partners. This environment would also afford providers the opportunity to observe pregnant women and their partners and look for signs of coercion and domestic abuse. Research [23,34,35] has also shown that involving users in shared decision-making improves overall psychological and wellbeing outcomes such as reduced anxiety.

Time constraints will be addressed through the shared decision-making process model as it enables providers to determine the information required for discussion and assist with the problem of information overload, thereby facilitating understanding. Users would be able to arrive at a decision quickly when engaged in a dialogue that involved their beliefs, values and life circumstances [36].

Discussion

This paper highlights organisational issues affecting decision making processes and the contradictions in the current fetal anomaly screening programme. It presents a proposal for a social model of care to help inspire and support front line providers to improve care. Adopting the model involves a paradigm shift that is often difficult, but there are contradictions in the fetal anomaly screening model of care. Policy makers and providers can resolve them by changing the screening policy and the way screening is offered so that the two can be consistent. Consistency in the implementation of the screening guidelines and a move to the proposed shared decision making process model of care would be affirming and beneficial for the programme.

Conclusion

The current policy of objective, rational, dichotomous biomedical model of informed choice in the context of fetal anomaly screening is idealistic and inhibit rather than support personalized care. This is often due to the overwhelming constraints to service provision being underestimated in the current programme, which have health, ethical and legal implications. Consistency in the implementation of the guidelines/policy to orientate the offer of fetal anomaly screening is imperative to inform service provision. There is a need to move to alternative social models of care that encompasses the trusts, relationships formed in the antenatal context and ensure dialogue that includes the beliefs, values and life circumstances of users. A wholesale adoption of SDMP in the fetal anomaly screening programme (paradigm shift) will provide consistency to the programme and ensure service users including those with limited health literacy, avoid falling into cognitive traps by supporting their decision making processes. In addition, the SDMP model of care improves the psychological well-being of users, inspires and support front line providers to improve care.

Practice Implications

The organisational constraints within the screening programme highlight the need for prior information. When the information is given before booking appointment, women may be able to process the information adequately. When the information is provided again at booking, it will aid comprehension and active engagement in the decision-making processes. Information given in schools, healthcare settings and wider social networks has been advocated by Lewando-Hundt et al. [37]. The booking appointment should ideally be divided into two separate visits. This has been recommended in the NICE guidelines [38]. Adopting two separate visits may reduce the overwhelming feeling of information overload and time pressure. Alternatively, to avoid the pressures in the maternity services due to the multiple complex competing issues at booking [12], screening could be offered by decision counselors in GP practices. However, some women may feel it is a 'separate' visit that is not part of the booking visit. It also meant negotiated decision making with healthcare professionals women are not used to, thereby disrupting continuity of care.

The concept of risk in screening information presents extra challenges to users. If service users and providers are to have informed discussions, providers are likely to need more resources such as more training and time for informing women. For example, midwives need training on how to support pregnant women and their partners to cope with the emotional and psychological impact of participating in fetal anomaly screening. Given the importance of informed consent for fetal anomaly screening, it is critical that these organisational issues be prioritized in healthcare research and policy. The research may include exploring the characteristics and skills needed by service providers and users, the cost and legal implications of adopting the SDMP model of care [39].

Conflicts of Interest

None declared.

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