

## Evaluation of a fetomaternal–surgical clinic for prenatal counselling of surgical anomalies

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**Abstract** With increasing ability to diagnose fetal anomalies, it is imperative that parents receive appropriate counselling to reach their decision. The aim of this study was to evaluate the fetomaternal–surgical clinic held jointly by an obstetrician and a paediatric surgeon. At this monthly clinic the patients are first scanned by the consultant fetomaternal specialist in the presence of a consultant paediatric surgeon and subsequently counselled jointly in an adjacent quiet room. Other specialists such as geneticist and neonatologists provided further counselling where needed. All 43 parents who attended this clinic in the year 2005 were included in this study and were counselled by the same paediatric surgeon. A questionnaire was designed to assess the different aspects of service provided by this clinic. In this study the diagnosis was changed in 3 (7%) babies, 2 (4.6%) parents miscarried and 1 (2.3%) neonatal death occurred, unrelated to the surgical anomaly. The site of delivery was changed in 20 (48%) patients and the mode of delivery in 7 (10%). All 43 (100%) parents were satisfied with the fetal counselling, eight patients (18.6%) felt increased anxiety post-counselling and 95% had a better understanding of their unborn babies condition after counselling. Two (4.6%) parents decided to terminate the pregnancy due to complex

fetal abnormalities, and 31 (72%) felt they understood the future pregnancy risks. Fifty-six per cent of parents felt that further counselling from religious person should be offered.

**Keywords** Prenatal counselling · Surgical anomalies · Fetomaternal clinic

### Introduction

The ability to diagnose fetal anomalies has improved significantly over the past three decades with advancements in research, skill and technology. Routine screening of pregnancies allows those that are at a higher risk of anomaly occurrence to be identified and offered further investigations, allowing individual anomalies to be diagnosed [1].

The detection of fetal anomalies early during pregnancy removes the unforeseen shock of diagnosis at the time of birth and offers parents the opportunity to formulate management plans and coping strategies for that pregnancy [1]. The initial decision to be made is that of whether to continue with the pregnancy or terminate early, law permitting [2]. This decision can be extremely psychologically distressing for those involved, and is made easier by adequate counselling and support from medical staff.

Many surgical fetal anomalies that are detected during pregnancy are amenable to surgical intervention, either shortly after birth or rarely during gestation [3]. In order for parents to fully understand the consequences and treatment options for these anomalies, joint clinics are held at our institution by the obstetricians involved in detecting and monitoring the development and potential complications of the diagnosis, and the paediatric surgeon who would be involved in explaining the surgical management for the condition.

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Many studies have been performed to evaluate the psychological sequelae of termination of pregnancies for fetal anomalies [4–6] and the value of counselling in these situations, both before and after termination [7]. Few studies have been undertaken to evaluate the benefit offered to parents from joint clinics such as those held at our institution. This study hopes to assess the value of these clinics to the parents and identify potential areas for improvement.

The aim of this study was to evaluate the fetomaternal–surgical clinic held jointly by an obstetrician and a paediatric surgeon.

## Methods

This specialised joint antenatal clinic with a fetomaternal obstetrician and a paediatric surgeon has been running for the last 6 years in our institution. This is a monthly clinic where parents are referred due to already diagnosed fetal surgical anomaly either internally or from peripheral hospitals. During the appointment, an obstetrician in the presence of a paediatric surgeon to confirm the diagnosis and discuss any related findings and anomalies scans the patients.

Following the scan parents are taken into a quiet room and jointly counselled regarding the condition of their baby in the presence of a midwife. Where appropriate, further counselling was independently offered either before or during the same visit, by a geneticist, neonatologists, fetal cardiologist or any other specialist relevant to the fetal anomaly.

All the parents who attended this clinic in the year 2005 were included in this study. Ethical permission was obtained and the study conducted over a 4-month period from December 2006 to May 2007. Parents were contacted either by telephone or during their baby's follow-up clinic appointment and two independent medical staff carried out a questionnaire verbally.

The questionnaire was designed to gather information including patient demography, antenatal and postnatal diagnosis, outcome of pregnancy and any change in the planned site or mode of delivery. For the counselling (Fig. 1) parents were asked which specialists were involved in providing antenatal and postnatal counselling and at what stage in the pregnancy the initial consultation was held. Information was collected on whether parents felt sufficient time was allowed for the appointment, and if they received adequate information regarding the fetal condition and management options, possible outcomes and future

**Fig. 1** Questionnaire design

<b>Counselling:</b>				
<b>With whom?</b>	Surgeon	Neonatologists	Both	Other
<b>When?</b>	Before investigations After Ix with diagnosis Follow-up meetings Post-natally			
<b>How?</b>			Y	N
	Sufficient time? Sufficient information? – Facts relating to disease Treatment options Likely outcomes Future pregnancy risks			
	Useful? Increased anxiety? Changed management decision as a result? Fully understood disorder afterwards?			
<b>Others?</b>	Would counselling from the following have helped? Obstetrician Geneticist Social Worker Ultrasonographer Ethicist / Clergy			
<b>Joint fetal medicine – surgical clinic</b>				
	Helpful	Unhelpful	Indifferent	

**Table 1** Medical professionals involved in counselling and the outcome

	Parents (%)
Counselled by paediatric surgeon	43 (100)
Further counselling by	
Neonatologist	28 (65)
Geneticist	10 (23)
Further follow-up by obstetrician	29 (67)
Sufficient time and information	43 (100)
Improved understanding	41 (95)
Increased anxiety	8 (18.6)
Changed management decision	2 (4.6)
Understanding of future risk	31 (72)

**Table 2** Parents’ preference for alternate and additional counselling

	Parents (%)
Alternate counseling	0
Additional counselling	
Geneticist	21 (49)
Obstetrician	12 (28)
Faith person	24 (56)
Social worker	2 (4.6)
Ultrasonographer	7 (16)

pregnancy risks. The impact the counselling had on the level of parents understanding, and whether it influenced their decision regarding progression of pregnancy was also assessed. Fetal cardiac assessment and counselling was not included in this study. Parents were asked if they would like further or alternate counselling from other specialists such as obstetrician, geneticist, social worker, ultrasonographer, clergyman (or person from any other faith).

**Results**

Forty-three parents were seen in the year 2005 at this specialist clinic and all 43 parents were recruited into our study. Twenty-nine (67%) were questioned during the follow-up clinic and 14 (33%) by telephone.

Out of 43 scanned patients, the diagnosis was changed in 3 (7%) babies. Two (4.6%) parents miscarried and 1 (2.3%) neonatal death occurred, unrelated to the surgical anomaly.

During the counselling session the planned site of delivery was changed in 20 (48%), 12 to a tertiary hospital, and 8 to a district general hospital. In 7 (10%) the original planned mode of delivery was changed, five to a normal

vaginal delivery and two to a caesarean section delivery (large sacrococcygeal teratoma and large exomphalos with entire liver in the sac).

In all 43 cases counselling was provided after the initial investigation and diagnosis. Throughout the study period the same paediatric surgeon counselled all 43 (100%) parents. A neonatologist further counselled 28 (65%) parents and 29 (67%) parents were followed up by an obstetrician (Table 1). In 10 (23%) cases there was a confirmed genetic disorder, and geneticist also independently counselled these parents during the same visit.

All 43 parents felt they had sufficient time to discuss and gather facts and understanding during their appointment. Forty-one (95%) parents felt their understanding of the fetal condition was improved after the counselling session. Eight (18.6%) parents felt their anxiety had increased after the meeting due to large amount of focus on poor outcome of the pregnancy. After counselling, 2 (4.6%) parents decided to terminate the pregnancy due to complex fetal abnormalities, and 31 (72%) felt they understood the future pregnancy risks (Table 1).

Regarding further or alternate counselling from other professionals, none of the parents felt they needed any alternate counselling. However, 21 (49%) of parents would have appreciated additional counselling from a geneticist, 12 (28%) from an obstetrician, and 24 (56%) from a clergy/religious faith person (Table 2). Only 2 (4.6%) felt that they would have benefited from the involvement of a social worker. Seven (16%) thought ultrasonographers should provide basic information, as they are the first contact as part of the initial assessment. All 43 (100%) parents in our study group felt the counselling sessions provided a valuable service and were useful to them.

**Discussion**

Advances in prenatal diagnosis of fetal anomalies have facilitated in improving prenatal and postnatal care. Our increasing understanding of the nature of congenital anomalies and their development has led to providing affected couples with a range of management options.

In this study we reviewed efficacy of prenatal counselling service provided by our institution. All 43 parents of our study group felt our service was consistently useful.

Increasingly, paediatric surgeons are called upon earlier in the pregnancy to be part of multidisciplinary team counselling the parents. Paediatric surgeons are expected to provide explanation regarding nature of surgical anomaly and possible management options and its outcomes [3]. In our study all 43 parents felt that the fetal condition, anticipated surgical care issues along with risks and quality of life were adequately discussed.

Medical information and literature if poorly communicated or misinterpreted can contribute to increased anxiety and may lead to adverse effect on patient health. Clear and effective communication remains a core element in improving patient understanding. By improving parents understanding of fetal condition, they are able to participate actively in decision making processing. Ninety-five per cent of parents of our study group felt their understanding had improved after discussions with the professionals during our joint clinic and were able to make informed decision regarding future of pregnancy.

This joint specialist clinic allows the members of multidisciplinary team to exchange information and also to tailor the services according to parents needs. It allows the decisions regarding timing, place, and mode of delivery to be made in conjunction with members of multidisciplinary team and parents. In our institution genetic counselling was offered to all parents in whom the fetal anomaly was thought to be a consequence of a genetic disorder. However, our study showed that 49% of the parents would have like to have an opportunity of further counselling with a geneticist.

The diagnosis of fetal anomaly may lead to crisis for the affected couple, forcing them to face difficult decisions. In these circumstances, parents often find solace in discussing with friends, family members, or a person of their religious faith. In the present study group over half the parents (56%) would have liked to have the availability of further counselling from a religious person (e.g. clergy, priest). Most of these parents admitted that on the whole they were not

religious; however they might have used this service had it been available to them. To improve our services we may need to offer access to religious faith person post-counselling to all parents allowing them to make the choice of utilising the service.

In conclusion, the parents were satisfied with the level of care and counselling received in the joint clinic. They also felt that the service offered was valuable and they could make an informed decision regarding the complex conditions affecting their unborn baby.

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