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THE PSYCHO-SOCIAL SEQUELAE OF A TERMINATION OF PREGNANCY FOR FETAL ABNORMALITY

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Thesis submitted to the Faculty of Medicine of the University of Glasgow for the degree of Master of Science

Margaretha C.A. White-van Mourik,
University Department of Medical Genetics,
Yorkhill Hospitals,
GLASGOW, G3 8SJ
Scotland
UK.

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To each member of "CARE", and to all
who, in spite of having to come to terms
with painful loss themselves,
have found the time and the compassion to help others.

You can not prevent
the birds of sadness and sorrow
from circling above your head, but
you can prevent them from making
their nests in your hair.

Chinese Proverb

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LIST OF ABBREVIATIONS

AFP	alphafetoprotein
Ch of Sc	Church of Scotland
CF	cystic fibrosis
D&C	dilatation and curettage
D&E	dilatation and evacuation
DMD	Duchenne muscular dystrophy
DN	District nurse
DS	Down's Syndrome (Trisomy 21)
ERPC	evacuation and removal of products of conception
FA	fetal abnormality
g	gram
GP	General practitioner
HV	Health visitor
LB	live birth
LUCS	lower uterine caesarean section
mL	millilitre
MMPI	Minnesota multiphasic personality inventory
MW	Midwife
NTD	neural tube defect
p	probability
P - =	partner does not agree and does not feel the same
P + =	partners (husband and wife) agree
PND	prenatal diagnosis
Scr PND	detailed prenatal diagnosis after screening
R + =	the "desired" family size realized
R - =	the "desired" family size not realized
Resp	response rate
RC	Roman Catholic
SVD	spontaneous vertex delivery
S.S.Interv	semi structured interview
TOP	termination of pregnancy
Trimester	a period of three months
WOS	West of Scotland
W +	wants another pregnancy after the TOP
W -	does not want or is doubtful about further reproduction

SUMMARY

Although all couples who embark on a pregnancy hope for a normal child, about 2% will have an abnormal outcome. For a proportion of these couples the abnormality will be detected prenatally and they may elect for termination of pregnancy. In Scotland there are about 200 terminations of pregnancy (TOP) for fetal abnormality (FA) each year and for each couple this represents one of the most difficult times of their lives.

This project undertook to examine the current management of TOP for fetal abnormality to identify if there was scope for improvement. The study consisted of two parts; management aspects of detection and termination for neural tube defects (NTD), and a detailed assessment of sequelae of TOP for various FA.

In the NTD study, women who had elected for TOP were identified from the West of Scotland Regional Genetics Service. After appropriate consent, they were visited at home and were asked to complete a questionnaire regarding aspects of the management before, during and after the TOP. 215 consultands were identified over the three-year period 1983-1985. 49 were excluded as the TOP had been an induced labour for intra-uterine death. The remaining 166 agreed to complete a questionnaire between 2 months and 8 years after the event.

Although the majority (137, 82%) of consultands were satisfied with the way that prenatal diagnosis was handled, more than one third of the women felt ill-prepared for the TOP and entered hospital with no conception of the procedure or timescale of the termination. Care during the termination procedure was perceived as very good by most (126, 76%) and 95% (158) found the staff attending them kind and sympathetic.

After the TOP, many (52, 31%) were nursed in the post-natal ward, often in a sideroom but usually within hearing distance of the newborn nursery and found this very upsetting. On leaving hospital, the post-termination sequelae were discussed or mentioned to only 25 (15%) patients. This left 135 (81%) confused and bewildered by the postpartum reactions of their bodies.

Aftercare was perceived as unsatisfactory by 113 (68%). A quarter (42, 25%) did not have, and were not invited for, a post-termination appointment and many wondered if the reproductive

parts of their body had returned to normal; especially multigravidae who had had postnatal examinations in the past. They did not always have an opportunity to discuss this or other questions as 86 (51.8%) had no visit from any member of the primary health team.

Some form of genetic counselling was given to 95 (57%), and 24 (14% of the total) of these visited the West of Scotland Genetic Counselling Service. Of the 71 (42%) who received no counselling a visit to the genetic counselling service had been arranged for 25 (15%). 14 (8%) refused any form of genetic counselling and 32 (19%) had not been offered any. Of those counselled 54 (57% of the total of 95) found it helpful. 25 (26%) found it only fair or disliked the session. Differences were apparent depending on who provided the counselling.

The second study was intended; to monitor sequelae, to investigate in more detail why couples perceived aftercare as inadequate, to consider if this is related to specific factors, to ascertain which groups had particular difficulties in coming to terms with the experience and finally, to assess the effect of the TOP for FA on family planning and further reproduction. All couples in the West of Scotland who had had a termination in 1986 for any fetal abnormality were identified from the the West of Scotland Regional Genetics Centre records. After consent was obtained, couples were interviewed at home by one experienced interviewer, using an exhaustive, structured questionnaire with open and closed questions from 22 to 26 months after the TOP.

Of 137 consultants identified, 8 couples were excluded as intrauterine death preceded TOP and 33 (24%) had moved and could not be traced. Of the remaining 97 who were approached, 5 refused to talk about the experience as the subject was too painful. Seven initially agreed to an interview but did not make themselves available for an appointment. Thus 84 (87% of 97) consultands were interviewed. However only 68 (70% of 97) spouses completed the questionnaire.

In 59 (70%) the indication for TOP was neural tube defect, there were 12 (14%) chromosomal abnormalities, 8 (10%) multiple congenital abnormalities, 5 (6%) single gene defects, and 1 (1%) abdominal wall defect. The consultands' age and social class distribution was not significantly different from that of normal

confinements in the West of Scotland.

Common difficulties were encountered in several areas; pain and fear during the termination procedure, the decision whether to see the fetus; the lack of medical and psychosocial advice and support in the post-termination time on leaving hospital; the perceived lack of understanding of the sequelae; and the consultands' own reticence to voice their needs, fears and worries.

24 (28%) women experienced physical pain and 38 (45%) felt very frightened during the termination procedure. 16 (19%) mothers and 18 (26% of 68) husbands (partners) saw the fetus after the delivery and after two years none regretted the decision. This was in contrast to 38 mothers (55% of 68) who did not look. Consultands who had TOP for Trisomy 21, Cystic Fibrosis, or Duchenne Muscular Dystrophy preferred to maintain an abstract notion of the fetus even on reflection two years later. Of the women who had been too frightened to look at the fetus after the termination because there were obvious malformations, 99% regretted the decision. More younger women and those identified by screening regretted their decision not to look. 49 mothers (58% of 84) would have liked a photograph of the fetus to be kept in the medical records, and only 25 (29%) were not interested in this.

41 (57%) consultands did not receive a home visit from the primary health care team and this was similar to the NTD study in 1983-1985. Although 17 (20%) did not mind this, 47 (56%) would have appreciated the attention. 51 (60%) reported physical discomfort and emotional anguish. 17 (20%) women discovered that when they contacted their GP, he/she was unaware that the termination had taken place. In general women explained their reluctance to ask for help by their confusion and doubt over their status: they wondered whether the post-termination patient was considered the same as a postnatal mother. Most couples reported a state of emotional turmoil after the termination and even after 2 years about 20% still complained of regular bouts of crying, depression and irritability. None had experienced this before the termination. This was not related to any type of FA, but to risk factors such as; immaturity, lack of supporting relationships, a vulnerable pre-TOP personality and the disappointment of secondary infertility.

Most men (40 - 58% of 68) and women (46 - 55% of 84) found

it very hard to communicate about TOP and did not mention their reactions to anyone. For 81 (96%) of the women the termination had the importance of the loss of a wanted child. 56 (66%) reported prenatal attachment, especially those not at a high risk for fetal abnormality and who had felt movements and had seen the fetus on US. Conflicting and confusing feelings made it difficult for the couples to discuss them with others or, in some cases, with each other. Social isolation was experienced because people (especially relations) tended to shy away from the problems of heredity, handicap and abortion. This combination often led to tensions in the marriage; 16 couples (19%) grew further apart and 15 (18%) reported increased quarrelling more than 6 months after the termination, where prior to the termination the relationship was reported to be harmonious. 10 couples (12%) separated for a while and one couple divorced. More marital conflict was reported in the younger age-groups and in the lower socio-economic groups. Couples reported difficulties in vocalising their needs. The perceived lack of skilful questioning by community staff and clergy often led to the belief that they were not interested. Where support was given by family and friends; good listening, maintaining close bonds, giving practical help and understanding were rated as the most important aspects. More older women in the higher socio-economic groups felt supported by the primary health care team, the younger age-group found the opposite.

Reassurance and detailed information were given as the most helpful aspects of genetic counselling by 45 (56% of 80). The ideal time for such a consultation was given as 4 to 6 weeks. For 36 (42%) of consultands there had been doubt before, during and just after the TOP about their decision to abort, and after two years 2 women and 3 men still regretted the decision. 81 (96%) would in principle accept prenatal diagnosis in a subsequent pregnancy, and in fact all 55 who had another pregnancy, had prenatal diagnosis. 82% achieved or were trying to achieve their wished for family size, those who were not sure about PND gave up progeny rather than having a pregnancy without testing for fetal disorders. The 15 couples (18%) who experienced reproductive conflict included several unexpected diagnoses (which differed from the one for which they had sought PND), and the older age-group. All these patients had surviving children.

Both studies demonstrate scope for improvement in patient

management following TOP for FA. The recurring theme which was present in all sections we examined was impaired communication at all levels and a lack of understanding of the psychological sequelae after this traumatic event. Improved education of those involved in the care and support of these families and more information for those in close contact with the couple could help to reduce excessive anxieties and this might well be an area in which a self-help group will be of particular benefit.

CHAPTER 1

INTRODUCTION

1.1 General

The idea that fetal defects may be diagnosed in utero early enough to allow a safe termination has been in existence for a very long time. Concurrent with developments in the obstetric, biochemical and cytological aspects of prenatal diagnosis, the Abortion Act (1967) legalised abortions for various indications, including severe fetal abnormality. Hence the possibility for prenatal diagnosis of fetal abnormality with selective termination of pregnancy became a reality. Nowadays, 2200 abortions for fetal abnormality (FA) are performed annually in the United Kingdom, of which about 200 are in Scotland. For couples who have planned and wanted the pregnancy this is a very distressing experience, yet surprisingly little research has been conducted into the impact of prenatal diagnosis and termination of pregnancy (TOP) for fetal abnormality (FA) on the couple and their families.

Although all couples are unique, and this prevents the description of a typical response to prenatal diagnosis and TOP for FA, they nevertheless have similarities in many respects. For this reason, the implications of pregnancy and of spontaneous pregnancy loss, are reviewed before considering the various aspects of abortion, prenatal diagnosis and the sequelae of TOP for FA.

1.2 Literature Review

1.2.1 The Psychodynamics of Pregnancy

Pregnancy has frequently been viewed as a psycho-biological crisis akin to puberty and the menopause (Blumberg 1984). Emotional disturbance in pregnancy is a normal, rather than a pathological, response and in most cases women are able to regain a state of equilibrium spontaneously or with minimal therapy (Bibring , 1959, Bibring and Valenstein, 1976). In the first stages the pregnancy is characterized by narcissistic concerns with prominent physiological and anatomical alterations; later the pregnancy involves a growing awareness of the fetus as an independent entity. Thus what is first experienced as "putting on weight" and a developing abdomen, changes into empathy for a developing child

(Feldmann 1977). In the last weeks of pregnancy the earlier narcissistic interest re-emerges when the fears of self-injury caused by the delivery are added to the woman's concern for the well-being of the child to be. The woman's pre-pregnant personality strongly influences her response to the biological and psychological changes and challenges of pregnancy (Blumberg 1984).

Little has been written about the emotional adjustment of fathers during pregnancy. Although less involved with the biological aspects, the social and economic implications require adjustment from the expectant father. The occasional occurrence of Couvade syndrome (psychosomatic experience of physical sensations of pregnancy in the father) suggests that pregnancy may bear paternal emotional consequences similar to those in the mother (Blumberg 1984). Pregnancy may accentuate paternal self-doubt regarding the ability to provide for the emotional and financial needs of the family unit, and if an abnormal fetus is diagnosed this insecurity may be exaggerated.

The conclusion of pregnancy, regardless of its outcome, challenges emotional stability and requires psychological adjustment. Even after an uneventful, full-term delivery, maternal post-partum depression is commonly observed. This may be a reactive depression representing a response to changing environmental circumstances and incomplete reorganisation of psychic equilibrium (Bibring and Valenstein 1976) or may be due to hormonal influences, (Nott _et al_ 1976). The depressive state is characterised by despondency, feelings of inadequacy, self-reproach, irritability and anxiety; it involves psychosomatic manifestations of hypochondria or sleep disturbance. Blumberg (1984) observed that mild depression may persist in a small number of women for as long as a year. More severe, affective disorders are usually related to pregravid psychiatric instability, and occur in about 1 in 500 to 1 in 1000 deliveries.

1.2.2 Fetal Bonding

Although the "infant-mother" relationship develops gradually, quickening (maternal awareness of the fetal movements) in the 14-20th week of pregnancy is often, but not always, seen as a milestone (Bibring _et al_ 1961; Hollerbach 1979a). Current techniques make fetal life audible (fetal heart sounds) and visible

(ultrasonography) from the 8-10th week, and present the woman with undeniable evidence of fetal life at this early stage (Lumley, 1980), thus enabling the mother to prepare psychologically for the future relationship with her offspring. Even in other cultures there is a personification of the fetus before the birth (Cranley 1981a). The relationship with the fetus does not start after the delivery, but is continued in a new way. The Ojibwa Indian mother speaks to her fetus during pregnancy and teaches its soul the ways of animals and elements, thus preparing it for its future development. The Siriono of East Bolivia perform the same bereavement ritual for a miscarried fetus as for a deceased adult. In our Western culture we still have not decided officially on the moral status of the human embryo (Dunstan 1984; Reilly 1979,Dunstan 1988). Cranley (1981b) reported on the relationship of parents with their "unborn", that there was a wealth of interaction between the mother and her fetus. She observed that father and mother both developed a "bonding behaviour" towards the fetus. She sees this phenomenon as behaviour which displays an involvement with the fetus and in which the fetus is experienced as a future child.

In our culture, new prenatal diagnostic techniques have been shown to induce an earlier, and more intense involvement with the fetus (Reading 1981; Fletcher & Evans 1983; Blumberg 1984). It is not unusual for the first ultrasound picture to be saved as the first photograph of the child.

1.2.3 Grief and Spontaneous Pregnancy or Neonatal Loss

If a normal pregnancy can induce depression and a disturbed state of mind, pregnancy loss through miscarriage, intrauterine death or stillbirth is clearly more traumatic (Bourne 1968; Pasnau and Farah 1977; Wolff et al 1970). Many women who abort spontaneously experience anguish, loneliness and depression following the realization of pregnancy loss (Borg & Lasker 1982). Although there may be differences, the loss of an embryo or fetus can be considered essentially as the loss of a beloved person. There may be guilt feelings, following miscarriage or other fetal loss, due to prior ambivalence towards the pregnancy, a sense of physical inadequacy, and responsibility for the loss (Simon et al 1969). At the same time, because the woman may not see the aborted fetus, its sex, size

and personality become the objects of fantasy. There may not be a funeral to ritualize the bereavement because there is no legal requirement to bury a fetus at less than 27 weeks of gestation and sometimes relatives, friends or even close family do not know that something has happened (Huisjes 1984).

With the loss of a later pregnancy, the parents' greater awareness of the fetus as an independent identity must be considered. Thus fetal loss is appropriately viewed as an experience of bereavement (Morris 1976). Grieving is not a pathological symptom but a normal and even necessary reaction after personal loss (Pedder 1982). Bereavement follows a pattern of non-clear-cut phases; the bereaved may pass between them or may indeed become locked in one or another. Shock, numbness and disbelief may give way to anger, protest, guilt, despair and pining. To quote Pedder (1982), "during this phase of pining it is not uncommon for widows, for example, to experience a sense of presence of the deceased or even frank hallucinations; but as 'grief work' proceeds and the reality of the changes are painfully grasped, a moment comes when pining gives way to nostalgia and recollections of the lost object. The object is now found internally, just as hope is given up of ever meeting again externally". Subsequently one can take leave of the deceased, accept the loss and reintegrate into life with new and satisfying attachments which are, valued in their own right (Raphael & Madison 1981, Clayton 1980). Bowlby (1980,1982) observed that the process in psychologically well-adjusted people took much longer then the 6 months which had previously been presumed normal. Bluglass (1984) suggests that some parents may continue to mourn a lost child for very much longer before resolution is complete without being in a stage of pathological grief. The duration of the reaction depends on the success with which the individual does "the grief work" which chiefly entails the acceptance of feelings of intense distress. Avoiding them and denying what has happened may lead to morbid grief, which is a delayed reaction precipitated by circumstances (sometimes years later), or a distorted reaction which may be difficult to recognise as originating from grief.This unresolved grief may in turn have an adverse affect on health (Stroebe and Stroebe 1987).

Unresolved grief after fetal loss is often characterised by accentuated normal grieving stages, for example; numbness, denial,

anger, hostility and selfblame, which are excessively prolonged or excessively profound (Bluglass 1984). There can be vivid, crystal-clear memory, and frequent flashing through the mind, of the events surrounding the loss. An anniversary effect is often noticed, and there may be persistent emotional reaction when the woman talks about the loss, and a welling-up of emotion when subsequent crises occur (Stack 1980).

Equally important are the mechanisms of denied or suppressed grief, which may present themselves in milder forms as "the British stiff upper-lip", in the more bizarre "defence gaiety" in the face of loss, or simply as an inability to accept the death. "Blocked" grief can be expressed, given appropriate help (Mawson et al 1981).

Merely comforting a couple does not help; it is important for them to accept the pain of bereavement, to express their sorrow and sense of loss, and to put into words the feelings of guilt (Lindemann 1944).

Lewis (1979) was of the opinion that: "Mothers of still-born children can only mourn when they have seen the dead baby; when it is brought back to death". Initially the couple may feel disorientated but the emotions will gradually settle down to a normal level (Stack 1980).

Peppers & Knapp (1980) point out that the husband is often pushed into the role of protector and decision-maker and must suppress his own grief and thus not declare his own needs for support and advice. This process might also interfere with his wife seeing the baby. They emphasized the critical importance of sharing this experience for the stability of the couple subsequently, as it gives them a chance to grieve together. It allows for the husband's expression of his grief too, and its recognition by his wife.

Grief also has an impact on personal relationships: Borg & Lasker (1982) reported that parents assume that since they shared a tragedy, helping each other to recover will draw them together after pregnancy loss. In many cases this does happen and there is no negative change in the relationship, but with others, existing problems are made worse or new ones created. The authors observed that grieving is a lonely process and that the parents can only provide each other with limited support on losing a baby; they cannot

make the pain disappear and each one grieves at a different pace and in a different way. Failure to communicate is the most serious obstacle to resolving the tensions that frequently arise from the loss of a child or pregnancy loss. When individuals feel angry with each other or depressed, it is hardly surprising that their desire to relate sexually is temporarily stopped. The connection between sexuality and tragedy can create fear for another pregnancy (Wiener 1970; Helmrath & Steinnitz 1978; Benfield 1978).

There have as yet been few studies on the impact of birth tragedy on other children in the family. Cain et al (1964) observed emotional disturbance in children related to their mother's miscarriage as a response to her grief. Lewis and Page (1978) found profound disturbance of mothering with a subsequent live baby (the "replacement baby" syndrome), and overprotection of remaining children may also occur. The damaging impact of a "sick" parent on the development and behaviour of children is well described in the literature (Rutter 1966), especially where the parental illness involves withdrawal of interest, affection and care, as opposed to more frank psychotic features. Parental mourning may add to a child's feeling of alienation and insecurity, and may increase if explanations are kept from him/her (Rabkin and Krell 1979). If the opportunities to ask questions and be comforted are not available, substantial emotional problems and reactions may develop.

When parents lose a pregnancy, especially the first one, it is understandable that they themselves may wish another child as soon as possible. The surrounding family members may encourage them to do so, believing this to be helpful advice. Closer questioning may reveal, however, that the parents are still actively grieving for their lost pregnancy. Indeed it seems that being in the active stages of mourning may be physiologically undesirable in pregnancy. Conversely, where a subsequent pregnancy continues without mishap studies (Lewis 1979) suggest that being pregnant may inhibit or delay the full realization and acceptance of grief; mourning may be suspended until such time as the pregnancy is safely over. The problem is when this suspension "catches up" with the bereaved in the early neonatal period, especially when the mother is susceptible to emotional changes.

1.2.4 Stress and Coping

Fetal loss and neonatal death are stressful life events. To discover how people come to terms with these, coping strategies were examined.

Lazarus (1966) defines the coping process as "the cognitive and behavioural efforts made to master, tolerate or reduce external and internal demands and conflict". Such coping efforts serve two main functions: the management or alteration of the person - environment relationship that is the source of the stress (problem-focussed coping) and the regulation of stressful emotions (emotion-focussed coping). Coping is thus only employed if the individual experiences a situation as stressful.

The coping medium is central to the cognitive approach and underlines the importance of an individual's appraisal of a threat ("Am I in trouble?") and the possibilities and personal capabilities to confront the threat ("What can I do about it?"). In response to appraisal the individual may set out to change his/her behaviour (Problem orientation) or use defense mechanisms (denial, avoidance, sublimation, rationalisation) in which case the subconscious regulates the coping strategy. It is believed that the coping pattern which the individual displays will depend on previous coping experience, genetic makeup and the complexity of the situation.

All contributors to the field of stress and coping indicate the importance of maintaining the individual's self esteem. Psychologists who emphasize the cognitive aspects indicate in addition that it is possible to develop, and provide, strategies for the individual in anticipation of problems that lie ahead (Falek 1984).

1.2.5 Induced Abortion

Induced abortions became legal after the Abortion Act (1967) which came into operation in England, Wales and Scotland in April 1968. Whereas in Scotland abortion performed in good faith was not a criminal offence (MacGillvray and Horobin 1973), the Abortion Act (1967) officially created important exceptions to the Offences Against the Person Act (1861). A person is not guilty of an offence

under section 58 (or 59) of the 1861 Act when a pregnancy is terminated in an approved place by a registered medical practitioner if two registered practitioners are of the opinion that the continuance of the pregnancy would involve:

(a) risk to the woman's life, or of injury to the physical or mental health of the pregnant woman or any existing children of her family, greater than if the pregnancy were terminated

(b) that there is a substantial risk that if the child were born, it would suffer from such physical or mental abnormalities as to be seriously handicapped

(c) in determining whether the continuance of a pregnancy would involve such risk of injury to health as is mentioned in paragraph (a) account may be taken of the pregnant woman's actual or reasonably foreseeable environment

In an emergency, the requirements as to the opinion of two practitioners and the place in which the operation is performed do not apply. The Act provides that no person shall be under a duty to participate in any treatment under the Act to which he or she has a conscientious objection, but this does not affect a person's duty to participate in treatment necessary in a grave emergency.

Rapid changes in the social climate have influenced changing concepts regarding the female role, and society's fluctuating acceptance of induced abortion must influence the emotional responses of women experiencing elective termination of pregnancy. These fluctuations are apparent when passionate public debate and opinions flare up with each proposed amendment to the Abortion Act (1979,1988)). It becomes clear that the social taboo surrounding abortion has lessened, but it is still not an easy subject for open discussion. The social attitudes regarding abortion as a whole will inevitably be reflected in the individual's perception of the termination of pregnancy.

1.2.6 Psychosocial Implications of Induced Abortion for "Social" Indication

When a woman perceives a pregnancy as unwanted on the ground of psychological, social or economic complications, and there are no

clear medical reasons regarding the immediate health of mother or fetus, a termination may be offered on the grounds of "social indication".

Payne et al (1973); Doane and Quigley (1981); McCance et al (1973) all reported that few women felt long-term negative effects after an abortion for "social" indication; indeed the opposite was observed, women going to term suffered more long-term depression than those who obtained an abortion and the former reported new possibilities for personal growth. These results were given in the later literature (after 1970) when the social climate had changed after legalization. The older literature was often influenced by the more restrictive social and legal climate regarding abortion or the author's own viewpoint (for or against) and are thus not appropriate (Osofsky and Osofsky 1973). Many methodological and definitional problems were noticed in research into the psychosocial implications of these abortions, both before and after 1970.

Doane and Quigley (1981) in their review article observed that only 5% of the women felt emotionally worse a few months after the abortions, 71% felt better, and 24% felt the same as before the intervention. When negative symptoms are defined, the most common were depression, with or without grieving, guilt, and crying (which comprised 57% of the complaints mentioned in the literature).

Little is known about the women who are at higher risk of a negative emotional outcome. Payne et al (1973) identified, out of 102 women studied, several risk factors; those who lived alone, were without children, had a troubled history such as serious emotional problems, had conflicts in the relationship with their partner, had a bad relationship with their own mother, and those who had strong negative ambiguity because of religious or cultural attitudes towards abortion. Ashton (1980) also identified risk factors for a negative emotional outcome (5% of 84 patients), and included; ambivalence about abortion, poor psychiatric history, and a medical indication for the intervention. Both Ashton (1980) and Doane & Quigley (1981) assumed that in an abortion for medical indication, the pregnancy was wanted and give this as an explanation for a negative outcome. Finally, it appeared that mid-trimester abortions were over-represented in the group with negative emotional symptoms (Kaltreider et al 1979; Osofsky and Osofsky 1973).

1.2.7 Induced Midtrimester Abortion

The chance of physical and/or psychological complication is higher with increased gestation in a mid-trimester termination of pregnancy (between 13 and 27 weeks gestation) (Osofsky and Osofsky 1973; Doane and Quigley 1981; Alberman and Dennis 1984). Two obvious explanations are; the more invasive techniques employed for TOP, and increased maternal awareness of the fetus. It is difficult to draw conclusions on the psychological impact in these studies because second trimester induced abortions often occur in a very polarized group of women who are not representative of the abortion group as a whole. On the one end of the scale are the older women who have already had a family, and on the other side unmarried girls (<18 years of age). The reasons given for the late gestation abortions were (apart from medical considerations); ambivalence towards the pregnancy, difficult access to medical facilities (especially in low socio-economic groups and ethnic minorities) and, in adolescent pregnancies, parental permission delays .

The increased risk of medical complications in advanced gestation terminations may be linked to the abortion technique used (Kaltreider et al 1979). After the 12th week of pregnancy the simpler technique of D&C (dilatation and curettage) may not be possible or advisable. Intra-amniotic infusion of hypertonic saline, urea or prostaglandin, extra-amniotic methods with catheter and prostaglandin, or D&E (dilatation and evacuation) have been widely used. The last technique may not be suitable after 17 weeks (Kafrissen et al 1984). For late abortions in Britain D&E is more often used in the private sector then in the National Health Service (Stanwell-Smith 1984). Reports from Canada and the USA found D&E to be of greater safety than prostaglandin or other methods between 13 and 16 weeks (Cadesky et al 1981; Grimes et al 1980). Hysterotomy is rarely used nowadays because of increased risk of complications and safer alternative methods (Stanwell-Smith 1984). What part the method of termination plays in the negative emotional outcome is not totally clear in the literature. When medical and psychological advantages and disadvantages were compared, prostaglandin methods were preferred medically after the 17th week of gestation (Kafrissen et al 1984), but the women had more pain and reacted with more anger and depression afterwards than those who experienced the D&E or

hysterotomy methods.

Nurses were more disturbed by "amnio-abortions", in which they played major roles in supporting the patient as well as carrying-out the abortion procedure. Physicians reported the D&E procedures to be emotionally difficult (Kaltreider 1979), and this latter method may have limitations in termination for fetal abnormality where confirmation of diagnosis is important.

1.2.8 Psychological Implications of Induced Abortion for a Medical Indication

A medical indication for abortion is given if there is danger to the mental or physical health of the pregnant woman or her fetus. Serious maternal renal or cardiovascular disease and serious psychiatric ill health have long been considered indications for abortion . Latterly, rubella infection in the first trimester of pregnancy, cancer, radiation exposure, and pharmaceutical complications (Thalidomide) have been added.

Research which systematically compares medical and non-medical indications is rare, but as was observed in the abortion for social indication review (Section 1.7), authors found in the small group of women who experienced an unfavourable psychological post-abortion sequelae an over-representation of women with a medical, non-psychiatric indication (Peck and Marcus 1966, Niswander and Patterson 1967).

Between 1963 and 1965, Peck and Marcus reviewed 50 women six months after abortion for a medical indication. Because of a rubella epidemic, about half the women had had non-psychiatric indication. This group presented with more negative symptoms (36%). The authors observed guilt feelings and transient depression, both of which were comparable to bereavement reaction.

At the same time Niswander and Patterson's study (1967) of 116 women in New York with medical indications, found few negative symptoms after 8 months, but confirmed more post-abortion complaints in the non-psychiatric group (17 rubella and 10 other indications). The doubt whether the right decision had been taken was prominent and an additional sense of guilt was observed in women whose pregnancies

were aborted as a result of their own health (Simon et al 1967). This reflects the woman's self-perception of personal imperfection and inadequacy in the fulfilment of her desired maternal role. Again, as in abortion for social indication, authors assumed that the important difference between the groups was due to the loss of a wanted child.

1.2.9 Medical consequences for reproduction after abortion

The possible biological consequences of abortion on reproduction were investigated by various authors. These can be important factors in reproductive behaviour which in turn may be linked to negative psychosocial abortion sequelae. Some authors (Liu et al 1972; Richards and Dixon 1976; WHO 1979; Bracken & Holsford 1979) found increased deleterious effects including prematurity and fetal loss, while others (Chung et al 1982; Roht and Aoyama 1974; van der Slikke & Treffers 1978; Hogue et al 1982; Frank et al 1985,) could not confirm these effects. Most concerned first-trimester terminations of pregnancy. Hogue (1982), in his review article, found few deleterious effects but observed a lower birth weight in those with a previous D&C abortion. He was cautious about the results regarding multiple abortions, because they were contradictory. Frank (1985) in a comparison of 745 women and 1339 controls, confirmed few deleterious reproductive effects after first trimester abortions.

Sellers and Hancock (1985) noted the effects of mid-trimester induced abortion on the subsequent pregnancy. They compared outcome of the next pregnancy following mid-trimester termination of pregnancy (TOP) for 77 fetal neural tube defects (NTD) and 13 fetal Down's Syndrome, with 119 term deliveries of a baby with NTD. They found subsequent fetal loss relatively high in all three groups, and that a previous NTD per se might increase fetal loss in the next pregnancy. A mid-trimester TOP for NTD was not associated with an increased risk for; premature labour, small for dates babies or congenital abnormalities in the next pregnancy. There was a slight increase in the number of babies weighing less then 2500g in the next pregnancy. These findings suggest that late TOP for fetal abnormality does not generally have medical implications for subsequent pregnancies.

1.2.10 The psychosocial aspects of prenatal diagnosis and subsequent reproductive behaviour.

Genetic abnormalities and prenatal diagnosis (PND) are likely to have an emotional impact on parents-to-be because they influence the strong basic drive for reproduction and survival through one's descendants. In the past, couples at risk of genetic disease were often deterred from planning further pregnancies (Carter et al 1971; Emery et al 1972, 1973; Reynolds et al 1974; Klein and Wyss 1977). Prenatal diagnosis now gives many of these couples sufficient reassurance to proceed with another pregnancy..

In the early seventies, before the development of PND, reproductive behaviour after diagnosis of genetic conditions was mainly determined by factors derived from genetic counselling, including quantitative information about the recurrence risk and detailed information about the nature of the abnormality. Initially only the increased recurrence risk appeared to be the major factor in this decision. At a high risk (arbitrarily defined as more then 10%) the majority refrained from reproduction, and a low risk (<5 %) they took another chance. However, Carter et al (1971) noticed that as many as one third of the high-risk group opted for another pregnancy, and as much as 25% of the low-risk group refrained from pregnancy. They observed that other factors played a role. Those who proceeded with a high risk usually had a medical disorder or one which resulted in neonatal death, rather than prolonged handicap. Later, many authors observed similar influences on the reproductive decision, but added that the existing family experiences may be important; in particular a handicapped child in the immediate or extended family, cultural and religious attitudes, and socio-economic factors (Leonard et al 1972; Hsia et al 1979; Lippman and Fraser 1979a, 1979b and 1979c; Ekwo et al 1985; Beeson and Golbus 1985). Only Wertz et al (1984) could find no relationship between reproductive behaviour and, respectively, the nature of the illness, the risk factor, the possibilities for treatment, and the couple's understanding of medical and genetic facts.

Many authors have reported changed reproductive behaviour after the introduction of prenatal diagnosis in that many couples dared to try to achieve their planned family size (Everts-Kieboom et al 1980, 1982; Modell 1982; Roghman and Doherty 1983; Scriver

et al 1984; Kaback et al 1984). Everts-Kieboom (1980 & 1982) studied couples with fetuses affected by neural tube defect or Down's syndrome, and Roghmann investigated women with advanced maternal age. Both observed an increased reproduction due to the availability of prenatal diagnosis.

In contrast, Laurence and Morris (1981) observed in the same indication group (NTD) as Everts-Kieboom, that a large number of couples refrained from reproduction in spite of the availability of amniocentesis.

Fletcher(1973) and Lipmann (1979a, 1979b and 1979c), studied perceptions of patients after genetic counselling and difficulties which couples encountered in their decision making process . The latter found that after reducing risk into a binary form (it can happen again or it cannot happen again) three categories emerged: difficult assessment of the emotional, social and physical aspects and burdens of the specific handicap, doubt about their own abilities as parents in case the child is affected, and doubt about their choice and how others may react to that choice. In her conclusions Lipmann mentioned that the subjective, imaginary processes are of greater importance to the couple in their reproductive choice after abnormality than are the objective genetic information on diagnosis, prognosis and recurrence risk.

As indicated in section 1.2.1, in an average pregnancy some emotional disturbance is normal, but more disturbances may be expected in pregnancies monitored by non-routine medical examinations or screening. Of all the prenatal diagnostic techniques, the emotional impact of amniocentesis has been frequently studied and this literature clearly demonstrates that amniocentesis subjects the prospective parents to stresses of varying degree (Fava et al 1982; Phipps and Zinn 1986; Beck et al 1984).

Some authors reported that the subjectively experienced beginning of pregnancy is influenced by the procedure. Beeson & Golbus (1979) observed that women were reluctant to become emotionally involved with the pregnancy until the test result was known and the fetus welcomed as a prospective child. More recent studies could not always confirm these findings (Ashery 1981; Dixon et al 1981). In the study of Verjaal et al (1982), as many as half the women informed their acquaintances about the pregnancy before the

amniocentesis was performed.

Fears of fetal injury or defects are common. In the study of Finley et al (1977) half of the women recalled these particular fears and 69% of the women in the study of Verjaal et al (1982) were afraid that the procedure would damage the fetus. Leonardi & Esrig (1982) reported that 10% of patients were still concerned about induced fetal injury after the test had been performed. Another cause of anxiety is the fear of amniocentesis producing a miscarriage. Findley et al (1977) found this in 30% of women and Dixon et al (1981) reported that preceding the test, 38% of women feared that amniocentesis might cause a miscarriage.

A number of women also reported that fears relating to the unknown aspects of the procedure, or to pain caused by the test, made them more reluctant to opt for this form of prenatal diagnosis (Findley et al 1977). When asked about their perception of the procedure, Everts-Kieboom et al (1988) reported that a considerable number of women did not find the procedure a frightening experience. However 25% of the women found the amniotic puncture and the pain associated with it most unpleasant. Women who were not bothered by the procedure were mostly those who chose amniocentesis for advanced maternal age (older age group).

For couples, the time interval between the performance of the test and the communication of the test-result is fraught with anticipation anxiety. McGovern et al (1986) found 83% of women at least moderately anxious during this time and 62% of women,studied by (Dixon et al 1981) reported the waiting time as the most difficult aspect of amniocentesis. Women who had amniocentesis because of a previous defective child experienced increased anxiety if compared with, for instance, maternal age indication (Robinson et al 1975; Beeson & Golbus 1979; Everts-Kieboom et al 1988). However, Verjaal et al (1982) and Fava et al (1983) could not confirm this finding. Notwithstanding the concerns raised, the overall evaluation of the procedure is almost always positive (Godmillow et al 1978; Dixon et al 1981); most couples would recommend the test to friends (Vinson et al 1980; Dixon et al 1981; Verjaal 1982).

In trying to assess the attitudes of women to chorionic villus sampling (CVS) versus amniocentesis, Perry et:al (1985) noted that although risk information was the most important factor for

women preferring amniocentesis (50.2%), the timing of the test and the termination procedure were the most important factors to those preferring CVS (45.1%). However, risks of miscarriage after CVS were not clear at the time. In the hypothetical case that CVS had the same risks attached as amniocentesis, 82% would prefer this procedure. The Canadian Collaborative CVS-Amniocentesis Clinical Trial Group (1989) however, noted that women considered more then just the fetal loss rates. Factors such as the likely success of the procedure on first attempt and the accuracy of results are also likely to influence their choices.

Because maternal serum alphafetoprotein (MS-AFP) screening is essentially a non-invasive procedure, it is unlikely to provoke the level of anxiety commonly associated with amniocentesis but for some a raised MS-AFP may cause residual prenatal anxiety, despite normal diagnostic studies,such as ultrasound and amniocentesis (Fearn et al 1982; Bern-Fromell and Kjessler 1984). For those with elevated MS-AFP who refuse further diagnostic tests, extreme anxiety may persist throughout pregnancy and even after the birth of a "normal" child (Burton et al 1982). This negative effect of an abnormal initial screening result may be difficult to erase completely.

For 7% of the couples opting for prenatal diagnosis, fetal abnormality will be revealed and this will produce emotional trauma. They will be confronted with the decision to abort a wanted pregnancy and thus prevent the birth of a handicapped child or to continue the pregnancy and have consequent difficult choices about further reproduction.

There is little known about the psychosocial and reproductive consequences for the couples who elect for abortion for FA. From the few studies conducted it appears that this form of fetal loss produces an intense and long-term emotional impact, often described as emotional trauma.

the published literature (Blumberg et al 1975; Donnai et al 1981; Adler 1982; Leschot et al 1982; Lloyd et al 1985; Becker et al 1984; Jones et al 1984; THomassen-Brepols 1985) regarding abortion for "genetic indication" usually reports the opposite (see table 1).

Blumberg et al. (1975) provided the first data on this subject and found that the incidence of depression following elective abortion was 92% of women and 82% of men. This was greater than that usually associated with elective abortion for psychosocial indications or with the delivery of a stillborn child (see section 1.4). Further contributing to the emotional burden of the elective abortion was the sense of guilt associated with genetic disease and this was particularly damaging when genetic responsibility was derived from only one parent (Blumberg, 1984).

Autosomal recessive conditions, where both parents shared genetic responsibility, were less damaging. Blumberg (1975) stressed that the prolonged difficulties described by couples indicated the need for supportive counselling after the selective abortion. Donnai et al. (1981) confirmed that the small numbers of women undergoing termination of a planned or wanted pregnancy after prenatal diagnosis constituted a higher-risk group, vulnerable to depression and social disruption. Adler et al. (1982) found that only four couples (33%) involved religious factors in their decision to either terminate or continue the pregnancy. Two of these families were Roman Catholic but all four stated that they received support from their church leaders and relatives in their decision. The interviews with husbands revealed that their decisions seemed to require less soul-searching than their wives. In several families the grief persisted for over a year and the anniversary of the termination often reopened mental wounds. Leschot et al. (1982) concluded that termination of a pregnancy because of a malformed fetus was associated with long-term psychological side effects, and that the emotional upheaval persisted for variable periods after the diagnosis and the decision concerning pregnancy outcome. Becker et al. (1984) drew conclusions regarding patient care or lack of it and emphasized the need for support by both partners. Seeing, holding, naming the baby after delivery, and subsequently receiving autopsy results were the most helpful factors for 90% of the respondents: none of the respondents considered any of these to be deleterious to their coping process. All the above

Table 1. Review of literature of the follow-up after termination for fetal abnormality.

Area Year published Author	Study	Research design	Number method	Interval termin-months.	Method interv in	Results	Reproductive behaviour
California 1975 Blumberg	ab-cohort	interview, MMPI	N=13 resp.87%	0-37 m=21	unknown	92% depression measure:MMPI	Sterilised: 8%
England 1981 Donnai	ab-cohort	unstruct interview	N=12 resp 80%	3-49 m=17.7	hysterot=7 prostG =5	High risk for depression+social disruption	unknown
New Jersey 1982 Adler	ab-cohort	oral quest.	N-12 resp.80%	3-33 m=15.4	unknown	post-abortion depression traumatic experience	W+50%
Netherlands 1982 Leschot	ab-cohort	oral quest +s.s.interv	N=19 resp 95%	10-56 m=32	prostG =11 hyp.sal.=7 hysterot=2	long-term psychological side effects or induced abortion	W+=58%
Wisconsin 1984 Becker	ab-cohort quest	postal resp=63%	N=45	unknown	unknown	90% saw fetus need for understanding	unknown
California 1984 Jones	ab-cohort	audiotapes quest inter-raters	w=14 m=12 resp=52%	4-43 m=17.6	prostaG hyp.sal.	short term:sympt longterm:coping non-resp = problem	W+=80%
Wales 1985 Lloyd	control groups	structured interview	N=48 resp ?	12-60. m=?	unknown	77% active grief resembles stillbirth unlike miscarriage	unknown
Netherlands 1985 Thomassen -Brepols	ab-cohort	audiotapes inter-raters	N=30	6-27 m=?	unknown	77% loss wanted child feeling moral+biological incompetence feeling isolated.	unknown

quest=questionnaire, s.s.interv=semi-structured interview, MMPI=Minnesota Multiphasic Personality Inventory
resp=response rate, W+ =wishes another pregnancy

these to be deleterious to their coping process. All the above authors reported that about half the patients refrained from further pregnancies but none looked into the reasons for this.

Jones et al (1984) was the only paper which found long-term deleterious effects in a minority (30%) of the 14 women and twelve men they interviewed. They observed that 80% chose further reproduction. Their response rate, however, was low at only 39%. The reasons given by the non-participants were; "this subject is too painful, we do not want to discuss this". The authors observed that most of the negative outcomes may have been in the non-response group. They reported that those who did respond coped well with the sequelae after TOP. However, as the response group did not appear to be representative, the value of the conclusions is uncertain.

Except for the last study, all quoted authors have similar conclusions. A couple may have to pay a high price, in psychological terms, for the prevention of genetic or congenital abnormalities by the termination of an affected fetus. Blumberg (1984) was the only author to examine the cause of the depression. As in stillbirth (Lewis and Page 1978; Turco 1980; Kirkley-Best and Kellner 1982; Forrest et al 1982) the abortion may create a feeling of regret, disappointment, and the notion of having lost a wanted child. Blumberg (1984) noted additional factors and mentioned that; "Perhaps the role of decision making and the responsibility associated with selective abortion explains the more serious depression after the latter. A stillbirth is usually regarded as an unfortunate accident. Even when selective abortion is accepted as the only alternative and preferable to the birth of a defected child, the responsibility of making the decision to abort may prove to be an uncomfortable burden for the parents. This loss does not "just happen", indeed one chose it and is thus responsible. As a third factor, Blumberg emphasised that, comparable to the birth of a handicapped child, diminished feelings of self-value occur through failure to produce healthy progeny. Finally he mentioned as a complicating factor the duration of the pregnancy, through which the fetus is viewed as a future child and the baby about whom the couple start to fantasise and to relate. Not only is the pregnancy terminated, but also the process of psychological and physical preparation for the parent-child relationship is disrupted.

interviewing 30 women 6 to 27 months after the TOP. For 77% the event had the psychological meaning of the loss of a wanted child, and at the time of the interview, one third appeared to have coped with the event. Coping was complicated by feelings of moral and biological incompetence. The loss of hope for a healthy child played an important part. The author reported that conflicting emotions were subsequently elicited by two conflicting images: the image of the wished-for, fantasized baby and the image of the handicapped child. She observed that couples frequently became isolated because people tended to avoid problems regarding heredity, handicap and abortion.

Thomassen-Brepols (1985) was also the only author who conducted a separate study into the psychosocial aspects of family planning and reproduction after a mid-trimester TOP for FA. Of 100 women who responded to a questionnaire, about half did not want another pregnancy, but only 9% were content with this decision. Of the others, 41% showed conflict between actual reproductive behaviour and the desired family size. Not wanting another termination of pregnancy was the main argument for refraining from reproduction (50%). Others wanted another child but were frightened of renewed confrontation with fetal malformations (39%), and the difficult decisions concerning continuation and termination of pregnancy. No mention was made concerning management, or whether lack of after-care had contributed to the conflict. Risk of reproductive conflict was greatest amongst the women who had had a fetal abnormality associated with maternal age. The pressing time factor with approaching end of fertility, ignorance of the syndrome, and the first confrontation with reproductive failure were commom causes for this conflict.

Ignorance of the disease or malformation in women who were confronted by a diagnosis different from their indication for prenatal diagnosis was another reproductive conflict risk factor. Objective genetic risk and family constellation appeared to be not of prime importance in the reproductive decision and she reported that all women who became pregnant (39% of the total) had prenatal diagnosis in that pregnancy.

When reflecting on the influence of the actual method of medical procedure employed for second trimester induced abortion, Blumberg (1984) noted that "vaginal delivery of a non-viable fetus following prostaglandin administration (or similar technique) has

been especially traumatic for selective abortion recipients". The stark reality of the observed fetus denies the opportunity to consider the abortion in abstract and more comfortable terms, unlike a D&E under general anaesthesia. However, ultimate resolution of the grief process may actually be facilitated by the direct contact with the fetus. Being forced to face the fetus, the parents are required to acknowledge and to deal with their grief.

Lloyd and Laurence (1985), used a control population, to compare the reactions of three categories, women who had a spontaneous abortion, a previous stillbirth or neonatal death; previous termination for medicosocial reasons; and 48 women after TOP for FA. They found an acute grief reaction in 77% after the TOP for FA and 45% remained symptomatic at 6 months after termination while 20% required treatment. This compared with no such reaction after spontaneous abortion or medicosocial abortion earlier in pregnancy. They found the response to termination of a wanted pregnancy to be similar to post-stillbirth reactions. When examining the management aspects, they found the lack of coordinated home-visiting after the termination surprising, and the liaison between the gynaecological wards and the primary health-care team not as effective as the liaison between the same professionals and the obstetric services. Although the routine hospital follow up at six weeks was uniformly efficient as a postnatal check, there was generally no opportunity for the complicated and highly personal attention that many needed. They reported that lactation and mastitis were distressing, although surprisingly few patients presented to the general practitioner with these problems. Twelve patients (of the 48 TOP for FA) did not embark on further pregnancies and eight subjects experienced problems severe enough to influence reproductive behaviour. They concluded that with the advances in prenatal diagnostic techniques, provision of support after termination had not proceeded at the same rate and services had not developed to meet this unperceived need. They remarked, finally, that as well as elucidating the nature and consequences of response to TOP for FA, further studies are needed to identify the risk factors for a negative sequelae.

Although all of these authors agreed that some painful psychosocial sequelae are to be expected after TOP for FA, many were

psychosocial sequelae are to be expected after TOP for FA, many were surprised by the duration and intensity. However, it is still difficult to find clear confident and uncontroversial pronouncements on the psychosocial implications of a termination for fetal abnormality. The numbers researched have been small (study numbers ranging from 12 to 48) and research is complicated by various definitional and methodological problems identified by Hollerbach (1979b). These included; failure to include pre-abortion psychological assessment of the woman and her partner to act as a baseline; failure to distinguish differential effects of abortion by indication by abortion method and by probability of recurrence; small sample sizes; and inattention given to possible interviewer bias or sampling bias in the return of questionnaire; wide variations in timing of follow-up interviews; variation of timing of studies and ignorance of the legal and cultural acceptability of abortion; absence of appropriate control groups; use of ambiguous terminology and problems of definition and comparability of such concepts as "depression, guilt, regret, or uncertainty"; and finally lack of standardisation to measure the effect of an abortion.

1.3 Aims of the Present Study

The overall aim of the present study was to examine the current management of TOP for FA, to identify whether there was scope for improvement. Special attention would be given to the following questions

1 Do couples experience the sequelae of a TOP for FA if so what are these?
2 What percentage of men and women have an adverse outcome after TOP for FA.
3 Does the adverse outcome relate to the factors set out in table 2 (depression, duration and intensity) ?
4 Does TOP for FA cause reproductive conflict?
5 What alternatives to current management might improve the situation?

CHAPTER 2

MANAGEMENT ASPECTS AFTER DETECTION AND TERMINATION OF PREGNANCY FOR NEURAL TUBE DEFECTS

2.1 Introduction to the First Study

In the West of Scotland, the incidence of neural tube defects is high (1 in 300), and in view of this antenatal screening by maternal serum alphafetoprotein assay (MS-AFP) was introduced in 1975. Most pregnant women in the region are offered, and accept, this screening test and when confronted with a positive diagnosis, the vast majority of women opt for termination of the pregnancy (TOP).

When the West of Scotland joined the Medical Research Council's "Randomised Clinical Trial of Folic Acid and other Vitamin Supplementation in the Prevention of Neural Tube Defects" (M.R.C. Vitamin Study), a large number of women in the West of Scotland (over 1300) and with a history of fetal NTD were interviewed at home. A large percentage of these women had had a TOP for NTD and it soon became apparent that most were very keen to talk about their experiences and their perceptions of screening, prenatal diagnosis and termination of pregnancy. It transpired that although women felt grateful towards hospital staff, many had very clear but often unhappy memories of the management around the event and felt unprepared for the physical and emotional impact of the termination and the sequelae.

2.2 Aims of First Study.

To assess the management around prenatal diagnosis, and before, during and after a TOP for NTD and to evaluate whether, in general, management fulfils the women's perceived needs.

2.3 Patients and Method

The patients for this retrospective study were identified from the records of the West of Scotland Regional Genetics Service. The patient's date of termination was ascertained along with the nature of the NTD, the patient's date of birth, her address, the name of her maternity hospital and her hospital number. In order to

obtain the name and address of her General Practitioner (GP) and to confirm termination for NTD, the records of 16 maternity hospitals were consulted. After permission had been obtained from the GP the patients were visited; in the first instance, to inform them about the M.R.C. Vitamin Study. However, this opportunity was taken to interview 40 women about their management before, during and after termination. Notes were made about their comments. With this information a detailed questionnaire was compiled, including open and closed questions, and tested on 15 women (after TOP for NTD). After final amendments, 215 women were visited at home between 1983 and 1985 and asked to complete the questionnaire (Appendix I) in the presence of an experienced interviewer (MW). After re-examining hospital records, 49 patients were excluded because they did not have a true termination for fetal NTD they had had an intra-uterine or neonatal death with NTD. Thus the results of 166 questionnaires are reported.

2.4 Results

166 women were interviewed and the results for this study are divided into six sections; 2,4.1 Patient's background information, 2.4.2 Prenatal diagnosis, 2.4.3 Explanation of the abnormality, 2.4.4 Care during termination, 2.4.5 Post-termination hospital care, and 2.4.6 Post-termination community care.

2.4.1 Patient's Background Information

Age Distribution at Termination

The majority of women were aged between 20 and 30 (123, 82%) and their husbands between 25 and 35 (105, 63%). This is not significantly different from the statistics for Scotland (as supplied by the Greater Glasgow Health Board Information Services Unit).

Social class

Although socioeconomic group 3 seemed slightly over-represented, the social class distribution (Classification of Occupations, 1980) appeared to reflect the general population for

Scotland (as supplied by the Greater Glasgow Health Board Information Services Unit).

Affected Pregnancy

For 67 (40%) of the women it was a first pregnancy, for 55 (33%) a second, and 50 (30%) had had more then two pregnancies before the TOP for NTD. 5 (3%) patients had more then one affected pregnancy but only the most recent termination was assessed for this study.

Findings in aborted fetuses

90 (54%) of the fetuses had anencephaly, 65 (39%) had open spina bifida, 8 had an encephalocoele, 2 had closed spina bifida and 1 had iniencephalus.

Time between the interview and the termination

Women had their TOP for NTD between 1980 and 1985. Many (61, 37%) completed the questionnaire between 4 and 8 weeks after the TOP, 53 (32%) between 2 and 6 months and 52 (31%) between 7 months and 8 years. The events around the termination were clearly recalled by all, only minor details e.g. type of analgesia, being forgotten.

2.4.2 Care During Prenatal Diagnosis

Was screening offered ?

Patients were asked whether they had been offered maternal serum alphafetoprotein (MS-AFP) screening. 124 (of 166) were offered screening and accepted. Those replying "no" gave the following reasons; 3 were not offered screening (ultrasound detection), 3 were offered screening but refused (NTD detected by ultrasound), 4 were over 20 weeks of pregnancy and outside the screening period, 3 were detected at amniocentesis for previous NTD/Down's Syndrome, 27 were detected by ultrasound before the MS-AFP screening period and 2 were screened without knowledge or permission.

Identification of NTD pregnancies

The pregnancies were primarily identified by MS-AFP (66%), by ultrasound scan (29%) and by amniocentesis in 4%.

Expression of doubt voiced to patient

Doubts that there might be something wrong with the pregnancy, were expressed to 40% of the patients after a routine scan, to 10% after one high MS-AFP result, to 28% after their second MS-AFP, and to 7% after amniocentesis.

Preparation for possibility of NTD in fetus

The possibility of a NTD pregnancy was mentioned to 104 (62%) of the patients following an abnormal scan or elevated MS-AFP. 11 (7%) of the patients could not remember what was said to them and the remaining 49 (30%) were told that something was wrong with the pregnancy, but left guessing as to what it could be.

Confirmation of NTD

The abnormality was confirmed by ultrasound in 99 (60%), by amniocentesis 66 (40%), and by X-ray 1 (1%).

Time between the expression of doubts and confirmation of NTD

The time from initial doubts expressed to the patient to the confirmation of a NTD lesion varied. Most women (87, 52%) had the NTD pregnancy confirmed in less then a week, for 32 (19%) it took a week or more, for 28 (17%) two weeks. 19 (12%) had to wait between 3 and 6 weeks for confirmation. This was mainly due to samples sent and received during the Christmas holiday period and in one instance a four-week wait was due to a laboratory error.

PATIENTS' OVERALL ASSESSMENT OF PRENATAL DIAGNOSIS

Patients rated the care received on a scale from bad to excellent.

Bad 3 (2%). Poor 7 (4%). Average 19 (11%). Good 111 (67%).
Excellent 26 (16%)

The twenty-six patients who scored average and poor had various complaints, most commonly concerning communication,and the time for test results to come back.

The three "bad" respondents were:-

1 The patient was not scanned at amniocentesis (patient saw bloody amniotic fluid and this was followed by massive haematoma around her waist).

2 The patient was reassured despite 2 raised sera (of which she was not informed), and thus the diagnosis of NTD came as a total surprise.

3 A wrong result due to an analytical error (discovered by the laboratory) was detected four weeks later.

Patients' comments in relation to prenatal diagnosis

Body language and tension in the ultrasonographer suggested problems yet there was no further communication at the time of the examination. This was very frightening.

2.4.3 How was the Abnormality Explained

Which person gave the patient the final diagnosis?

The final confirmation of the diagnosis was given to 71 (43%) patients by their obstetric consultant, and to 76 (46%) by ultrasonographer (some of whom were obstetric consultants). The remainder were told by a registrar 8 (5%) at home by their general practitioner 9 (5%) or by a health visitor 2 (1%). The patients preferred to be told by their obstetrician (or by an "authoritative" ultrasonographer) so that options for action could be discussed.

Who accompanied the patient at the time?

Most patients (97, 58%) were accompanied by their husbands. Some asked a relative (15, 9%) or a friend (4, 2%) to be with them. However, 51 (31%) were alone when they were told that their fetus had NTD and although patients realized that this was not always possible, all would have liked to have been accompanied to share and pool the information offered.

What was perceived about the NTD lesion?

The majority of patients (142, 86%) remembered being told that the lesion was severe and the prognosis bad. 13 (8%) were told that the lesion was visible but could not remember prognosis, 11 (7%) remember the prognosis to be doubtful, and 2 (1%) understood the fetus to be possibly dead.

Was the diagnosis understood?

Although patients found it hard to remember any information given about NTD, the vast majority (157, 95%) had heard about spina bifida and had some idea what the implications for the fetus could be. 4 (2%) felt confused at the at the time and 5 (3%) had no idea of what they were told.

With whom was the diagnosis discussed?

During the decision-making time, 79 (48%) discussed the implications of the NTD with their husband only. Others asked for the opinions of relatives (33, 20%), friends (3, 2%) or their health visitor (3, 2%). 28 (17%) had a discussion with their GP. 15 (9%) patients made another appointment with their obstetrician for a further explanation (they were not the patients who reported that they did not understand the diagnosis) and 5 (3%) women made the decision alone.

How was the pre-termination counselling and the discussion assessed?

Most (113, 68%) could not think of any way of improving this difficult task. 4 (2%) felt it could have been done more sensitively, but could not suggest how, 27 (16%) felt that they should have been encouraged to be accompanied before being told the final diagnosis or that arrangements should have been made for their return journey home. Many patients felt that the staff were embarrassed at the sight of their distress instead of displaying some empathy. Two couples felt that the counsellor had strong views against TOP for FA and felt confused about this. 22 (13%) had felt numb and could not give an assessment of the counselling.

Was the termination procedure discussed before admission to hospital?

The TOP procedure, length of labour, pain and analgesia were discussed with 86 (52%) patients, with 12 (7%) only some aspects were discussed, 2 (1%) could not remember and 62 (37%) entered hospital thinking that they would be asleep during the termination and that all would be over in a couple of hours.

PATIENTS' OVERALL ASSESSMENT OF HOW THE ABNORMALITY WAS EXPLAINED

Patients rated the care received on a scale from bad to excellent

Bad 5 (3%). Poor 29 (17%). Average 30 (18%). Good 83 (50%). Excellent 19 (11%)

Comments of patients who scored bad and poor were mentioned earlier

Patients' comments in relation to how the abnormality was explained

I heard that the diagnosis was serious and I went numb; I just could not remember anything about the consultation.

I was unaccompanied and still can not remember how I got home (One lady got into the wrong bus and found herself 60 miles from home)

I felt so ambiguous about the decision making. On the one hand I wanted more time on the other, I wanted the NTD pregnancy terminated as soon as possible.

I wish that I would have been told how long I should expect to be in hospital for, so that I could have made better arrangements for the animals

2.4.4 Care During Termination

Time between the initial screening or PND and the termination

Those detected by US or one raised serum (48, 29%) were able to have the termination in one week or less, for the majority it took between two and three weeks (84, 49%). 36 (22%) had an anxious four to seven weeks before they had their termination. This was due to a combination of doubt about the diagnosis (30, 18%), the patients own indecision about whether to terminate or not (6, 3.6%), mistakes in sample handling (one case), and lack of response to a raised serum report (one case).

Waiting time for admission to hospital for termination

Some women (36, 27%) were admitted the same day, although four of them would have preferred to have been admitted later. Most (74, 45%) were admitted the following day. 44 (26%) were admitted between 2 to 4 days after their decision of whom 15 (34% of 44) would have preferred an earlier admission. Those who waited between 5 to 8 days 12 (7%) offered no complaints. This left 147 (89%) satisfied because they were admitted at the preferred time, and 19 (11%) dissatisfied.

Place of termination.

Most women (110, 66%) had their TOP in a labour room; this was perceived as painful when the crying of newborn emphasised the fruitless labour, but on the whole patients understood the safety aspects of this ward. In some hospitals patients (46, 28%) delivered in the same sideroom (in an ante- or post-natal ward) to which they were admitted; in general this was liked as long as the side ward was well removed from the nursery. 9 (5%) were delivered in the side room of a gynaecological ward and felt doubtful about this and 1 patient delivered in a geriatric ward and found this upsetting especially as she was told that the labour-room staff refused to look after any patients who opted for a TOP. The fact that the fetus was not viable (anencephaly) made no difference.

Pain control

Most patients found it difficult to recall the analgesic given. 76 (46%) were doubtful as to what they had received. 53 (32%) thought that they were given pethidine. 35 (21%) received an epidural and 2 patients refused all analgesics, in spite of being in great pain, as a way of punishing themselves. Most (118, 71%) recalled the pain control to be effective, 19 (11%) could not remember, and 28 (17%) experienced a lot of pain.

Those complaining of ineffective pain control found the time between the injections too long (four to six hours). At times the epidural was not effective and only one side of the body would be free of pain.

Perceived attitude of staff during TOP procedure

Staff were perceived as kind and caring by 159 (95%), 7 (5%) women found the attitude cold and uncaring partly because they were left alone for long periods. One lady delivered alone and had no way of attracting attention but by screaming.

PATIENT'S OVERALL ASSESSMENT OF CARE DURING THE TERMINATION

Bad 3 (2%). Poor 14 (8%). Average 23 (14%). Good 105 (63%). Excellent 21 (13%)

Those reporting "bad" mentioned the following adverse factors.

- Allowed to deliver alone.
- Allowed to deliver in same room as social termination.
- Feeling that doctors and nurses "disapproved" of termination.

Patients' comments in relation to care during the termination

I was made to wait such a long time after admission before I saw a doctor(4 hours) and nearly discharged myself again.

I honestly thought that I would have a general anaesthetic and that when I woke up all would be over.

I had never seen a labour room before and felt terrified by the equipment and the bed like an island in the middle of the room. All that technology and me in the centre of it all. I broke down in tears. Other mothers to-be have an opportunity to see the labour room before their actual labour as part of their antenatal classes.

Having had two normal births I found the obstetrician's comments that this would be a mini-labour laughable. It was much more painful then a normal birth.

Although I hated the long labour, I gave the baby a birth and prevented it from being pulled about: it was least I could I could do for "my child".

I was terrified that the staff would think me uncaring, and would show me their disapproval by being polite but distant.

A registrar and a junior hospital doctor conducted a debate on the morality of abortion at the end of my bed while I was in labour. They talked about me as if I was not there. I still feel upset about this.

2.4.5 Post-Termination Care in Hospital

Place of care after termination.

Many patients 52 (31%) were moved to a postnatal ward, and where possible, most were allocated a side ward. 31 (19%) moved to a ante-natal ward and 45 (27%) to a gynaecological ward. 38 (23%) remained in the room in which they were terminated. Patients preferred this arrangement or the gynaecological ward as long as they were not isolated and staff came to see them from time to time.

Perception of post termination care and staff attitude

159 (96%) found the staff kind and 116 (70%) the care good. 4 (2%) could not remember the staff and 6 (4%) could not recall the care! Only 3 (2%) found staff indifferent or unkind but **44 (26%) were unhappy about the time spent in hospital after the TOP.** The major complaint was being placed in hearing distance of the nursery,and in addition they felt lonely and outcast as no one came to see and talk to them. At times staff had not read the notes and asked where the baby was.
(As more then one comment was recorded percentages may not add to 100)

Time in hospital.

Days	0	1	2	3	4	5	6	7	8	9	10	11
Patients	1	9	43	64	28	14	-	5	-	-	1	1

Were medical and psycho-social sequelae discussed on discharge from hospital?

With 15 (9%) of the patients the consequences of a second trimester TOP were discussed, such as lactation, vaginal discharge,

emotions and going back to work. Two could not remember and 10 were informed about one or two aspects. Yet 135 (81%) patients were given no information at all. This included the 67 (40%) primigravidas, who were consequently bewildered by their engorged breasts and duration of vaginal discharge.

PATIENT'S OVERALL ASSESSMENT OF POST-TERMINATION HOSPITAL CARE

Bad 2 (1%). Poor 29 (18%). Average 32 (19%). Good 91 (55%). Excellent 12 (7%)

Patients' comments in relation to post-termination hospital care

When I went back to a ward,I was put in a side room, but also near a nursery, I do not wish to remember this nightmare.

Two nights after the termination I was wakened by a baby crying, and without realising it I got up to feed it. It was not till the sister asked me what I was doing with a bottle of milk, that I realised there was no baby for me. I wished they had put me further from the nursery.

Cleaners and others who came to my room asked me what I had delivered. I found that, and the empty cot outside the door, very painful.

The nurses were amazed that I could not cry and it made me feel so guilty.

I was lying there hour after hour ,without seeing anyone for more then a few minutes. I felt such an outcast.

My loss became real to me when I was told at lunchtime that I could go home. From then ,until I left two hours later I saw no-one. I walked out of the ward with my husband and no-one spoke. Yet when I got to the exit a woman with her baby was also leaving and 4 nurses were seeing her off. I felt such a failure.

2.4.6 Post-Termination Community Care

The post-termination appointment at 6-8weeks

103 (62%) returned to hospital to see their obstetrician, 10 (6%) saw a registrar and 8 (5%) saw their GP after 6-8 weeks; for a discussion or examination and found this very helpful. 17 (10%) had an invitation and would attend in the coming weeks, 3 could not remember, but 42 (23%) were neither invited nor made their own arrangements.

Home visits from the primary health care team or other professionals

80 (48%) patients were contacted at home in the first three weeks, 40 (24%) by their GP, 20 (12%) by a sister from Medical Genetics, 18 (11%) by a health visitor, one by a medical social worker and one by a district nurse. 8 patients were visited by two or more professionals.

55 (69% of the 80 visited) found the visit helpful. 6 could not remember if the visit was helpful and 19 (16% of 80 visited) viewed the visit with indifference. The main complaint was an apparent lack of understanding of the women's feelings, and conflicting information received about the fetus and the recurrence risk. However, 86 (52%) were neither contacted, nor invited to the surgery nor visited at home, 39 of them contacted their GP for sick leave confirmation.

Was the GP aware of the termination?

Patients reported confusion about their status after their termination. 44 (27%) found it a relief that the GP was informed. 18 (11%) were very upset when the GP enquired how their pregnancy was progressing, and 81 (49%) had no idea if the GP was informed or not.

Genetic counselling

Many couples (95, 57%) received an explanation about the implications of the NTD for their family and further pregnancies. This information was given to 55 (33%) by their obstetrician, to 24 (14%) by a counsellor of a genetic advisory unit, 5 (3%) by a GP, 3 (2%) by a Pre-conception Clinic and 8 (5%) by others. For 25 (15%), a visit to the genetic advisory clinic had been arranged, but not yet

completed. 14 (8%) refused counselling and 32 (19%) had not been offered any.

Of those (95, 57%) who received counselling, 54 (57%) reported it to be helpful, 12 (13%) were doubtful. 16 (17%) could not remember anything about the session and 13 (13%) found it not helpful.

Perceptions of genetic counselling by obstetrician.

Many couples (55, 33%) received an explanation about the implications of the NTD for their family and further pregnancies by their obstetrician, 26 (47% of 55) found this helpful, 13 (24% of 55) did not remember anything that was said at the counselling session, and 9 found it not helpful and felt more confused after the session than before. The most common remarks were;

> "I would have liked more detail about NTD and how this applied to my fetus."

> "My doctor mentioned that it could happen again, no further information was offered and I was too upset to ask further questions".

> "I was told there is one in a million chance of it happening again, and there is no reason to worry. Very little information was given about NTD, I was too shy to ask".

> "I did not understand the expressions used and felt confused and rushed"

Patients reporting the counselling to be fair had similar complaints but less strongly expressed. 27 (49.% of the 55 counselled) remembered the correct risk. 14 (25% of 55) recalled an incorrect risk. 14 (25% of 55) could not recall their recurrence risk.

Perceptions of genetic counselling by genetic counsellor

Of the 24 patients who consulted a genetic counsellor, 19 (79%) found it helpful, one could not remember, 3 (13%) did not feel

happy about the session and one patient found it unhelpful (4%).

Patients remarks were

"The doctor used a lot of difficult words,and I was none the wiser after counselling."

"I found the counsellor distant".

"I did not understand about the hereditary factor of NTD".

"I found explanation given very vague".

Only two people did not remember the quoted recurrence risk.

Perceptions of genetic counselling by preconception clinic

All 3 patients were happy about their counselling session in the preconception clinic and all remembered the correct recurrence risk.

Perceptions of genetic counselling by GP

Of the 5 patients counselled by GP one found it helpful, 2 could not remember what was said to them and 2 (40%) did find it not helpful and found that not enough information was given. One patient remembered the correct recurrence risk, one remembered an incorrect recurrence risk, and 3 could not remember what they had been told.

Perceptions of genetic counselling by others.

8 patients were given information by others (midwives, health visitors, medical social worker,). 3 (38%) found it helpful, one could not remember, and 4 (50%) patients did not find it helpful. Those unhappy remarked:

"The midwife mentioned a one in five chance for it to happen again" (correct risk 1:25).

"On leaving hospital the nurse mentioned that the next baby could be another NTD", no further information given. Because of this the patient is frightened to become pregnant again.

4 patients remembered the correct recurrence risk, 3 forgot, and one remembered an incorrect risk.

PATIENT' S OVERALL ASSESSMENT OF AFTERCARE

BAD 2(1%) POOR 27(16%) AVERAGE 84(51%) GOOD 47(28%)
EXCELLENT 6(4%)

Patient's comments

When I came home I did not know what was happening to me. I would have liked to have talked to a professional person who knew all about termination for abnormality.

I felt that the medical profession had lost interest in me, the baby was terminated, so 'end of problem'. However, my problems were just starting.

I did not know when I could make love again, what was happening to my body.When could I try for another baby? Was this a birth, a miscarriage or what?

I felt that I was the only person in the world to whom this had happened.

I would have loved to have met other couples who had gone through the experience

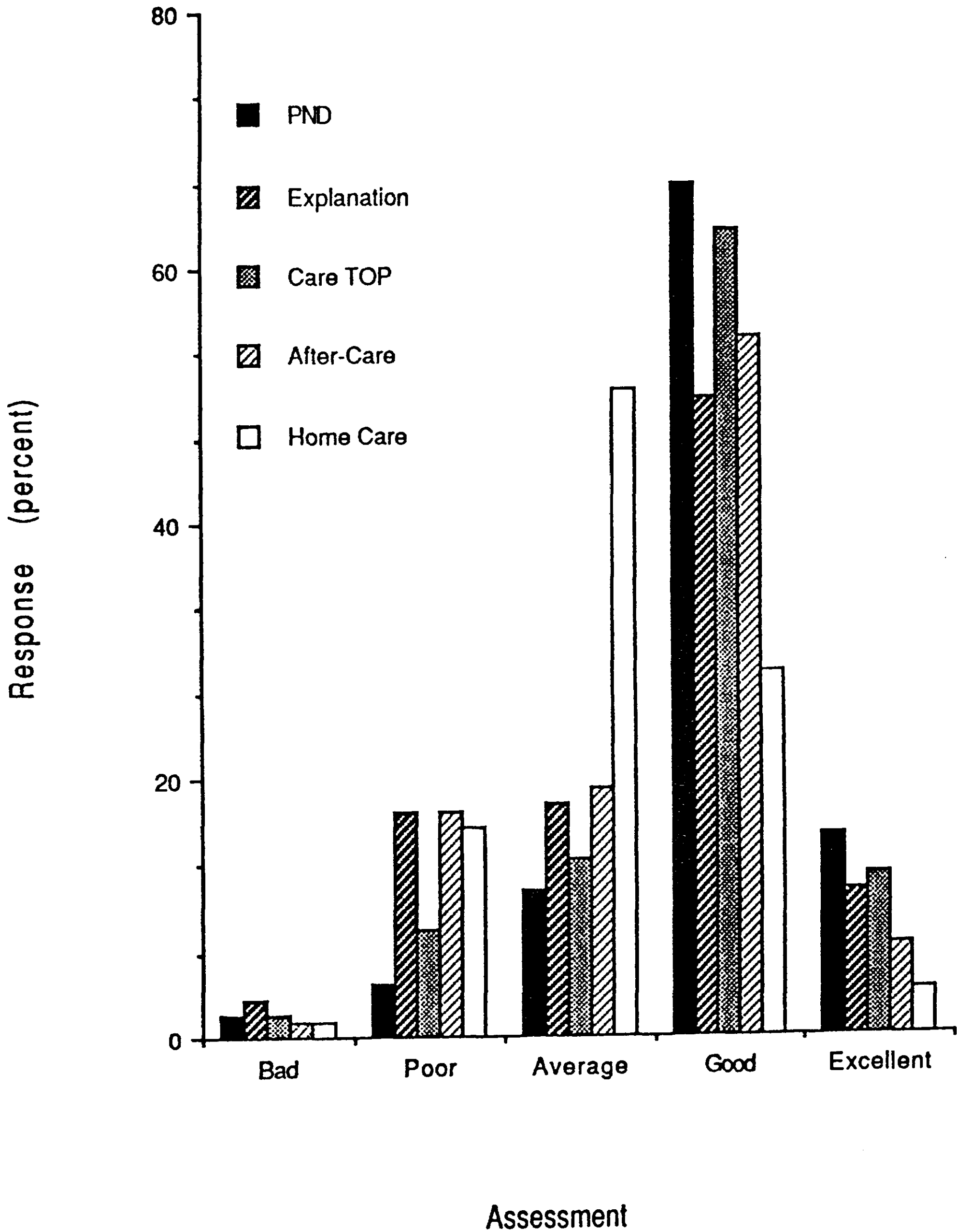


FIGURE 1 Quality of perceived care around TOP, patients overall summary.

CHAPTER 3

SEQUELAE OF TERMINATION OF PREGNANCY FOR VARIOUS FETAL ABNORMALITIES

3.1 Introduction to the Second Study and Aims

The results of the first study highlighted the importance which consultands attached to good management around TOP for NTD. The majority of consultands were satisfied with prenatal diagnosis and hospital care, although most could suggest some ideas for improvement. There was, however, general dissatisfaction with the lack of care in the post-termination period. The second study was designed; 1) to explore the factors contributing to this dissatisfaction; 2) to verify the observations in the literature about the psychosocial sequelae of this intervention; 3) to identify specific factors contributing to an adverse psychological outcome; 4) to identify vulnerable groups; and 5) to assess the effect of TOP for FA on family planning and on further reproduction.

3.2 Patients and Method

All patients who had a TOP for FA in the West of Scotland in 1986 were identified from the West of Scotland Regional Genetics Service records. The patient's date of termination was noted with; the nature of the abnormality, her date of birth, the name and address of her maternity hospital, and her hospital identification number. After obstetric consent was obtained (Appendix IIa), the appropriate records of 16 different maternity hospitals were consulted to ascertain the name and address of the patient's general practitioner (GP) to confirm the indication for, and method of, termination and to identify the obstetric sequelae. After consent was received from the GP (Appendix IIb) patients were invited to take part in the study two years after the intervention (Appendix IIc,IId) and if no objections were voiced they were visited at home or given the option to attend for a clinic appointment. 62% had already been approached at least once in connection with the Medical Research Council Randomised Clinical Trial of Folic Acid and other Vitamin Supplementation in the Prevention of Neural Tube Defects (M.R.C. Vitamin Study)

Six first trimester TOP for FA were identified in the medical genetic records, all of them having had a TOP after CVS.

However, of these six, two felt the memory of the TOP too painful to discuss, and three had moved and could not be traced. The answers of the woman who was interviewed were not included in this study.

A detailed questionnaire, with open and closed questions, was compiled and subsequently tested on 10 women (after TOP for FA). An appendix to the questionnaire was included for the partner in the relationship. This could be filled-in at the time of the visit or if completed later, returned by post in a stamped addressed envelope (supplied).

Of the 137 consultands identified, 8 couples were excluded because intrauterine death preceded TOP or the TOP did not take place in 1986. 33 (24%) women had moved and could not be traced. Of the 97 couples who were subsequently invited to take part in the study, 5 declined to be visited as they felt the subject still too painful to reflect on, 7 initially agreed to take part in the study but did not make themselves available for home or clinic appointment. Thus 84 (87% of 97) women were interviewed. 68 (78% of 84) spouses were seen, or returned the completed questionnaire. 12 medical records could not be made available thus the information of 72 records (86% of 84) was recorded.

3.2.1 The questionnaire

Research factors mentioned in Table 2 were taken into consideration during the design of this questionnaire. The questions regarding psychological adjudgement and psychosomatic symptoms were guided by the "Leeds scales for the self-assessment of anxiety and depression" (Snaith Bridge and Hamilton 1976) and "The General Health Questionnaire" (Goldberg 1972 and Goldberg & Hillier 1979) and care was taken to reduce bias associated with a bimodal response scale (Appendix III). A separate coding sheet was used to preserve confidentiality.

3.2.2 Statistical analysis

The data obtained from the medical records and the questionnaire were coded to enable computer analysis using the SPSS-X programme (Statistical Package for the Social Sciences). Frequency distributions of all the answers in the questionnaire were obtained and selected factors were cross-correlated using the Pearson

Table 2. Factors affecting the intensity and duration of depression after TOP for FA (Hollerbach 1979).

1. Desire for the pregnancy and the time it took to conceive.
2. Responsibility for the fetal disorder and the abortion decision.
3. Prior stress before and during the pregnancy.
4. The trauma of second-trimester termination.
5. Identification with the fetus.
6. Mode of inheritance.
7. Social support for the abortion decision by family and friends.
8. Social support for the abortion decision from the medical community.
9. Coercion by family,friends or medical staff.
10 Religious or moral opposition.
11 Previous emotional health and experience with the disorder.
12. Previous and subsequent experiences with amniocentesis and TOP for FA.
13 Need for counselling and the response to this need.

chi-square test of significance adjusted to small numbers. The significance level of 5% ($p<0.05$) was taken to mean that other factors are playing a part and that the deviation from the hypothesis is significant. These results are marked with an asterisk.

The answers to 20 key questions (Appendix IV) in the questionnaire (Appendix III) were cross-correlated with; 1) age, 2) religion, 3) socio-economic status, 4) prenatal diagnosis (fetal abnormalities detected via planned prenatal diagnosis, because of maternal age, previous or family history of abnormalities, or abnormalities detected via screening programmes (ultrasound or MS-AFP)).

3.3 Results

The results are divided into subsections, 3.3.1) Socio-biographical Observations and Obstetric History; 3.3.2) The Termination of Pregnancy; 3.3.3) Medical Sequelae and Management; 3.3.4) Psychological Sequelae; 3.3.5) Social and Religious Implications; 3.3.6) Reproductive Behaviour Assessed Two Years Post-TOP; and 3.3.7) Subjective Assessment Two Years Post-Termination.

3.3.1 Socio-biographical Observations and Obstetric History

Age and socio-economic status

The age and distribution of the consultands was similar to those mentioned in the Maternal and Child Health Statistics produced by the Greater Glasgow Health Board information service unit for 1985/86. The women's ages ranged from 17-46 with a median of 27, their husbands or partners ages ranged from 17-48 (median 29 years). The socio-economic status was classified using the occupation coding of the office of population censuses and surveys. Again, the socio-economic status distribution was similar to the GGHB statistics. 15% of the consultands were unemployed, mostly in social class 4 and 5.

Marital status in 1986.

4 (5% of 84) had no partner, 7 were cohabiting, one woman had obtained a divorce 4 weeks before the TOP, and the remainder were married. The duration of the marriage/cohabitation at the time of the TOP ranged from less than one year to 23 years (median 5 years)

Obstetric history

As the many different combinations of parity in the study group could be of interest when reviewing the reproductive behaviour these were illustrated in Table 3.

What pregnancy outcome preceded the TOP for FA.

For 28 (33% of 84) the terminated pregnancy was the first pregnancy, and 37 (44%) had had a previous normal live birth preceding the termination. Of those who had a negative outcome, 9 (10%) had a miscarriage, 4 (5%) a handicapped live birth, 4 (5%) a TOP for FA, 1 a TOP for "social" indication and one had experienced an intra-uterine death. There was no difference between the age groups, but a significant difference was found ($p<0.04$) in the abnormal previous outcomes in the social class 1-2 (see Table 4).

Indication for TOP

The variety of fetal abnormalities is set out in Table 5.

Previous history of TOP

Eight women had one previous second trimester TOP for NTD.

3.3.2 The Termination of Pregnancy

The termination procedure

All pregnancies in this study were in the second trimester and ranged in gestation from 14 to 26 weeks with a median of 18 weeks.

Method of termination

Nearly all pregnancies (59, 82% of the 72 hospital records available) in the 14 different hospitals were terminated using extra-amniotic prostaglandin (Pg-E2 with syntocinon infusion at a

Table 3. Obstetric history and family composition before TOP for FA.

Family composition (N-84)	Variable	%
First pregnancy	28	33
Healthy children only	27	32
Healthy children and fetal loss	8	10
Fetal loss only	4	5
Healthy children and TOP FA	3	4
Healthy children and live handicapped	2	3
Live handicapped children only	2	3
Social termination only	1	1
Healthy children and social termination	1	1
Healthy children and abnormal stillbirth	1	1
Healthy children, fetal loss, stillbirth	1	1
Healthy children, fetal loss, abnormal stillbirth and TOP for FA	1	1
Healthy children, deceased handicapped, and fetal loss	1	1
Healthy children, deceased handicapped and abnormal stillbirth	1	1
Deceased Handicapped and fetal loss	1	1
Previous TOP for FA only	1	1
Previous TOP for FA and fetal loss	1	1
Total	84	100

Table 4. The outcome of pregnancy preceding the TOP for FA: a comparison between the socio-ecomomic groups.

Outcome before TOP	Social class		
	1-2	3-3M	4-5
None	2	12	14
Normal,healthy LB	5	19	10
Handicapped LB	2	1	0
Miscarriage	2	2	5
Intra uterine death	0	1	0
TOP for FA	1	1	2
"Social" terminations	0	1	0
Total Outcomes	12	37	31
Total abnormal outcomes	5 (42%)*	6 (16%)	7 (23%)

*= $p<0.04$
LB= Live birth.

Table 5. Indication for Termination of 129 patients in the West of Scotland in 1986.

Indication	In Study (84) Number	% of 84	Refused (12) Number	Moved (33) Number	Overall (129) Number
Anencephaly	34	40%	2	13	49
Spina Bifida	25	30%	4	7	36
Trisomy 18	5	6%	0	0	5
Trisomy 21	4	5%	1	0	5
Non-immune hydrops fetalis	3	4%	0	0	3
Turner's syndrome	2	2%	0	0	2
Renal abnormalities	2	2%	0	0	2
Multiple congenital abnormalities	2	2%	0	2	4
Body stalk anomaly and Exomphalos	1	1%	1	6	8
Cystic fibrosis	1	1%	0	1	2
Duchenne muscular dystrophy	1	1%	0	0	1
Klinefelter syndrome	1	1%	1	0	2
Phenylketonuria	1	1%	0	0	1
Jarcho Levin syndrome	1	1%	0	0	1
Multiple Pterygium syndrome	1	1%	0	0	1
Others (refused)	0		3	0	3
Others (moved)	0		0	4	4
	84		12	33	129

Others (refused) = Noonan syndrome, Radioactivity exposure, Osteogenesis imperfecta

Others (moved) = 2 Rubella exposure, Congenital heart disease, Cystic hygroma

later stage. In two TOPs the application of extra-amniotic Pg-E2 was preceded by intra-amniotic urea (20% solution). One had both intra- and extra-amniotic Pg-E2 (gestation 20-24 weeks), 2 pregnancies were terminated by D&C and suction (gestation 13-14 weeks), and two women had a hysterotomy and tubal ligation, both were aged 36+.

The duration of the procedure, from inserting the catheter to the delivery of the fetus, ranged from 6 to 62 hours with a median of 15 hours, with 62% of the patients complaining of nausea or vomiting. D&Cs and hysterotomies were not included in this calculation. 39 (46% of 72) women were given a routine D&C after the termination and had been informed about this before the TOP was started. Most women had minimal bloodloss, however 8 had bloodloss of more then 200 ml and of these 4 lost between 400 and 800ml (with 2 requiring transfusion). All of these had had evacuation of retained products under general anaesthesia.

Analgesia

Pain control using drugs was most common in this study. 42 (58% of 72) received Pethidine 150 or 100mg, Diamorphine 10 and 5 mg, Omnopon 20 mg or Methadone 800mg. This was repeated 1 to 8 times during the termination procedure with a median of 2 repeats. 19 (26% of 72) women were given an epidural, and 18 (25%) used Entonox (mixture of 50% nitrous oxide and oxygen)).

How did the patients feel during the termination procedure

20 (24% of 84) said they coped well with the procedure. 24 (28%) experienced a lot of pain. They mentioned that the time between injections was too long or that the epidural only worked on one side. However there was no significant difference in strength or frequency of analgesia between those who complained of pain and those that did not. Some women were under the impression that it was advisable to keep analgesics to a minimum towards the end of the TOP, so that an anaesthetic for a D&C did not have to be delayed. They consequently suffered a lot of pain towards the end of the TOP. As in the previous study one woman refused all forms of pain control to punish herself.

48 (57% of 84) found it extremely painful emotionally and could feel the fetus moving in the early stages of the procedure.

They were very worried about the fact that the fetus may feel discomfort or pain. 38 (45%) were very frightened during the procedure. For primigravidas the labour room was unfamiliar and rather intimidating. They were frightened of disapproval from the staff and of being suddenly confronted with having to look at a fetus with frightening malformations, with which they may not be able to cope. One women was convinced that she was going to die during the termination and suffered palpitations and sweating. She did not tell the staff in case they would ridicule her. This contrasted with another woman in the study who sincerely hoped that she would not survive the procedure. There was no difference to the reaction to the TOP procedure between socio-economic status and religion. The differences between age and screened versus planned PND are set out in Table 6. Younger women (especially the 16-20 age-group) were significantly (p=0.02) more frightened during the TOP procedures then the older women. They reported unfamiliarity with the labour room and a reluctance to ask questions before and during the procedures. In general more fear was felt by the lower socioeconomic classes and those identified by SEAFP screening. Those who had a TOP after a planned PND reported coping with the procedure, more often than those who had TOP after detection by screening. The age-groups 16-20 and 40+ found it more physically painful then other groups.

<u>Were husbands/partners present during the termination procedure?</u>

50 (73% of 68) husbands/partners stayed with their wives throughout their labour. Neither husbands nor wives regretted this decision. Only 7 (10%) husbands thought it better not to be present, 4 women from this group resented being left to cope without their partner during the TOP procedure. 7 (10%) other husbands wanted to be with their wife but were not able to do so because of domestic circumstances. 4 were sent away by hospital staff or their wife or could not bear to see their wife go through a labour for nothing.

<u>Should the couple see the fetus?</u>

16 (20% of 80 women who had a Pg termination) and 18 (26% of 68) husbands or partners saw their fetus. One fetus was born alive and lived for 10 minutes while the parents held it. One woman (gestation 20 weeks) was frightened when the baby was shown to her;

Table 6. The experience of the TOP procedure; differences between groups.

Number (Percentage)		Coped	Physical Pain	Emotional Pain	Frightened
All patients:	84	20 (24)	24 (28)	48 (57)	38 (45)
Age:					
16-20	5	1 (20)	4 (80)	4 (80)	* 4 (80)
21-35	66	17 (25)	13 (47)	36 (55)	34 (52)
36-39	10	2 (25)	3 (37)	5 (62)	0
40+	5	0	4 (80)	3 (60)	0
Social Class;					
1-2	12	5 (42)	6 (60)	7 (58)	2 (20)
3-3M	37	9 (24)	12 (30)	24 (64)	18 (49)
4-5	31	6 (19)	6 (19)	17 (54)	18 (58)
Prenatal diagnosis:					
Planned	20	7 (45)	5 (20)	6 (30)	2 (10)
Screen	65	13 (20)	19 (29)	42 (65)	36 (55)

*= $p<0.02$. Screen = FA identified by screening programme
As four answers could be given to this questions percentages do not total 100.

she wanted to touch it but did not like the exposed abdomen (exomphalos). Reflecting on it two years later, none regretted looking at the fetus.

Of the 68 (85% of 80) of the women who did not look, 23 were too frightened, 16 thought it was easier to come to terms with the termination if they did not look, 15 reported that no suggestion was made about seeing the fetus and were embarrassed to ask, 9 were advised by medical staff not to look, one was too drowsy to look and one husband objected to his wife seeing the fetus. After two years 38 (55% of 68) women and 10 (20% of 50) men ,who had not looked wished that they had seen the fetus. For 71% of the women the decision whether or not to see the fetus was what they wanted at the time. However, for 21 (25%) it was not. None of the 4 patients who had a TOP for Down's syndrome wanted to see the fetus, and none regretted this two years later.

Table 7 illustrates the significant difference between the groups. Younger women ($p<0.03$), those detected by screening, and Roman Catholic men ($p<0.04$) intensely regretted not looking at the fetus.

10 (13% of 80) women were given a photograph of the fetus, and on reflection were delighted to have this but a few complained about the very bad quality of the picture. 25 (30%) did not want a reminder of the fetus. 49 (58% of 84) would have liked a photo to be kept in their medical records, so that they could ask to see it when they were ready for it. The 4 women who knew that there is one kept in the medical record felt reassured by this.

<u>Complications and unplanned procedures</u>

Procedures which had not been recorded as planned before the termination, were considered. 14 (19% of 72) had retained placenta and a manual removal under general anaesthetic or epidural, 2 had evacuation and removal of products of conception and 3 women were given a blood transfusion. There was no correlation between method of termination and complications in this study.

<u>Confirmation of fetal condition</u>

The fetal condition was confirmed for 64 (88% of 72). The information was impossible to find in 8 records. 15 (23% of 64)

Table 7. Who did not see the fetus after the delivery, and regretted this two years later?

Consultands		Did not see fetus				Regret not # seeing fetus				Doubt about not # seeing fetus			
		F	(%)	M	(%)	F	(%)	M	(%)	F	(%)	M	(%)
Total (each section)	F 84 M 68	68	(81)	50	(73)	38	(56)	10	(2)	6	(9)	6	(12)
Age:													
16-20	F 5 M 5	5	(100)	5	(100)	4 *	(80)	0		0		0	
21-35	F 66 M 53	50	(60)	39	(74)	32	(64)	9	(23)	4	(8)	6	(15)
36-39	F 8 M 5	8	(100)	4	(80)	1	(12)	0		1	(12)	0	
40+	F 5 M 2	5	(100)	2	(100)	1	(12)	1		1	(20)	0	
Social Class:													
1-2	F 12 M 8	10	(83)	7	(88)	5	(50)	1	(14)	0		1	(12)
3-3M	F 37 M 32	31	(84)	23	(72)	17	(54)	3	(9)	2	(6)	3	(9)
4-5	F 31 M 28	27	(87)	20	(71)	11	(41)	6	(30)	1	(4)	2	(10)
Religion:													
Ch of Sc	F 53 M 41	44	(83)	32	(78)	20	(45)	2	(6)	3	(7)	5	(15)
R.C	F 25 M 19	22	(88)	18	(94)	14	(64)	6	(33)	1	(4)	1	(6)
Prenatal Diagnosis:													
Planned	F 20 M 14	16	(80)	11	(79)	6	(38)	1	(9)	0			
Screen	F 64 M 55	52	(81)	39	(72)	32	(62)	10	(19)	6	(12)	6	(20)

PND=Prenatal diagnosis, Ch of Sc =Church of Scotland
RC =Roman Catholic, Screen=Selected by screening programme
*=p<0.04, M =Male, F =Female, # = % is of those who did not see the fetus

fetuses had added complications such as spina bifida as well as the diagnosed severe hydrocephalus,and vice versa. 33 (52% of 64) conditions were confirmed by a report from Medical Genetics, and 61 (95% of 64) by post-mortem report (PM). The gestations of the pregnancies were confirmed to be between 9-27 weeks, with a medium of 19 weeks.

3.3.3 Medical Sequelae and Management

Post termination complications

3 (4% of 72) patients haemorrhaged, two before discharge, and one was readmitted via the "flying squad" 2 days after discharge from hospital. 6 patients went to see their GP complaining of heavy bleeding but did not need intervention. 5 had retained placental tissue on leaving hospital two patients has to be readmitted.

Time in hospital

The women spent between 1 and 15 nights in hospital around the TOP procedure. The majority of patients (48, 66% of 72) stayed from 2 to 3 nights. Those longer in hospital had been admitted before the termination with antenatal problems or their stay was extended for treatment of conditions not related to the termination e.g. badly controlled diabetes.

Was the GP informed about the termination?

Letters with a full explanation were sent to 59 (81% of 72) patients. The dates on the letters varied from 1 to 60 days after the termination (median 6 days). Communication by telephone was only recorded in one medical record.

Who was the first person to see the patient at home in the first three weeks after return from hospital?

Twenty-nine women (34% of 84) were visited by their GP, 75% of whom had been alerted by the hospital staff, and 17% visited after a request from the patient herself. 11 (13%) were visited by a health visitor or midwife, of whom 6 (7%) were referred by the GP. Two were seen by a midwifery sister from Medical Genetics. Patients were seen between day one and day 21 after

discharge from hospital (median 2 days). This left 41 (48%) who were not contacted at all. 16 (19% of 84) contacted their GPs themselves. Of all the women interviewed 17 (20% of 84) did not particularly want a visit, 20 (23%) were not sure, but 47 (56%) would have liked a visit for advice and support. 17 (20% of 84) women reported that their GP seemed unaware that the termination had taken place which led to some embarrassing consultations.

The post termination appointment.

Fifty-eight (69% of 84) women had, and attended for, a post-termination appointment; 55% with their obstetrician, 31% with their GP, 10% with another hospital doctor, and 3% with the pre-conception clinic. Of these 4 women had not been given an appointment but made their own arrangements. Women liked the opportunity to discuss the condition of the fetus, to be given reassurance that their body had not been adversely affected by the termination procedure, and a discussion about future pregnancies. The first visit back to the hospital was experienced as painful, especially if the clinic appointment was made at the same time as an antenatal clinic with pregnant women.

Nine patients were invited to an appointment but did not attend. The reasons given were lethargy or reluctance to go back to the maternity hospital. 17 (20% of 84) were not invited and thought that since they did not deliver a full term baby, they could not ask for a postnatal appointment.

During the appointment, the post-mortem (PM) report was discussed with 31 (53% of the 58 who attended). All couples appreciated this. One couple received a copy of the PM report, with explanatory notes in the margin, by post; they found the details of the multicongenital malformations confusing and distressing and would have preferred it if the report had been sent to their GP.

Who gave family planning advice

Family planning advice was given to 51 (60% of 84). The advice was given by the GP (52%), by the obstetrician (31%), the family planning clinic (8%) and by a combination of people (e.g. medical social worker and preconception clinic). 29 (36%) did not receive and did not ask for family planning advice; 19 of these would

have liked a discussion on the subject.

The physical implication after a TOP for FA

Women reported intermittent bleeding or staining unlike a normal menstruation pattern from 3 to 69 days (median 14 days). 15 (17% of 84) presented with complaints lasting longer then 3 weeks. In general, periods returned in 6-8 weeks. 51 (60% of 84) experienced engorgement and lactation which lasted about 5 days. Of the 21 (41% of 51) who sought professional advice, 14 (66%) were given painkillers or diuretics, the remainder were given advice. Of those 7 (13% of 51) who looked for advice given by relations or friends, 2 were given advice which made the engorgement worse or prolonged the lactation.

Was the recurrence risk and,or genetic implications mentioned?

The obstetrician counselled 29 (34% of 84) consultands. The others were advised by the NTD researcher (22, 26%), a genetic counsellor (14, 17%), GP (6, 7%), preconception clinic (4, 5%), and two by medical social worker and midwife. 4 were not counselled at all.

45 (56% of 80) found the detailed information and reassurance that they had not caused the FA to be the most helpful aspect. For 15 (19% of 80), the information about the recurrence risk and the management of the next pregnancy was helpful. 18 (22% of 80) felt the counselling session unhelpful. Some felt that the counsellor was merely interested in their medical history, not in what they felt and how they coped. This prevented them from concentrating. 29 (35%) couples had not been offered genetic counselling in a genetic clinic and of these, 11 (13%) would have liked to be referred. Couples were counselled from one day to 52 weeks after the TOP with a median of 5 weeks. Most consultands stated a preference for 6-8 weeks.

3.3.4 Psychological Sequelae

How did the woman feel about the pregnancy?

Most (60, 72% of 84) pregnancies were planned and welcome. One woman planned the pregnancy but felt ambiguous when her pregnancy

test was positive. 22 (26%) did not plan the pregnancy but it was welcome; of these two single young girls considered an abortion but decided against it. Two (2%) still felt ambiguous in their second trimester; both felt very guilty for a long time.

How did the woman relate to the fetus?

56 (66% of 84) thought of the fetus as a baby who had a place in the family, they fantasized about the future and in some cases talked to their unborn child. 24 (27%) had tried not to let themselves get too involved in the pregnancy. This group included the women who had a previous termination for FA. Four women were reluctant to recall their feelings. 50 (59%) of the women had been aware of fetal movements before the TOP but they did not fantasize significantly more about the fetus then those who had not been aware of movements.

Before a decision was made were the husbands given enough information?

43 (63% of 68) of the husbands had an explanation and an opportunity to discuss the diagnosis with the obstetrician. 4 (6%) with the ultrasonographer, and 2 (3%) with the family doctor, but 18 (26%) only discussed the information with their wife or partner (one answer missing). Subsequently, 39 (57%) husbands felt that they got enough information before making a decision, 6 (9%) were not sure, and 20 (29%) husbands felt that they did not get sufficient information. The main comments of those who saw professionals were that the doctor's unfamiliar accent or the words used, were not easy to understand,

Who took the final decision to terminate the pregnancy?

44 (52% of 84) couples made the decision together, 13 (16%) husbands left the decision to their wives. 4 (5%) of the husbands or partners made the final decision, and 5 husbands were against the termination but felt strongly that they should support their wife in her decision. 18 (21%) of the couples preferred not to answer the question. There was no correlation with age.

<u>How did the couples feel about their decision to abort at the time of the termination and on reflection two years later ?</u>

43 (51%) felt sad but confident about their decision; some representative comments were:

"I wanted the baby so much but I did not want it to suffer in the short time that it would be likely to live";

"It was the most difficult decision in our lives; the baby moved so much. We might have been able to cope with a mentally handicapped child, but who would take over when we are old or died before him, and who would cuddle, hug and hold our 40 year old baby then? It would not be fair on him." (Trisomy 21).

"The doctor said that it was not going to live and I could have a miscarriage at any time; there seemed no point in going on." (anencephaly)

"I sat by my baby's cot and hoped and prayed that she would live, she did not. I could not go through that again." (NTD)

"May be I should have tried, but I could not cope with another handicapped child." (CF)

Of the remaining women, 5 (6% of 84) could not remember what they felt and 36 (42%) felt ambiguous and unsure about their decision in spite of having given consent. When asked for a further explanation, 18 (50% of 36) said that they felt numb and could not believe that this could happen to them so the decision was made about an event which felt unreal. 10 (28% of 36) wondered if the doctors could have made a wrong diagnosis. One woman was confused because she was first totally reassured about the normality of the pregnancy by the staff in one hospital, but was told a very different story in a second hospital the next day. 3 (8%) had strong moral doubts about the termination and 5 (13%) could not explain their reservations.

How did the couple feel about the decision to terminate at the time of interview?

Two years after the TOP for FA, 2 (2% of 84) women and 3 (4% of 68) men still regretted the TOP, 75 (89%) women and 56 (82%) men had no regrets and felt that they made the right decision at the time. 2 women and 4 men were not sure. There were 4 husband answers missing. Table 8 shows the difference between the age, socio-economic status and the PND groups. 100% of the 16-20 age-group (5 couples) felt unsure about the decision to terminate at the time or after the TOP ($p<0.04$). More in the planned PND group (70%) then the screened group (45%), felt sure about the TOP. The same was observed between social class 1-2 (75%) and social class 3-3M, (46%) 4-5 (45%). The women who regretted the TOP were age 21-39, social class 3-5 and the FA detected by screening. The numbers of those regretting after two years was too small to be of statistical significance.

Would couples agree to a TOP again under similar circumstances?

If faced with a similar situation, only 3 men would refuse to consider terminating the pregnancy again (none of their partners felt the same way), and 7 women and 2 men were unsure on what their decision would be. The question was not answered by 4 men. The differences between the various groups are set out in Table 9.

Emotions

Couples were asked to recall the strength of their feelings where they had answered "more then usual" or "much more then usual", and requested to recall for how long they experienced these feelings. All had a combination of emotions. The frequency of the reported emotions was noted for both partners, including the numbers of those who still felt them more than 12 months later (12+). As feelings may mean different things to different people, the most representative comments were mentioned.

1) Anger was felt by 78% of the women interviewed, this lasting for 28% more than 12 months (28% 12+) It was felt by 33% (6% 12+) of their partners. Comments were:
"I am so angry that this had to happen to my child, life seems

Table 8. Feelings regarding decision to terminate the pregnancy, at the time and after two years.

		Around Procedure						After Two Years					
		Sure		Not sure		Do not know		Sure		Not sure		Do not know	
		n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Total	84	43	(51)	36	(42)	5	(6)	75	(89)	2	(2)	2	(2)
										P- =2		P- =2	
Age:													
16-20	5	0		*5	(100)	0		4	(80)	0		0	
21-35	66	35	(53)	27	(40)	5	(7)	62	(93)	1	(3)	1	(3)
36-39	8	5	(62)	3	(37)	0		5	(62)	1	(12)	1	(12)
40+	5	4	(80)	1	(20)	0		4	(80)	0		0	
Social Class:													
1-2	12	9	(75)	3	(25)	0		12	(100)	0		0	
3-3M	37	17	(46)	17	(46)	3	(81)	34	(92)	1	(3)	2	(6)
4-5	31	14	(45)	16	(52)	1	(3)	30	(97)	1	(3)	0	
Religion:													
Ch of Sc	53	31	(58)	21	(40)	1	(2)	50	(94)	1	(2)	2	(4)
R.C	25	10	(40)	11	(40)%	4	(16)	24	(96)	1	(4)	0	
Prenatal diagnosis:													
Planned	20	14	(70)	6	(30)	0		17	(85)	0		3	(15)
Screen	64	29	(45)	30	(56)	0		59	(92)	2	(3)	3	(5)

F= female Ch of Sc = Church of Scotland RC = Roman Catholic
Screen=Selected by screening programme

Table 9. Would consultands terminate again if the same abnormality was found in a future pregnancy?

Consultands	Number F	Number M	Yes TOP F n	Yes TOP F %	Yes TOP M n	Yes TOP M %	No TOP F n	No TOP F	No TOP M n	No TOP M %	Do not know TOP F n	Do not know TOP F %	Do not know TOP M n	Do not know TOP M %
Total	84	68	77	92 %	63	93%	0	0	3	4%(P- =3)	7	8%(P-=6)	2	3%(P-=1)
Age:														
16-20	5	5	3	60%	4	80%	0	0	0	0	2	40%(P-=2)	1	20%(P-=1)
21-35	66	53	63	95%	49	92%	0	0	3	6%(P- =3)	3	5%(P-=3)	0	0
36-39	8	7	6	75%	7	100%	0	0	0	0	2	25%(P-=1)	0	0
40+	5	8	5	100%	7	87%	0	0	0	0	0	0	1	13%(P+=1)
Social Class:														
1-2	12	8	11	92%	6	75%	0	0	1	13%(P- =1)	1	8%(P+=1)	1	13%(P+=1)
3-3M	37	32	35	95%	30	94%	0	0	2	6%(P- =2)	2	5%(P-=2)	0	0
4-5	31	28	29	93%	27	96%	0	0	0	0	3	7%(P-=3)	1	4%(P-=1)
Religion:														
Ch of Sc	53	41	49	92%	37	90%	0	0	3	5%(P- =3)	4	8%(P-=3)	1	2%(P+=1)
RC	25	19	23	92%	18	95%	0	0	0	0	2	8%(P-=2)	1	5%(P-=1)
Prenatal Diagnosis:														
Planned	20	14	17	85%	12	86%	0	0	1	5%	3	15%	1	7%
Screen	64	54	60	94%	51	94%	0	0	2	7%	4	6%	1	2%

F= female M= male Ch of Sc = Church of Scotland RC = Roman Catholic
Screen=Selected by screening programme
P+ = Couples agree. P- = Couples disagree.

to be so unfair"

"Why did I have to make such a decision, nobody understood how difficult this was. It is easy to have theoretical views about abortion " .

"I was angry with all the people who mistreat their children or complain that they did not get a boy or a girl".

"I was angry with my husband, because I thought he failed me when I needed him."

2) Depression was felt by 79% of women, (21% 12+) and 47% of men (3% 12+). Comment:

"I had no interest in anything, and was tired, empty and broken. I did not want to go out because I could not bear the sight of other mothers or having to explain to anyone why I was not pregnant anymore. I wished that I could sleep all the time so that I did not have to bother with anything. Sometimes I still feel this."

One husband found that he could not concentrate at work, every thing seemed a problem and he could not even bother seeing his friends. He drank more alcohol but usually alone.

3) Guilt was felt by 68% of the women (38% 12+) and 22% of the men (7% 12+). Comment:

"I wondered what I had done wrong and wondered if the baby's abnormality was my fault".

A father mentioned that since the TOP of his trisomy 21 fetus he notices Down's Syndrome children and adults everywhere and feels grateful and guilty about the decision at the same time.

4) Relief was experienced by 30% of women (16% 12+), 32% of men (16% 12+) Comment:

"The initial relief I felt was when the termination was behind me but that was only a short time."

A father was grateful that his "child" was saved a lot of suffering and his wife was not having to face the physical and emotional burden

5) Shame was felt by 40% of the women (28% 12+), and 9% of the men (5% 12+). Comment:
"I felt shame about the word abortion, I never thought that I would be associated with it as I was a member of SPUC (the Society for the Protection of the Unborn Child) and very much against abortion".

6) Fear was mentioned by 77% of the women (53% 12+) and 37% of the men (24% 12+). Comment:
"My greatest fear is that it may happen again and we will have to repeat the whole decision making process with all the consequences."

7) Sadness felt by 95% of women (65% 12+) and 85% of the men (48% 12+). Comment:
"I never realised how much it would hurt to lose this pregnancy, the feeling of emptiness is like a big black hole; similar to a bereavement I suppose. I have done so much crying; Just when I think that I am coping again, I meet someone who was due at the same time, with her new baby and the whole thing starts all over again."

A father said;" I could not look at other peoples babies or men playing with their children, that parent could have been me. It broke my heart to see my wife hurting so much when there was nothing that I could do about it."

8) Failure was experienced by 61% of the women (29% 12+) and 26% of the men (16% 12+). Comment:
"I felt a failure because all my sisters and brothers produced healthy normal children: even this I could not get right. I felt I had failed the baby by not having been able to protect it from this. I feel so underconfident now in many areas of my life."

9) Vulnerability was only mentioned by 35% (18% 12+) of the women and not at all by men. Comment:
"I thought if this could happen to me, what other mishaps are in store for me or my children. I feel so negative at times."

10) Isolation was experienced by 27% of the women (13% 12+) and 20% of the men (9% 12+). Comment:
"Some times even being with neighbours and colleagues I feel so lonely; everybody is trying to do their best, but how could they understand what it felt like to lose a baby in this way? Even my family would rather not talk about it now. They feel that it is all behind me and life must go on but they don't recognise that I am still hurting so badly."

11) Numbness was reported by 23% of the women (none at 12+) and by no men. Comment:
"They all told me that crying would help but I just could not do it. It was like being wrapped in cotton-wool, everything was dull and unreal. I knew what was going on but I could not feel anything. They must have thought me so hard and cold in the hospital. When the numbness vanished I could not stop crying."

12) Panic spells were experienced only by 20% of the women (9% 12+) but not by men. Comments:
"Panic would suddenly come over me, my heart started racing and I felt all sweaty. It could happen at home while watching TV, or when my husband was out. I had to get out of the house in that case. It could happen in the street or in the supermarket. There was no particular trigger for it. It was very frightening."
"I need the light on all night long, because I get these horrible nightmares about a baby without a head chasing me."

13) Feeling withdrawn was only reported by men (32% it lasted 12+ for 13%). Comment:
"I did not want to talk about it or dwell on it. I found it too upsetting; I just wanted to be left alone and get on with life."

14) Feeling left-out was felt by 12% of the men (none at 12+), not by women. Comment:
"Everyone asked how the wife felt but nobody seem to consider

> that I had feelings too. Even when things went wrong the obstetrician only explained things to my wife and her mother and by the time I came home from work (they did not want to worry me) they had already decided to terminate my baby whom I had felt kicking against my back the night before. I felt so angry and redundant"

Figures 2 and 3 deal with the frequency and duration of the feelings and underlines the fact that many women still have intense feelings of; anger, guilt, shame, fear, failure and sadness two years after the TOP for FA.

Somatic complaints

At the same time as coping with the above feelings, many couples displayed somatic symptoms. Of these, sleeplessness, listlessness, loss of concentration, irritability, and crying were the most frequently mentioned.

Nightmares were only reported by women in the age-group 16-34. They took the form of persecution; in these dreams people came to take the woman's baby away and in spite of trying to run, the pursuers succeeded. In another dream the main theme was blame; the baby or family members would appear in the dream and accuse the woman of murder. Some went through the termination procedure night after night in their dreams, continuing intermittently up to a year after the termination. The time-span over which couples experienced these complaints was set out in Figures 4 and 5.

Correlation between feelings, somatic complaints and age, socio-economic status, planned PND and screened consultands. lasting 12 months or more.

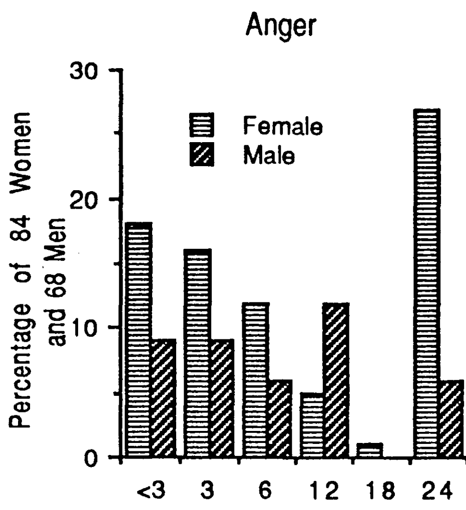
Table 10 reflects the significant differences in feelings and somatic complaints between the age-groups. It was interesting to note that palpitations, panic attacks and nightmares were only reported by the 16-35 age group in social classes 3 to 5. This was the same group who complained of the inability to "find the words" to express their feeings. Although there were some small differences between the other groups they were did not reach statistical significance. Relief at not having a handicapped child was slightly

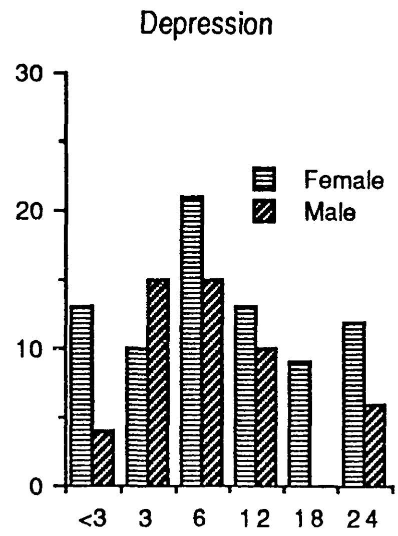
Table 10. Correlation between age and emotions or somatic complaints lasting longer then 12-24 months after the TOP for FA

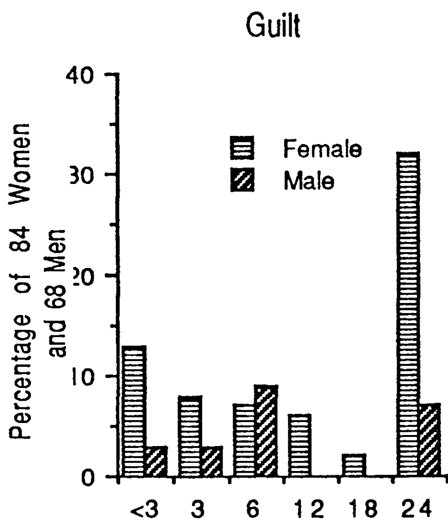
Female Complaint	Agegroup Number	16-20 5	21-35 66	36-39 8	40+ 5
Depression		*3 60%	24 36%	2 25%	0
Crying		*4 80%	28 42%	3 37%	0
Irritable		3 60%	24 36%	1 12%	0
Anger		3 60%	16 24%	1 12%	0
Guilt		3 60%	21 31%	2 25%	1 20%

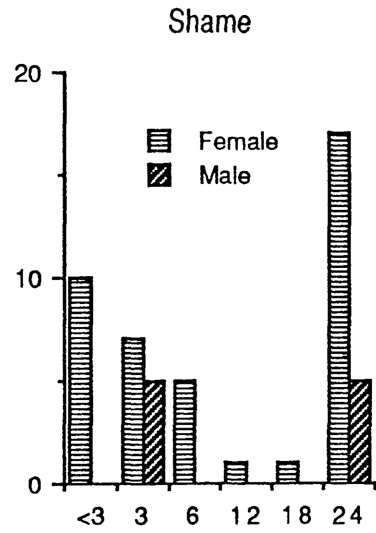
Males Feeling	Agegroup Number	16-20 5	21-25 53	36-39 6	40+ 2
Relief		*2 36%	8 13%	1 12%	0

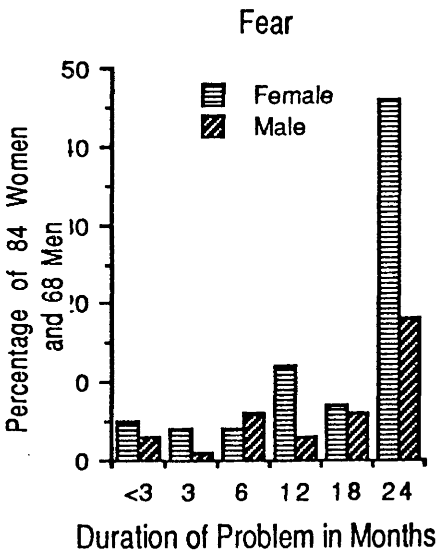
* = $p<0.04$











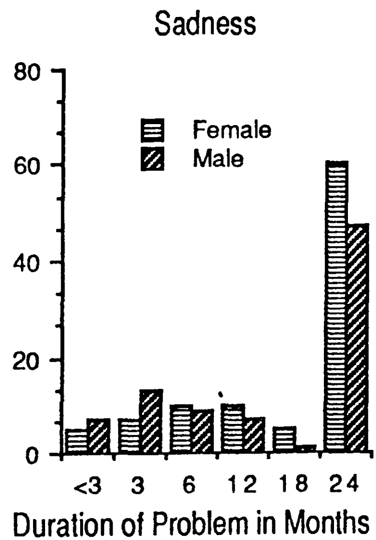
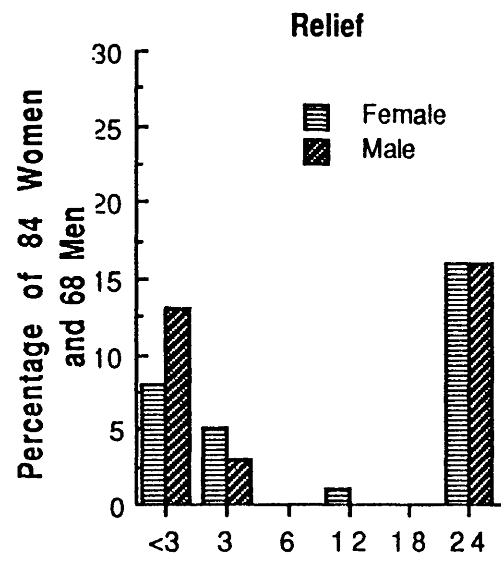
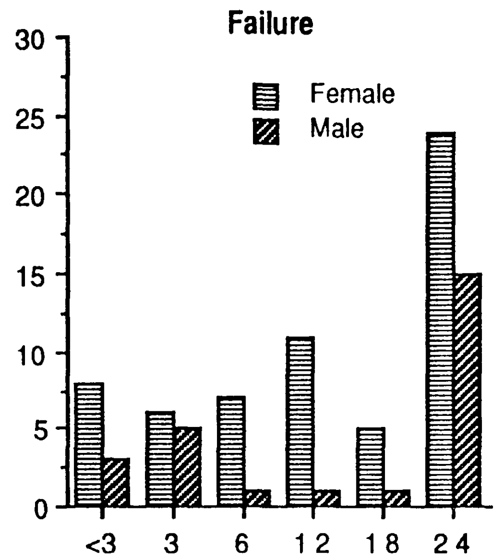
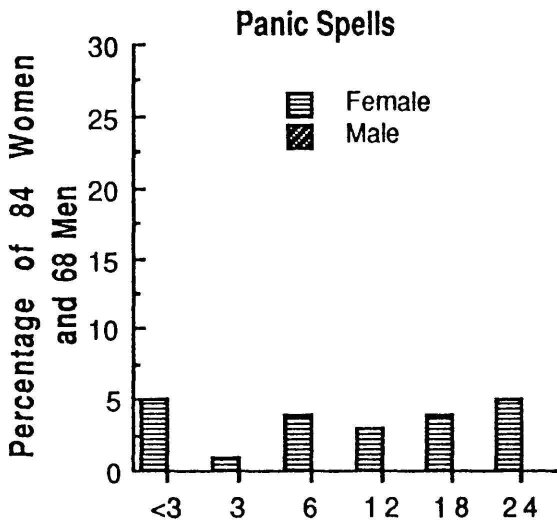
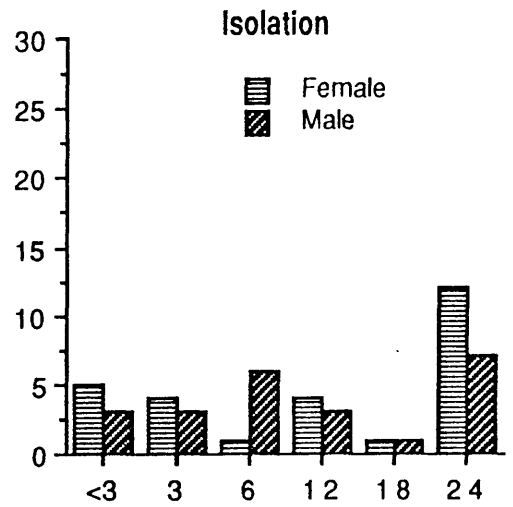


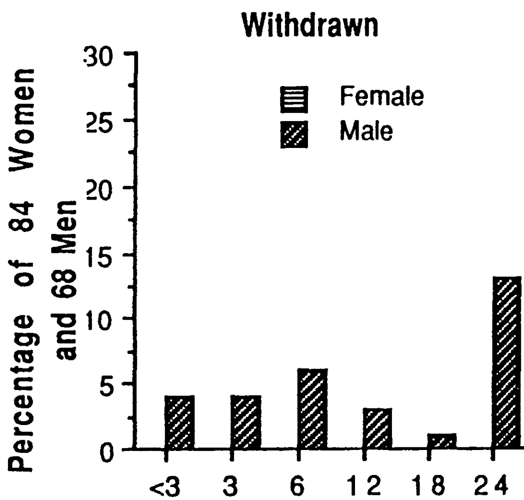
FIGURE 2 Duration of emotional feelings in months.











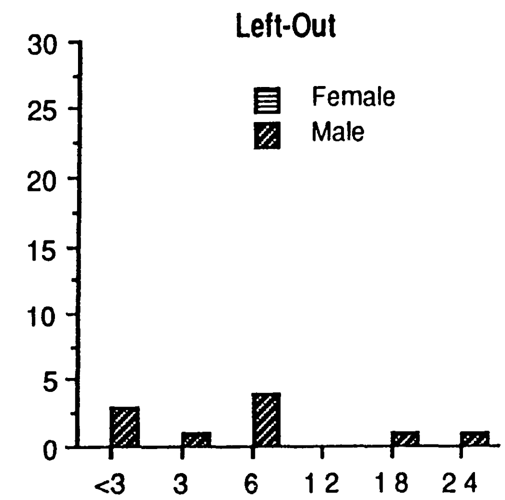
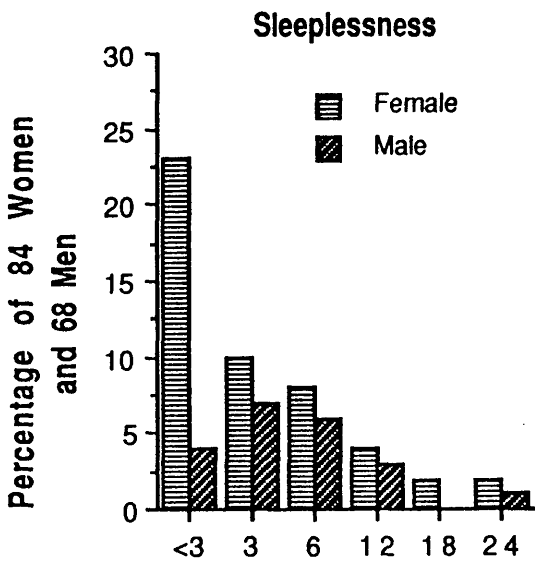
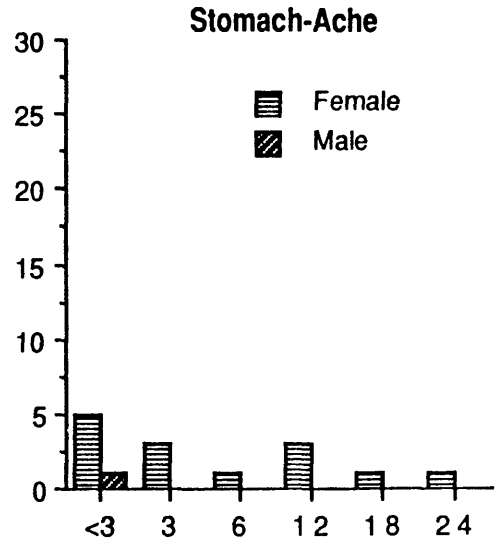
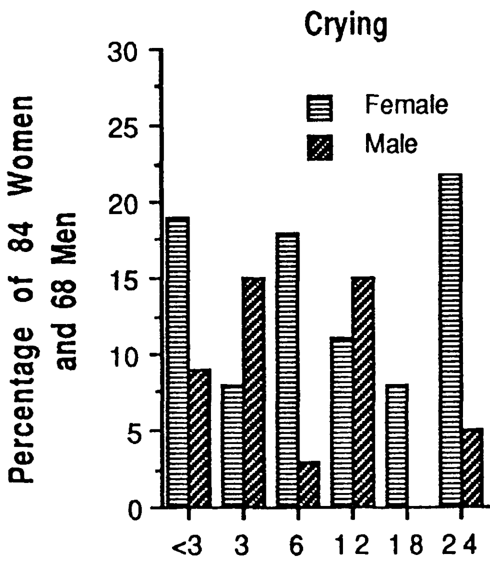
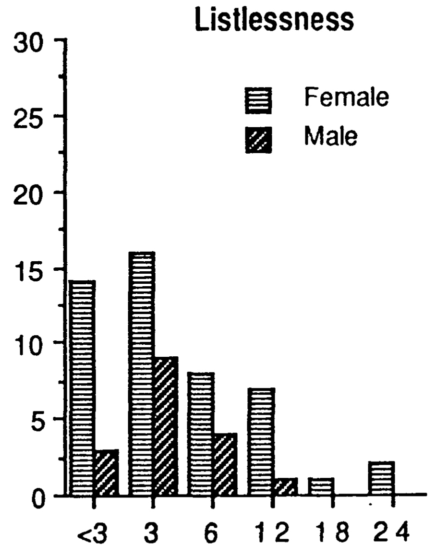


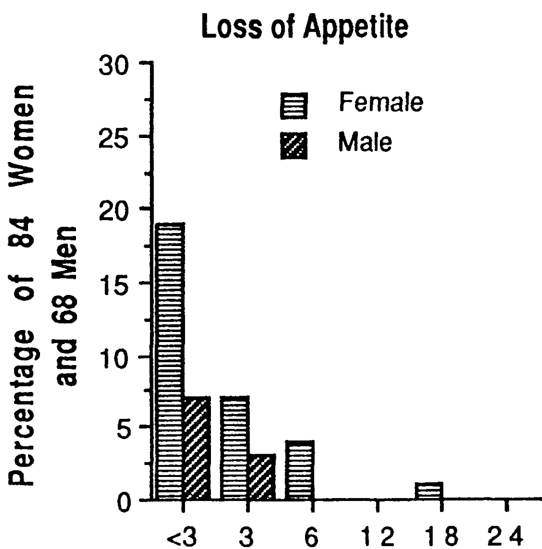
FIGURE 3 Duration of emotional feelings in months.











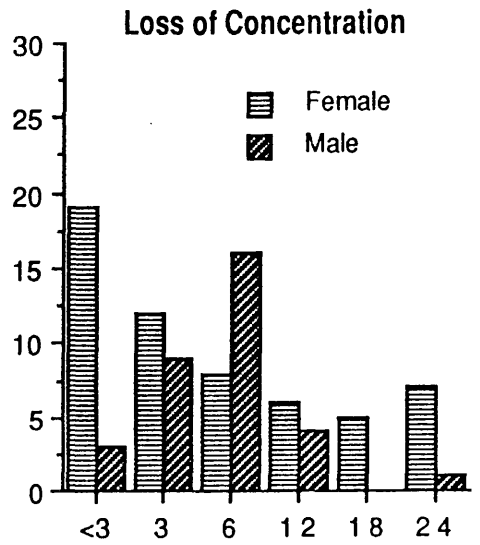
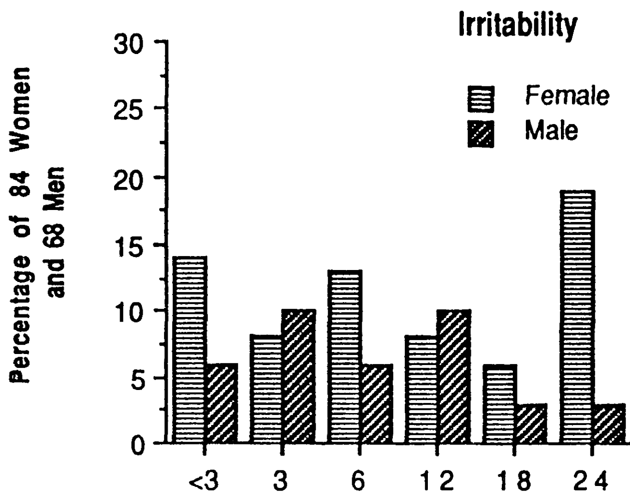
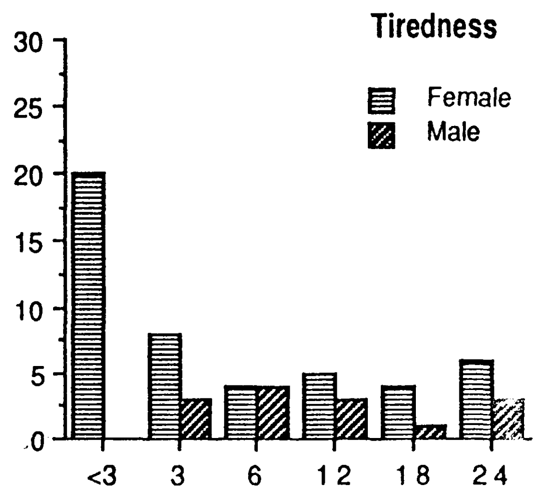
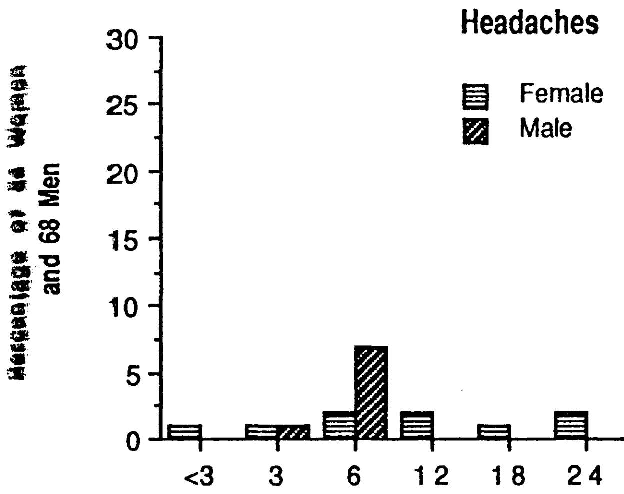
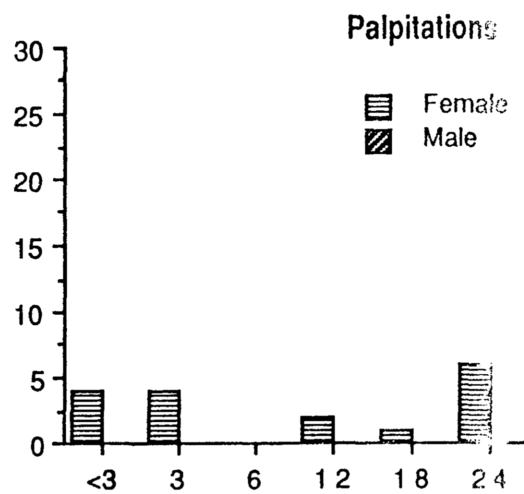


FIGURE 4 Duration of somatic complaints in months.









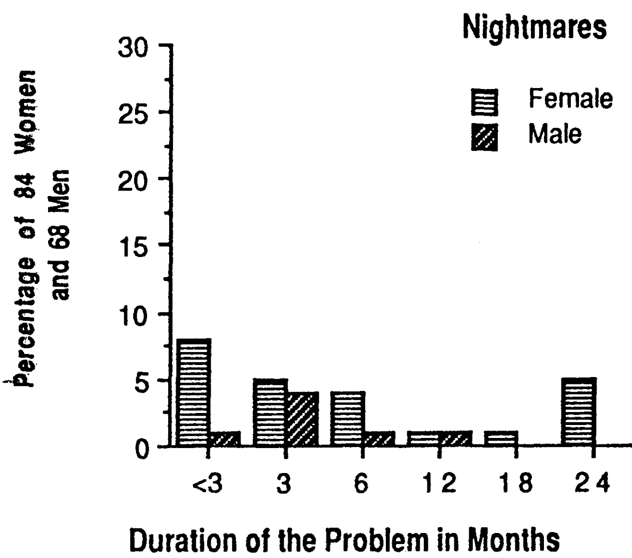


FIGURE 5 Duration of somatic complaints in months.

more frequent in the 40+ age-group and social class 1-2.

Did the couple discuss their complaints and their feelings with any one?

46 (55% of 84, 4 answers missing) of the women and 40 (58% of 68, 7 answers missing) men did not discuss their complaints or feelings with any one at all . 16 (19%) women and 14 (20%)men only discussed them with their partner, 16 (19%) women and 4 (6%) men talked about it with their GP, and 2 (2%) women and 1 (1%) man talked to a friend, one man went to a clergyman and one man talked to his psychiatrist.

What help was given?

Of the 34 women who discussed their problems 19 (56% of 34) felt they received adequate help. 11 received it in the form of counselling, 5 were given antidepressants or sleeping-tablets (3 were offered anti-depressants but refused as they were frightened of dependency). Treatments lasted from 1 to 52 weeks (median 4 weeks). One woman was admitted to a psychiatric unit for 2.5 weeks; she had had a very unfortunate obstetric history with repeated fetal loss.

Of the 21 men who discussed their problems, 6 felt they received help of whom 3 were counselled, 2 were given valium and one received largactil and anti-depressants. The last was treated in a psychiatric unit for 3 months, he had no history of psychiatric illness before the termination but at the time of the TOP, he lost his job and a friend died suddenly.

Why did the couples not discuss their feeling or problems?

18 (39% of 46) women did not want to bother anyone with their problems. People did ask how they felt, but they found it easier to say "fine", and nobody asked further questions. 9 (20%) women were frightened of other people's reaction to the TOP. 8 (17%) women and 2 (5% of 40) men felt that this was not a medical problem and so there was no point in discussing it with a doctor or obstetrician. This was more often mentioned in the over 36 age-group and social class 1-2. 7 (15%) women and 6 (15%) men thought no-one would be interested in the way they felt. One husband explained that he would be delighted to have talked but no-one asked him! 4 (8%)

women and 11 (27%) men could not "find the words" to talk about it. This was only mentioned by the 16-25 age group and social class 4-5. 2 (4%) women were frightened that they would be put in a psychiatric hospital or put on addictive drugs if they told anyone about their feelings. One woman did not want to appear an hypochondriac and 1 (2%) woman and 19 (48%) men felt that they did not need any help from anyone. 9 (22%) men felt that their wives were more important and that their own feelings and reactions were not significant. 8 men, 20%, did not answer the question.

3.3.5 Social and Religious Implications

Pre-Termination Stress

40% of the couples experienced stressful life events before and after the TOP for FA, ranging from bereavement (which was recorded if the couple felt moved or disturbed by the death) to job loss, marriage and financial difficulties.

Social classes 4 and 5 experienced more stressful life events (48% of 31) than social classes 3 and 3M (39% of 37) and social classes 1-2 (33% of 12) Those women who admitted to have coped badly with a previous bereavement took much longer to come to terms with the TOP for FA.

Social support

Table 11 illustrates by whom the woman felt herself supported after the TOP and what aspect of this support was most important to her. Table 12 explores the frictions which were perceived after the TOP and their causes. 16-20 year olds and social class 4-5 complained of an indifferent attitude and insensitivity from their GP and at their post natal visit. Social class 1-2 and the 36+ age group found the opposite.

Did the husband understand his wife's reactions after the termination?

Most 39 (46% of 68) men understood their partner's reactions after the termination, but two said they could not cope with her irritability. 5 (6%) only understood in the first 6 months but got impatient with her sadness after this time as they believed

Table 11. Who gave support and what was the most positive aspect of this support?

Supported by:	Number	Percent	Aspects	Number	Support provided
Close relatives	68	81%	Understanding	19	30%
			Close contact	18	26%
Friends	50	59%	Good listening	23	46%
			Thoughtfulness	12	24%
General practitioner	35	41%	Good Listening	13	37%
			Understanding	3	8%
Colleagues	14	17%	Thoughtfulness	9	64%
			Understanding	2	14%
HV/MW/DN	12	14%	Good Listening	7	58%
			Understanding	3	25%
Other women who had TOP for FA	10	12%	Understanding	10	100%
Church/Religious group	8	9%	Spiritual support	3	37%
			Good Listening	3	37%
Neighbours	7	8%	Understanding	2	29%
			Thoughtfulness	2	29 %

Only the two most frequent aspects mentioned by consutands are reported in this table. HV/MW/DN. = Health Visitor, Midwife or District Nurse.

Table 12. In which relationship was friction experienced and what was the most important cause of this?

Relationship	Number	Percent	Negative aspect	Number	Percent
Close relatives	39	46%	Silence about TOP	17	43%
			Disapproval	9	23%
General practitioner	11	13%	Indifference	6	55%
			Lack of understanding	3	27%
Friends	18	21%	Silence about TOP	6	33%
			Disapproval	5	28%
Colleagues	8	10%	Disapproval	4	50%
			Distance in relationship	1	13%
HV/MW/DN	7	8%	Lack of understanding	3	43%
			Indifference	2	29%
Hospital staff	7	8%	Insensitivity	6	85%
			Disapproval	1	14%
Church/Religious group	6	7%	Disapproval	3	50%
			Lack of understanding	1	17%
Neighbours	5	6%	Lack of understanding	3	60%
			Insensitivity	2	40%

Only the two most frequent aspects mentioned by consultands are reported in this table. HV/MW/DN = Health Visitor, Midwife or District Nurse.

that she should have been over the event. 20 (29%) were bewildered by the reaction of their wives. Some common comments were;

"I gave her all my support and she gave me all her anger and frustration".

"I could not bear to see her cry so much."

"She coped much better then I thought she would, I did not understand that."

Four husbands did not answer the question.

At the time that the baby was due, 26 (38%) husbands had not been aware of their wives's response.

Was there a change in the relationship with your husband/partner after, and relating to the TOP.

71 (84% of 84) reported a noticeable, if sometimes temporary, change in the relationship. 10 (11%) did not, and 3 (4%) answered that they did not know.

Figure 6 explores the changes in more detail. Many couples found that the TOP for FA and the emotional time after the event, had brought a deeper dimension to the relationship and thus felt closer than two years after the event. Where difficulties were experienced, these were most acute between 3 and 6 months. Separation due to lack of communication, increased irritation and intolerance was reported by 10 (12% of 84). 20% of these separated in the first 3 months, 40% between 3 and 6 months, 20% between 6 and 12 months, and one couple after 18 months. 8 couples had reunited at the time of interview, one couple remained separated and another couple obtained a divorce after separating 6 months after the TOP. They stated that the termination was not the cause of the breakdown in the relationship but merely the last straw; it had amplified the weak points in the marriage.More marriage problems and separation occurred in the younger agegroups and socio-economic group 4-5. (Table 13)

Was this linked to a change in the sexual relationship?

No change was reported by 30 (36% of 84), 4 did not know, and 50 (59%) reported a noticeable change in their lovemaking patterns.

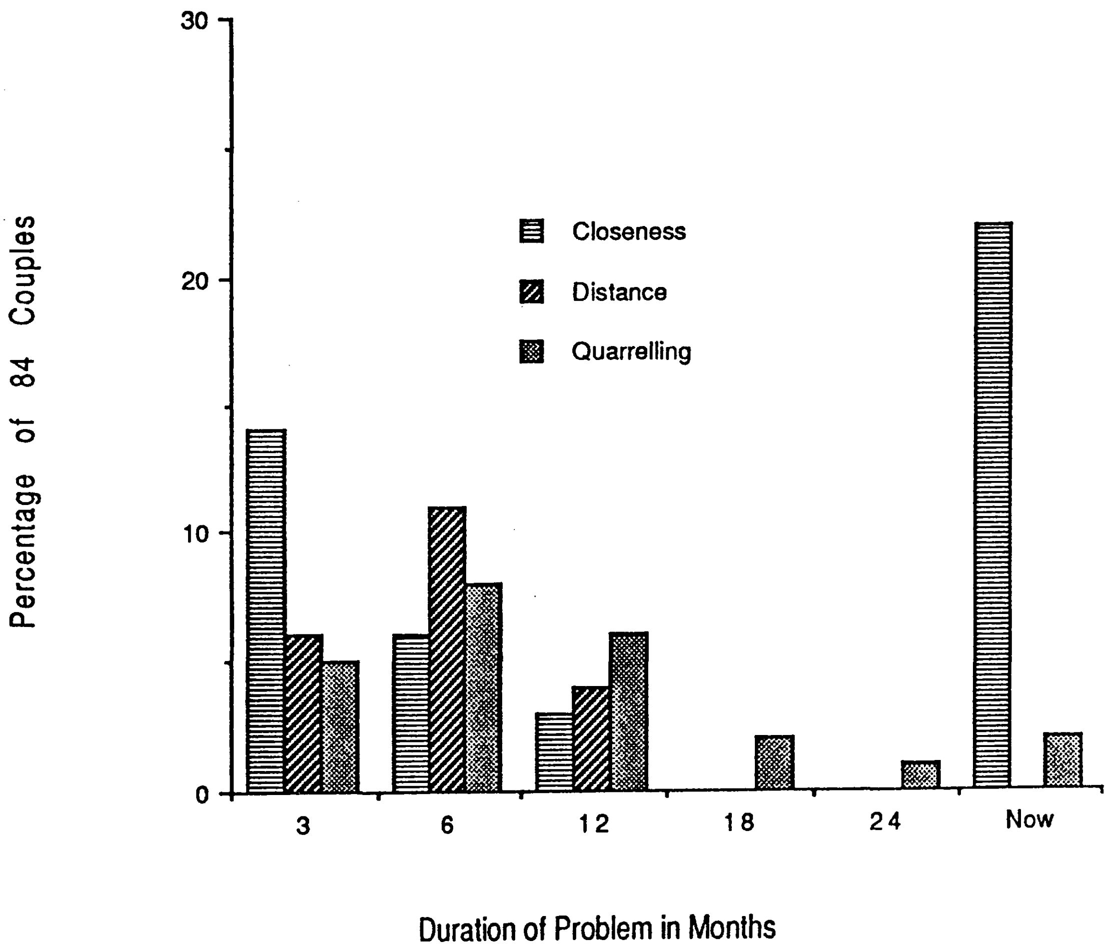


FIGURE 6 Effect of TOP on marital relationship.

Table 13. Marital aspects after TOP for FA, differences between age and social class.

Consultands	Number	Closer %	Closer 1y+ %	Distance %	Distance 1y+ %	Quarrels++ %	Quarrels++ 1y+ %	Separation %	Separation 1y+ %
Total	84	47	22	19	3	18	8	12	6
Age F :									
16-20	5	40	40	20	0	0	0	40	20
21-35	66	46	24	23	3	20	9	12	6
36-39	8	62	50	0	0	12	0	0	0
40+	5	75	40	0	0	20	0	0	0
Social Class :									
1-2	12	50	25	25	0	17	0	0	0 *
3-3M	37	54	32	13	11	11	5	11	5
4-5	31	39	19	26	19	23	16	19	10

1y + = Effect on the marriage one year to two years after the TOP
* = p <0.001

16% (of 50) couples made love more frequently then before, either to reinforce their closeness or in trying to get pregnant again (this did not include any couples in a high risk group; recurrence >1 in 10), 50% made love less frequently then before and reported a lack of interest because of depression and sadness, 24% very rarely made love after the TOP which was very different from their behaviour before the TOP because there was a fear for another pregnancy, in spite of available contraceptives. 14% (8% of 84) stopped making love and for 6 this was linked to a deterioration in the relationship as a whole. One husband had suffered impotence since the TOP and refused to request help in spite, of his wife's wish for another pregnancy.

42 (84% of 50 of those reporting change or 50% of 84) wives instigated the change in the sexual relationship, fear of pregnancy was most commonly mentioned and 5 (10% of 50 or 6% of 84) of the husbands instigated a change for the same reason. The difficulties lasted from 3 to 26 months (median 6 months) and 7 (8% of 84) experienced difficulties for more than 12 months after the TOP.

Only two couples who experienced sexual problems asked for advice and help, one from their GP and one from a medical social worker. One woman would like to get help but her husband thought that after two years it was too late to save the marriage.

<u>Did the TOP for FA influence and change your relationship with your other children.</u>

For 5 (11% of 84) there was no change, however 40 (48%) changed their behaviour towards the children. The aspects which were mentioned most frequently were that 18 (45% of 40) felt overprotective of the children and kept more of an eye on them, and 13 (32%) felt "overanxious" and worried a lot about the children. 9 (22%) were very irritable to the children and felt guilty about this and 2 women had a period of feeling indifferent towards their children and left their care for 6 months to relatives. One mother reported that her child now attends a child-guidance clinic; up to the TOP the child had been an easy toddler but after the event he turned to attention-seeking and became difficult.

Were there religious implications after TOP for FA

As a TOP for FA is not only touching on medical and social aspects but also includes moral and ethical issues, the influence of religion on the consultand's views about the decision were sought.

Table 14 sets out the frequency of various types of religion and degree of observance.

16 (19% of 84) women saw a religious leader, 5 before and 11 after the termination, 13 were seen at home (only 2 had requested the visit). 5 found the visit helpful and 11 found it disturbing and unhelpful. One woman remarked that the priest's reassurance that it was all for the best made her furious, "how could a severely malformed fetus be for the best?". On another occasion a clergyman was uncomfortable with the idea of fetal loss and one Church of Scotland minister mentioned that his church had changed their views on TOP for FA every year and he did not know what to advise.

Only 15 reported that the termination had not affected them spiritually. which left 69 (82% of 84) with spiritual disturbance. 21 (30% of 69) were very angry with their God, thought a lot about their childhood religion and felt let-down. 15 (21%) felt their belief turn into indifference. 14 (20%) actively turned away from church and religion but felt guilty about it. 5 (7%) experienced a growth in faith, and felt well-supported by their religious community. 8 (11%) felt a need for religion and went back to a church for the first time in years; 7 (14%) felt punished and wondered how they had displeased their God. Most women felt too frightened of disapproval to talk to anyone about these feeling.

After two years, 25 (30% of 84) felt indifferent about religion and God, 45 (53%) felt the same as before the TOP, 9 (11%) experienced a growth in faith and hoped that their dead babies would be cared-for in heaven. They had realised how vulnerable people were and how one could not escape fate, which increased their need for religion. Six (7%) still felt a deep resentment and hostility to God, the church and religion as a whole.

When religion was cross-correlated against various questions no significant aspects were observed. However, it was noted that Roman Catholic couples experienced slightly more disapproval from priests, relations and friends. They also experienced more silence about the TOP for FA.

Table 14. Distribution of religions in the study group.

Religion	Females	Males
Church of Scotland	53 (63%)	51 (61%)
Roman Catholic	25 (30%)	24 (28%)
Moslem	1 (1%)	1 (1%)
Episcopalian	1 (1%)	2 (2%)
Spiritualist Church	1 (1%)	0
Atheist	3 (4%)	6 (6%)

32% of the women and 16 % of the men were practising church members. There were 18 (21%) mixed marriages.

3.3.6 Reproductive Behaviour Assessed Two Years Post-TOP

Obstetric Information about pregnancies after the TOP for FA and the outcome?

Of the 53 (65% of 84) women who have had a further pregnancy since the termination, 42 (50%) had a normal live-birth. One had a live baby with Adam-Oliver syndrome which was not related to the previous NTD TOP. 2 (2%) had a miscarriage (between 7 and 12wks gestation). 3 (3%) had an intra-uterine death (2 between 6 and 12 weeks and 1 between 12 and 16 weeks). There were 3 TOP for FA; one for Multiple Pterygium Syndrome, one for Jarcho-Levin syndrome and one for NTD. Two women were still pregnant at the time of interview.

How much time was there between the TOP for FA and the outcome of the next pregnancy?

Of the women who had had an outcome of pregnancy, 19 (36% of 53) women had an outcome between 6 and 12 months after the TOP, 22 (42%) between 13 and 18 months and 10 (19%) between 19 and 25 months after the TOP. The median was 14 months. Those who had a miscarriage conceived 5 and 9 months after the TOP. Those who had a intrauterine death after the TOP conceived 1, 7 and 9 months after the TOP.

Antenatal complications?

There were 9 antenatal complications; 6 threatened miscarriages and 2 hyperemesis, and 1 hypertension .

Prenatal diagnosis of those who had another pregnancy

19 (36%) women had an amniocentesis (one amniocentesis was unsuccessful), the remainder had a combination of MS-AFP and detailed scanning after 16 weeks. One woman was too late for the MS-AFP but agreed to a detailed scan. None of the women interviewed had refused prenatal diagnosis.

Information about the labour after the TOP and birth.

32 women delivered SVD, 3 had a low or midcavity forceps (FD) delivery, 9 patients had a Lower Uterine Caesarian Section

(LUCS) and 7 women had a D&C or removal of products of conception. 3 women had another Pg-E2 termination of pregnancy.

The birthweight of the babies born after 28 weeks was in the range 1163 to 4308g with a median of 3355g. Weight and gestation correlated.

The placental weight was between 150 and 850g; median 600g. This was in correlation with gestation.

The gestation of the pregnancies was 6-42 weeks; median 39.5 weeks.

Post-natal complications?

One women had a positive post-natal smear, 2 had a haemorrhage and received treatment, 1 had retained products of conception requiring admission to hospital 14 days later and another a retained placenta and manual removal after second TOP of FA. Two women (4% of 55) reported postnatal depression lasting 6 months. Both had conceived in less then 6 months after the TOP for FA and had no history of postnatal depression.

Trying for a pregnancy

The 11 women who were still trying to conceive at the time of interview had not been using any form of family planning for 17-24 months (median 20 months). 4 women had been investigated and no reason for infertility was found; 2 husbands had low spermcount, 1 woman had an ovarian cyst, one couple had sexual difficulties and 3 had not been investigated. This group took much longer to come to terms with the TOP for FA and reported more guilt, sadness, failure irritability, depression, and crying at the time of interview than the women who had conceived.

Why did couples abstain from further reproduction?

Fifteen couples did try for another pregnancy.

Four couples were undecided about further pregnancies; all were very frightened that they may have to face a further TOP for FA. All couples used family planning (2 used condoms, 2 used pills).

Of the 11 couples who definitely wanted no more pregnancies, 8 found the recurrence risk too high and were frightened of another termination (one couple had adopted), 2 had marriage

problems. Of these 11 couples, 5 had a vasectomy or tubal ligation. All others used a recognised family planning method.

Who decided, for or against further pregnancies after a TOP for FA?

For ease of analysis, couples were divided into two groups, the 69 couples with a positive attitude towards further pregnancies were called W + (positive Wish). These couples had another pregnancy, were trying to become pregnant or were waiting a few years to space the children in the family.

The 15 couples with a negative attitude towards further pregnancies were called W -, and included those who were undecided about further pregnancies (4, 5%) and those who had decided against further pregnancies (11, 11%).

Which factors influenced the decision for or against further reproduction?

Religion was not an important deciding factor in the decision to have further pregnancies (see table 15) because although Slightly more RC women fell in the W - group and there were more mixed marriages, this was not found statistically significant (see table 15).

Age appeared of greater importance in the decision reproductive decision. Table 16 illustrates that more women in the older age group chose against further pregnancies but because of the small number involved no statistical significance could be found.

The small number of abnormalities other then NTD made it difficult, to show a clear correlation between the abnormalities but in proportion more women with chromosomal abnormalities fall in the the W - group. However, this could be linked to their age (all were over 34)see Table 17..

To make it easier to assess the 20 different family types displayed in Table 18. Couples were divided into four groups; Family 1 included those who had neither healthy children nor disappointments (such as handicapped children, stillbirths, neonatal death miscarriages), Family 2 only had healthy children, Family 3 included couples with healthy children and disappointments, and Family 4 couples only had disappointments.

The only woman in Family 1 who did not want further

Table 15. Correlation between religion and pregnancy wish after TOP for FA.

Religion		Total number	Wish + n (%)	Wish - n (%)
Church of Scotland		53	44 (83)	9 (17)
Roman Catholic		25	19 (76)	6 (24)
Others		6	6 (100)	0
Mixed marriages		18	12 (60)	6 (40)
Practising Religion	Female	27	23 (85)	4 (15)
	Male	13	11 (85)	2 (15)

Table 16. Correlation between age and pregnancy wish after TOP for FA.

Wish	Age Group Number	16-20 5	21-24 19	25-35 47	36-39 8	40+ 5	Total 84
Wish +		4	17	41	4	3	69
Wish -		1	2	6	4	2	15
% of age group		20	12	13	50	40	18%

Table 17. Correlation between indication for TOP and pregnancy wish.

Fetal Abnormalities	Number	Wish +	Wish -	Percentage
Anencephaly	34	27	7	18%
Spina Bifida	25	23	2	8%
Trisomy 18	5	3	1	20%
Trisomy 21	4	2	2	50%
Non-immune hydrops fetalis	3	3	0	
Turner's syndrome	2	1	1	50%
Renal abnormalities	2	2	0	
Multiple congenital abnormalities	2	2	0	
Body stalk anomaly	1	0	1	100%
Cystic fibrosis	1	1	0	
Duchenne muscular dystrophy	1	1	0	
Klinefelter syndrome	1	0	1	100%
Phenylketonuria	1	1	0	
Jarcho Levin syndrome	1	1	0	
Multiple pterygium syndrome	1	1	0	
	84	69	15	

Table 18. Correlation between family type and pregnancy wish after TOP.

Family Type	Number	Percent of 84 Families	Wish + Total = 69	Wish - Total = 15
Family 1	28	33%	27	1
Family 2	27	32%	21	6
Family 3	19	23%	11	8
Family 4	10	12%	10	0

<u>Family Types</u>
Family 1 = No children no disappointments.
Family 2 = Only healthy children.
Family 3 = Healthy children and disappointments.
Family 4 = Only disappointments.

pregnancies, was 17 years old, unmarried, felt pushed into the TOP for NTD by her boyfriend, and relations, and had not come to terms with the event. There were more women who chose against further pregnancies amongst those who had a combination of a healthy child or children and other disappointments than in other groups.

Correlation between planned PND or detected by screening and pregnancy wish

Of the 64 women whose abnormality was detected by screening, 6 (9% of 64) did not wish a further pregnancy. Of the 20 women who had "planned PND" 7 (35%) did not wish a further pregnancy.

No correlation was found between the pregnancy wish and; the woman's experience of the TOP procedure, the support given after the TOP, or a recurrence risk of more or less then 1-10.

Correlation between a pregnancy wish ,unexpected diagnosis and live healthy children,

It is the policy in the department of Medical Genetics in Glasgow to look at the fetal karyotype of an amniotic fluid sample with NTD indication as well as at the AFP level and acetlylcholinesterase banding pattern. Three women with an indication of previous NTD were found to have a chromosomal abnormality (Turners, Klinefelter's and Down's syndrome). One woman with a previous TOP for NTD was detected by US to have a fetus with Multiple Pterygium Syndrome.

Table 19 shows no significant difference between those with or without unexpected diagnosis but in this study only those without healthy children favoured another pregnancy after a previous TOP for FA.

The frequency of reproductive conflict.

In question 2107 and 3014 couples were asked if they now had the number of children which they had originally wanted, i.e. had they realised their "ideal family"? It was interesting to note that 28 couples (of 84) gave two conflicting answers to this question. However, only one couple disagreed in the W - group, where the husband had realised the hoped for number of children and the wife had a smaller family then she had hoped for. For ease of analysis

Table 19. Pregnancy wish, unexpected diagnosis and live children.

Abnormality previous TOP	Abnormality second TOP	Live children	Wish +	Wish -	Significance
NTD	NTD	0	1	0	$p<0.01$
NTD	NTD	1	0	1	-
NTD	NTD	2 (one adopted)	0	1	-
NTD	NTD	1	0	1	-
NTD	Klinefelter	1	0	1	-
NTD	Down's	1	0	1	-
NTD	Turner	3	0	1	-
NTD	Multiple Pterygium	0	1	0	$p<0.01$

only the woman's view is shown in Figure 7.

To find out which couples had reproductive conflict the following four groups were identified.

W + R + included couples who had another pregnancy after the TOP and now had their "ideal" number of children

W + R - described couples who may have had another pregnancy but wanted more children and those who did not have another pregnancy but were still trying to conceive

W - R + were those couples who had reached their "ideal family number" before the TOP for FA

W - R - identified the couples with a conflict. They did not have the number of children they would have wanted but decided against further pregnancies because of the fear of having to face the decision regarding another TOP for FA.

The group which did not want further pregnancies reported more irritability, anger and guilt at the time of the interview, but only the feeling of failure more than 12 months after the TOP was significantly higher in this group (46% for women $p<0.02$ and 55% for men $p<0.01$).

Feelings regarding the PND for a future pregnancy.

Table 20 shows that very few consultands would refuse PND in a future pregnancy. No significant correlation could be found between the age-groups, religion, planned PND and PND after screening, and socio-economic groups.

3.3.7 Subjective Assessment Two Years Post-Termination

Which events made the time after the termination more difficult for you?

50% of the women in this study found pregnant women and new

Figure 7. Correlation between the "desired" family and the reproductive wish.

Desired family realised?

Example.

	W +	W -
R+		
R-		**CONFLICT**

Pregnancy Wish figure in the Thomasson-Brepols Study 1985(total N110)

	W +	W -
R+	n = 16 (14%)	n = 10 (9%)
R-	n = 38 (35%)	n = 46 (42%)

Desired number of children realised?

Pregnancy Wish current study.

	W+ n=69	W- n=15
R+	n = 45 (53%)	n = 3 (4%)
R-	n = 24 (29%)	n = **12 (14%)**

R + = The "desired" family realised.
W + = Wishes further pregnancies.
R - = The hoped for "desired" family not realised.
W - = Does not wish further pregnancies.

Table 20. Feelings regarding PND for a future pregnancy.

Consultands		Yes PND again		No PND again		Not sure PND again.	
Total F	84	80	96%	1	1%	3	6%
Age F :							
16-20	5	5	100%	0	0	0	0
21-35	66	64	97%	1	2%	1	2%
36-39	8	7	87%	0	0	1	12%
40+	5	4	80%	0	0	1	20%
Social Class F:							
1-2	12	12	100%	0	0	0	0
3-3M	37	33	90%	1	2%	3	8%
4-5	31	31	100%	0	0	0	0
Religion							
Ch of Sc	53	50	94%	0	0	3	6%
R.C	25	25	100%	0	0	0	0
Prenatal diagnosis:							
Planned	20	17	85%	1	5%	2	10%
Screen	64	63	98%	0	0	1	2%

F= female   Ch of Sc = Church of Scotland   RC = Roman Catholic
Screen=Selected by screening programme

born babies hard to cope with. 31% were hurt by the silence about the subject of their TOP and the lack of recognition of their grief. 27% were very distressed on the day that the baby would have been due yet the majority 46% were sad but resigned. 14% were upset watching TV programmes which dealt with pregnancy or handicap, or abortion debates. 5% were upset after the birth of their new baby as they suddenly realised what they had missed the last time, and eight had a relapse of depression after every failed pregnancy. One woman complained that her husband thought that a holiday would be the end of all their problems.

Which events did women experience as helpful?

The birth of the new baby was mentioned as very helpful by 43% of the women.

19% found existing children comforting, and 19% found that the confrontation with the abnormality (seeing the fetus or a detailed explanation of a PM report) put their mind at rest about the decision to terminate. 8% found it rewarding to take part in research as they felt they might be instrumental in preventing the abnormality happening to other women in the future and thus the terminated pregnancy was not totally in vain. 5% found a holiday helpful. 7% felt supported by other women who had had a similar experience.

Both husband and wife were asked how care could be improved

14% of the women would like to see improvement in hospital care and the attitude of staff during the TOP and more attention during the next pregnancy.

13 % of the women and 29% of the men would have liked more information before the termination to help them in the decision regarding the fetus and to prepare them for the termination procedure.

27% of the women and 22% of the men would have liked more information about the baby and about the implication of a TOP for FA after the termination (the men especially wanted guidance on how to cope with their wives).

Counselling by a knowledgeable professional fairly early after the TOP was seen as essential by 18% of the women and 12% of

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the men.

23% of the women and 7% of the men would have liked to have a discussion with another couple who had experienced a TOP for FA both before and after the TOP.

CHAPTER 4

DISCUSSION

4.1 General

As the sequelae of TOP may be dependent on interlinked factors of great diversity, this study's observations are discussed under the following headings; 1) Patient selection, 2) Perceived Management During and After TOP for FA, 3) Psychosocial sequelae and the meaning of pregnancy loss through TOP for FA, 4) The medical sequelae of TOP for FA, 5) Reproductive conflict after TOP for FA, 6) Vulnerable groups, 7) Intervention programmes, 8) New developments, and 9) Conclusions and recommendations.

4.2 Patient selection

None of the consultands for the first "management" study refused to be interviewed, and all had had a termination for NTD. In an attempt to avoid sampling bias in the second "sequelae" study, all 129 patients in the West of Scotland, after TOP for FA, from one full calendar year (1986) were selected. There did not seem to be a particular bias in the 12.5% of patients who refused or the 26% who moved and could not be traced. 88% of the patients approached participated in the study and, with these reservations this second study group should be representative of the study population as a whole. However, the choice of a calendar year presented some analytical difficulties when cross-correlating various, very unevenly distributed groups. In comparison to other studies in this field, this population is younger (29% under 25 years) and there is a predominance of women where the indication for TOP was selection from the general population by a screening programme (Table 5).

4.3 Perceived Management During and After Termination of Pregnancy for Fetal Abnormality

This study was a reflection of women's perceptions of care and attitudes. Except for the time after the TOP, care was in general perceived as good and given by dedicated people. In spite of this there were still a lot of complaints which, on inspection could

be reduced to five themes:

1) Lack of preparation for all procedures and other events. This included preparation for bad news by taking care that the woman is accompanied at the time of revelation and is not given too much reassurance when the diagnosis remains in doubt. Also necessary are; having a discussion about the termination procedure and the time it may take, counselling whether or not to see the fetus, mentioning the possibility of a religious blessing or burial, and giving information about the physical and emotional sequelae on leaving hospital. These could have prevented the frequently hurtful experience of having to cope alone with, for example, unexpected lactation.

2) Lack of information. This was closely linked to the section above. It is generally accepted that couples feel numb on receiving the bad news, and this stresses the importance of two people being present. Two will retain different aspects of the information and this can be helpful in making the decision. Information may reduce the fear felt during the TOP procedure (Table 6). The post-termination visit after 6 weeks should be an ideal time for giving information about e.g. the PM report, and to answer questions, but as Laurence (1981) observed, in a busy outpatient clinic there is rarely an opportunity for the complicated and highly personal attention many couples need. These people would thus benefit from specialised genetic and/or pre-conception counselling clinics 6-12 weeks after the TOP.

3) Lack of understanding; of the couples' feelings, the issues involved, the psychological meaning of TOP for FA and the reasons for couples' reticence. Understanding is also required of the tensions generated in subsequent pregnancy and the ubiquitous parental dislike of the word "abortion".

4) Lack of communication; between the caring agencies, the couple, and the hospital. A lack of liaison often meant that patients returned home with little or no information and without support. Letters from hospital to GPs could take a long time and led to highly embarrassing and painful GP-patient encounters. Unlike the

policy which some hospitals have for care after stillbirths or neonatal death, no such policy appeared to be present at the time of the research.

5) Lack of regular reassessment of care given.

4.4 Psycho-social sequelae and the meaning of pregnancy loss through Termination of Pregnancy for Fetal Abnormality

The sequelae of induced pregnancy loss after detection of fetal abnormality are frequently described in terms of psychosocial trauma. This is in contrast to the often positive psychological reactions after an abortion for social indication. Only one study of those summarized in Table 1 showed fewer negative sequelae after TOP for FA, but the authors (Jones 1984) reported a low response rate with coping problems as one of the main reasons for not participating. In the present study couples with coping problems lasting more then 12 months were observed (40% women and 24% men), which was similar to the 43% noted in the Thomassen-Brepols (1985) study. The main psychological factors for this trauma, as identified by Thomassen-Brepols (1985), are verified in this study. These factors are considered further below and compared with observations found in the "sequelae" study, as well as simultaneously identifying factors specific to the study in the West of Scotland.

For most couples the TOP had the meaning of the loss of wanted, and for 66% a very much wished-for, child. Materno-fetal bonding frequently occurred and loss incurred mourning. However, efforts to cope and come to terms with this loss may have been complicated by:

1) A loss of biological competence because producing a handicapped child is still, if only unconsciously, perceived to be a reproductive failure. Feelings of shame and failure were felt by 61% of the women and 32% of the men and were frequently reinforced by family and in-laws who would fervently declare that this abnormality could not come from their side of the family. This often produced loss of self-value, yet as observed in the literature about grief response, a feeling of self-value is a

most important ingredient in the coping strategy. Further to complicate the issue, there is an increased incidence of fetal abnormality in subsequent pregnancies.

2) Loss of moral competence produced by the awareness of their own contribution to the pregnancy loss. Unlike stillbirth or miscarriage the loss was not passive; it was their own choice. There was a confrontation with one's own morality in making decisions about life and death. 40% of the women and 9% of the men felt a deep feeling of shame. Even the knowledge that a fetus would die anyway was found not to take away the overwhelming sense of responsibility for this new life. The decision to terminate frequently interfered with previously held strong beliefs about right and wrong. This ethical conflict and the moral pain of having to choose against life or for suffering, was strongly illustrated by the fact that couples kept looking for a purpose or reason. Although only 32% of the women in this study admitted to be practising members of a religious community or church, 82% of the 84 (Section 3.3.5) experienced a strong spiritual disturbance and a preoccupation with positive or negative thoughts about God or religion.

3) Loss of social competence. As observed in the introduction, marked ambiguity complicated matters further. Couples reported rationally recognizing the prevention of the birth of a handicapped child and at the same time, emotional mourning for the wanted baby. They felt supported, but at the same time isolated; grateful but angry et cetera. All these feelings were instrumental in the couples' reluctance to instigate discussion. This may explain why 55% of the women and 58% of the men did not discuss their feelings or complaints with anyone (Section 3.3.4), an observation which featured prominently in the present study but was not mentioned by other authors.

It is known in psychology, that coping is hindered by paradox, conflict and ambivalence, and that mourning may not succeed if the experience is not discussed. Couples may fail to unravel the complexity of the situation and thus they continue to experience anxiety and depression. Consequently, in this study

55% of the women and 58% of the men were potentially at risk of prolonged and unresolved grief. Considering this, it was not surprising that so many couples in this study experienced a degree of social isolation. Because this is a new kind of grief, complicated by problems of heredity, handicap and abortion, the general public find it is easier to shy away. This meant that couples who already felt reticent about discussing their feelings after TOP were actively discouraged from doing so by those surrounding them. This exacerbated the already mentioned feelings of failure and guilt, and in turn produced another risk factor for unresolved grief. Silence in people nearby was often well-meant. Outsiders may deduce that a strong grief reaction was linked to regretting the decision to terminate the pregnancy, and silence was used to prevent the couple feeling guilty. This deduction was not confirmed in this study, in which many grieved but only two regretted the decision. Society often fails to comprehend that it is possible to grieve sorely over the tragedy of loss, yet simultaneously acknowledge the other avoided tragedy.

The men in this study appeared to have been able to come to terms with their grief much quicker than their wives (Figures 2, 3, 4 and 5). This confirmed a similar observation made by Martinson (1980) where fathers, after the loss of a child, were twice as likely as mothers to report that the most intensive part of grieving was over in a few weeks, however she remarked that their responses may have reflected the social expectation of the father to "take it like a man" Like the observations of De Frain (1982), it became clear that men had a greater need to keep their grief private. This is apparent in this study, where 32% of the men admitted that they felt withdrawn and could not talk about the TOP. This lasted for a year or more for 13%. The archaic idea in our society that men should not show their emotions may be slowly changing, but was still very much in evidence during the interviews; 5 men walked out of the room to hide their tears, even two years after the TOP. Many avoided taking part in the interview but agreed to send their completed questionnaire by post. That the TOP was a major decision for them too was brought out by the fact that 5 men were uncertain if they

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would repeat their decision in a future pregnancy for similar abnormality (Table 9).

The problem with grieving for a child, but especially in the case of fetal loss, is that there is often a lack of synchrony in the grieving process between the partners. This was reported by 29% of the men (Section 3.3.5) who were bewildered by their wife's reaction or were irritable when their wives were still crying or felt depressed 6 months later. Although closeness was felt by 47%, this could turn to distance, quarrelling and separation as time went on (Figure 6). Similar marital discord was noted by Blumberg (1975). It became apparent in our study that where there is a mature and close relationship and good communication, a marriage weathers these pressures. Lack of maturity in the partnership or an inability to vocalise needs and feelings may have contributed to the fact that reported quarrelling and separations (12 to 24 months after the termination) was confined to the younger age-groups (16-35) and social class 3-5.

All couples gave some indication of factors which influenced the coming to terms with the TOP for FA (Section 3.3.7). These were reduced to four themes; recognition, information, communication, and the hope for another pregnancy with a good outcome.

Couples described recognition as outsiders' perception that there is understanding; for the grief which is felt, for the turmoil of ambiguous feelings and thoughts, and for the long time it may take to come to terms with the event. Thus recognition would prevent trivialisation of their pain with remarks like, "It is all for the best, forget about it".

Information and communication were reported to be very helpful towards coming to terms with the event. Explanations, not only about the fetal abnormality and its implications for further pregnancies, but also information about the prenatal and TOP procedures and the physical and psychosocial sequelae. This would minimise the feeling of being out of control and reduce continuing misconceptions, which in turn would help the couples themselves to express their feelings about the TOP.

The hope for another pregnancy is of great importance. A succesful subsequent pregnancy often counter-balanced the

loss of biological competence and to a certain extent social incompetence. Great importance is thus attached by consultands to discussions and counselling about future pregnancies in relation to the FA. Reassurance and/or factual information and preconceptive health education would increase confidence before embarking on an other pregnancy.

The couples own subjective assessment of the various factors plays a major role in the resolution of grief after TOP for FA.

4.5 The medical sequelae of Termination of Pregnancy for Fetal Abnormality.

This study was mainly concerned with the examination of the psycho-social aspects of a TOP for FA and management, yet medical and reproductive complications would inevitably influence the sequelae and would colour the patient's response after the intervention. The information in this part of the study was extracted from hospital and maternity records.

In a post-abortion sequelae study, Kaltreider et al (1979) mentioned an increased risk of medical complications in second trimester termination, but added that this may be linked to the abortion technique used. Miller et al (1972) noted that extra-amniotic use of prostaglandin-E2 was an effective and safe method of terminating pregnancy. As this method was favoured for 82% of the patients whose hospital records were reviewed, few primary and secondary complications were observed. Unplanned evacuation of retained products of conception (ERPC) and increased bloodloss (>200ml) for 19% in first week and 3% in the following two weeks, were the only complications of note. Although this was higher than observed in the Report of the Royal College of Obstetricians and Gynaecologist (1984), the latter felt that their 10% complication rate was an underestimate. Haemorrhage (loss of >500ml) occurred in 3% of the patients and fell into the 1-5% range observed by the Committee on the Working of the Abortion Act (1974).

None of those who experienced complications reported long-term medical or obstetric problems two years later, and there

was too little variation in methods to ascertain the patients preferences. When, tentatively, other abortion techniques such as D&E were discussed, mothers in our study retrospectively preferred the Pg-E2 method because the fetus was "born" intact. If a similar choice would have been made before the TOP procedure remains to be seen. In this study no correlation was observed between the different termination methods used, complications and an adverse psychological outcome. Neither did there appear to be a connection between complaints of pain during the TOP procedure and the amount of painkillers given. It may thus be concluded that the woman's own pain threshold and, possibly, feelings of fear may play a major role in coping during the TOP.

Patients' reticence, which was discussed earlier, could lead to under-reporting in the early stages of complications. These could progress unnoticed, especially when no post-termination visit had been arranged.

Trichopoulos et al (1976) noted a three or four-fold increase in infertility after TOP. In the sequelae study, 10 (14%) of the 69 women who wanted to conceive had not succeeded in spite of trying for a pregnancy for 18 months or more. In none of these women was this linked to a confirmed tubal occlusion and neither was advanced maternal age an issue here. Thus the present study could not confirm the increase of tubal occlusion which was demonstrated by Joupilla et al (1974) in 18% of their 93 cases.

4.6 Reproductive conflict after Termination of Pregnancy for Fetal Abnormality

The interviews revealed that most couples have a planned family size. This procreative wish may be amended depending on circumstances. Earlier in this study "the hope for a future pregnancy" was given as a helpful factor in the resolution of grief.

Although 3 women admitted to having become pregnant too soon, and in spite of the birth of a healthy child experienced depression and a strong feeling of delayed grief, most found the new baby a source of comfort, pleasure and joy.

In the sequelae study, 82% of the couples tried to achieve

their wished-for family composition despite the TOP and confirmed the observations of several authors (e.g. Everts-Kieboom 1980, 1982; Model 1982) that the availability of PND helped towards the decision to try again. However, as Laurence et al (1981) noted, some (15 couples in our study) did not dare to try again in spite of the availability of PND.

Of these 15 couples (18%) who were very unsure or definitely did not want further pregnancies 80% experienced a reproductive conflict and although the number who refrained from reproduction in the Thomassen-Brepols study was much greater (51%), the percentage of those with a conflict was identical. Who were these couples with this dilemma? The obvious group to review was a recurrence of greater than 1 in 10. As 75% of this group progressed to another pregnancy it was possibly to confirm Lippman's view (1979a) that the objective interpretation of the recurrence risk alone does not necessarily deter couples from further reproduction. Nor was religious conviction found to be a major influence in our study, but it was noted that most women with extremely strong moral or religious convictions would have refused PND or TOP and thus would be excluded from the study group. Negative feelings about the termination procedure or lack of social support after the TOP were not noted to be the deciding factor in the reproductive conflict.

This study found the groups which decided against further pregnancies and experienced reproductive conflict to be: firstly women who received an unexpected diagnosis instead of the FA for which they were at risk (see table 20); and secondly the older age-group (54% of the 36+), who often presented with an indication for TOP of chromosomal abnormality.

It was interesting to note that all couples in the conflict group had at least one healthy child. Those without a child or with a handicapped child tried, or intended to try, for a further pregnancy. They frequently continued trying even after nervous breakdown and depression necessitated hospitalization. This was very different to the observations of Thomassen-Brepols (1985) where 50% of those without children decided against further pregnancies. This finding could possibly be explained by the older age-group distribution in the study of Thomasson-Brepols (1985) and by the fact that 24% were sent the questionnaire less then a year after the TOP.

There is the consideration that indication and age was differently distributed in this study.

Those with an unexpected diagnosis experienced a great deal of conflict in coming to terms with the termination and reproductive choice. This had also been observed by other authors (Leschot et al 1982 and Thomassen-Brepols 1985). Previous knowledge of the fetal abnormality was not only helpful during the decision-making process but also in the attempt to come to terms with the TOP; thus a surprise diagnosis reinforced the loss of biological competence and decreased the feeling of self-value.

Older women, the other conflict group, reported not only the losses described in the psychosocial sequelae (section 4.4), they also frequently experienced disapproval for their desire for further pregnancies from their spouse, relatives and friends, especially if they had other, often older children. Before the TOP, these arguments were merely theory for the woman. A lack of understanding about chromosomal abnormalities, the knowledge that there is no genetic disease in the family, good pregnancy management and a healthy lifestyle often created a false feeling that FA only happens to other "older women". The diagnosis for FA made the increased biological fallibility a reality thus contributing to the reproductive conflict.

Although misunderstanding of the recurrence risk was rarely a major factor in the reproductive conflict, it was a major issue in the decision to refrain from further reproduction for two couples after one NTD pregnancy. They translated the 4% recurrence risk into a risk of 1 in 4 and found this risk far too high.

4.7 Vulnerable groups

Although emotional trauma was experienced by all couples after the TOP, there were great differences in the intensity and the length of time taken to cope with the loss. Many coped with their grief and there appeared no indication for long term counselling or intervention. Some, however, suffered prolonged anxiety and excessive grief reactions which interfered with everyday life. There was no clear indication in the literature about vulnerable groups. In general, men and women with a vulnerable pre-TOP psychological

make-up were mentioned. Thomassen-Brepols (1985) found in addition to this that more women with a X-linked indication for TOP experienced severe prolonged grieving patterns. As this indication for TOP was barely represented in this study (1 couple) no comparisons could be made.

The theory that religious conviction may play a major role in the psychosocial sequelae was not evident in the current study. Neither were there significant differences between socio-economic groups. It appeared that those with antecedent bereavement experience (section 3.3.5), could either have an increased or a decreased risk for a poor outcome. It depended on whether and how quickly they resolved the previous grief. This supported Brown's (1982) hypothesis that knowledge of one's own grief reactions and pattern of recovery could be helpful in coping with subsequent bereavement.

Another vulnerable group mentioned in the literature was that which had no support network. Indeed the one woman in the sequelae study who had not felt herself supported by anyone at all experienced prolonged emotional disturbance and became permanently separated from her consort.

Not mentioned in the literature, but observed in this study, was the group which had experienced a TOP after identification by screening or ultrasonography. Mothers complained of a more intense and long-lasting grief reactions. This could be explained by the fact that they were more often taken by surprise. Unlike an amniocentesis or CVS, the taking of a blood sample or US is a non-invasive procedure and less thought is usually given by the women, regarding the decision of consent, or to preparation for an abnormal finding. Confusion and ignorance about the nature of the abnormality, are deleterious to the grieving processes. However, it must be pointed out that this group contained a much higher percentage of younger women and the other responses of this group are in correlation with those of the younger age group, which will be further discussed.

Thus three groups were observed in this research who presented with a particularly poor outcome: 1) Those with secondary infertility, 2) couples with reproductive conflict, and 3) young and immature couples.

1) Women with secondary infertility or unsuccesful subsequent pregnancies.

As indicated earlier , the hope for a healthy child was given as an important helpful factor in trying to come to terms with the TOP. Women with secondary, post-TOP infertility have this hope dashed every month when their period appears. This disappointment reinforced the loss of biological competence and intensified the previous feeling of ambiguity. "Was the right decision made? Will they ever have an opportunity to have another child?". 70% of this group presented with continuing irritability, depression, guilt and anger 18-24 months after the TOP.

2) Couples with a subsequent reproductive conflict.

This group was discussed in section 4.6. They reported more irritability, anger and guilt at the time of interview but only the feeling of failure, two years after the TOP was significantly higher (section 3.6).

3) Young and or immature women.

Considering the points discussed in the psychosocial sequelae (4.4) it is not surprising that young, immature women in particular have a prolonged grieving pattern. Their ambiguity of feelings and their social isolation was often increased by the well-meaning actions of those around them .A similar observation was made by (Senay & Wexler 1972 and Raphael 1984) They often had strong idealistic, or ambiguous feelings about the fetus and more frequently felt pushed into the decision to terminate the pregnancy by the parents, the husband or the boyfriend. 100% of 16-20 year olds still felt very unsure about the TOP, even after the decision to terminate the pregnancy was made. As feelings of worthlessness and self doubt may more often be the underlying reasons for a pregnancy in this group in the first place, their self-confidence is even more diminished when the pregnancy ends in 'failure'. In many instances the consort was immature too. More younger men in this study felt relief after the prevention of the birth of a handicapped child and

admitted not to have been able to cope with the idea and felt unable to provide the support. Thus 40% of this age-group separated, and one year later 20% were still separated. In or out of a hospital setting, many of these women found it hard to assert themselves or felt ashamed to ask questions on matters not understood. This may explain why fear during the TOP procedure was only mentioned by the younger women (table 7). The resolution of grief is frequently hampered by those in charge who, in attempting to be kind, appear more often patronising. Although many women found it difficult to express their ambiguity and guilt, more younger women complained of an indifferent attitude and insensitivity from the healthcare team. The 30+ age-group, however, found exactly the opposite. Young friends were highly averse to problems related to reproduction and preferred not to discuss them. Relations told them to forget about it and trivialised their grief by remarks like: "You did the right thing dear, you are young yet and there is plenty of time for lots of other babies". This might have been true but was hardly helpful when the young woman in question was trying to work out if she had committed a murder. Many young women were reluctant to ask for help and felt that outward expressions of grief would be seen as signs of their own immaturity. Thus confused and isolated, young couples were rarely helped and guided into finding their own answers to the enormous dilemmas which accompanied a TOP for FA. As one 19 year old woman explained, "everyone gave me the ready made answers, I understood what was said, but could not 'feel' it deep down. It took me three years to find my own answers to my dilemma and to be at peace with myself." Obviously, skilled counselling could have helped this girl to find her answers sooner.

4.8 Intervention programmes

No care, however good, can take away the pain of losing a 'baby', neither can reassuring remarks take away the moral pain.

Resolution of grief does not mean forgetting the event as many women who lost babies decades ago could testify. But as discussed before we can give support by recognising the turmoil of feelings and emotions and by helping couples with the difficult unravelling of the mentioned ambivalence. The only examples we have in this field are the perinatal mortality counselling programmes which started to gain popularity in the mid eighties (Lewis and Page 1978; Phipps 1981; Kirkeley-Best and Kellner 1982; Forrest et al 1981 ,1982; Lake et al 1983; Bourne and Lewis 1984a; Leppert and Pahlka 1984; Kirk 1984; Kellner et al 1984). These programmes were instigated with a greater awareness of psychological problems of families after a stillbirth or neonatal death. The above authors emphasise that bereavement reactions should not be treated as psychiatric disorders. Mourning is temporarily painful, and may be disabling but it is necessary for recovery of bereavement. The programmes observe, and then encourage bereavement processes to run their course until resolution of grief. An immediate new pregnancy is discouraged. An important strategy is to encourage parents to see and hold their dead baby, so that they can say their farewells and thus have an end to a process that started with the discovery of the pregnancy. The opinion was that after the reality of the farewell, the grief process can begin, which in turn will lead to resolution. This applies also after TOP for FA. Many women, who took part in our study, regretted their refusal to see the fetus (Table &&). This fact could be overcome by keeping a good quality photo in the medical files. Although Forrest et al (1982) and other authors found that the duration of bereavement reactions was appreciably shortened by support and counselling, the possibility of iatrogenic effects (poor outcome due to intervention) is rarely discussed and their occurrence in psychosocial intervention have not yet, to our knowledge, been rigorously studied. In the light of this, no intervention programme for patients after TOP for FA should be started without prospective research into which form of intervention would be most beneficial these couples. Self-help groups have been seen as invaluable in supporting women and thus reducing isolation (Vachon et al 1980). Their role in public relations and their help in the education of professionals can do much to raise public awareness of the problems, and such a group was founded during this study (Appendix IX).

4.9 New developments

The greater availability of CVS, which would in turn facilitate a first trimester termination, may alter the sequelae of TOP for FA. The long wait for a result may be reduced. The earlier detection may come at a time when maternal-fetal bonding has not yet started or is at a earlier stage. The possibility of a D&E or D&C termination would avoid the long labours seen here. Thus it would be easier to make a rational decision, although the disappointment of the lost pregnancy would remain. There are, however, still difficulties attached to the relatively new procedure of CVS (Canadian Collaborative CVS-Amnio Study 1989). Test results may be ambiguous, necessitating confirmation by amniocentesis at a later date. There is still no firm statement of the relative risks of miscarriage and the test is not suitable for a variety of FA including NTDs. It remains to be seen if the sequelae are as favourable as those observed after first trimester TOP for "social" reasons. An indication of this may be the two women who declined to take part in the study two years after their first trimester TOP for an abnormality detected by CVS. Their reason was that the subject was still too painful for them. Possibly the emotional sequelae are more complex then at first presumed and further research into the psychosocial consequences of this event is essential to assess the specific needs of this group.

A second development is the addition to MS-AFP screening programme of Down's Syndrome Screening by considering low AFP levels. My observations made for those identified for NTD would be valid for the group identified as at risk for Down's syndrome. Because screening is non-invasive, women often consent to the procedure without giving full and serious consideration to the implications of an abnormal result. An increased risk factor might produce residual parental anxiety despite of normal result after an amniocenteses and in some cases the anxiety may persist throughout the pregnancy and even after the birth of a normal child. The unexpectedness of the diagnosis, may interfere with the decision making process and the ultimate coming to terms with the TOP. All these factors make it even more important to improve communication before, during, and

after screening/prenatal diagnosis and to give due consideration to psychosocial care in screening programmes.

4.10 Conclusions and recommendations

This project has verified the observations of previous, smaller studies in that while a second trimester termination of pregnancy for fetal abnormality may be physically relatively safe for the mother, it remains an emotionally traumatic, major life event for both father and mother. To the loss of the wanted 'baby' is added the loss of biological, moral and social competence; this is reflected in the long lasting feelings of anger, guilt, shame, failure and fear (Figures 2 and 3). These losses are in turn complicated by an ambivalence of feelings and thoughts, which originates from the two dimensions of the loss; the healthy baby of fantasy, and the handicapped baby of reality. An historically conservative, Calvinistic or Roman Catholic, Scottish background with deep-seated, inflexible social attitudes about right and wrong adds to the complexity of the situation and leads to fear of disapproval and consequent reticence. This in turn has an adverse effect on the grieving process.

A TOP for FA produces, for 12% of the couples, a reproductive conflict. The intense wish for another pregnancy is set aside for fear of having to repeat the decision-making process and face, again, the sequelae of a TOP for FA. Reproductive choice after the TOP for FA, is strongly influenced by the subjective interpretation of circumstances, information and recurrence risk.

Although management was perceived in general as caring, there is plenty of scope for improvement. The recognition that possible bad news can be conveyed by "body language" during prenatal diagnostic procedure makes information or verbal reassurance vital. A realization of the shock and numbness that diagnosis of FA produces, especially after screening or unexpected FA, may increase the necessity for repeated explanation of the FA, even after the TOP. A better preparation for the TOP procedure and discussion of pain control may reduce fear and suffering. Because many women regretted not seeing the fetus, a gentle introduction to the fetus should be

encouraged, but a strong wish not to be confronted with the fetus and the fear of the abnormality should be understood and respected. A reassuring attitude and word picture may help the parents to feel more at ease about their fetus. Even though not all couples felt the need for a photo of the fetus, no couples objected to a good quality picture being kept in their records, and for many the availability of this could be a crucial factor in the the process of coming to terms with the decision to terminate the pregnancy. Post-termination care in hospital could be improved by better understanding of grieving processes, of the fear of rejection and by an empathy for the hurt produced by crying babies and insensitive remarks. A proper preparation for discharge from hospital and a sympathetic send-off may increase the couple's self esteem. Post-termination care on leaving hospital was minimal or non-existent. Complaints centred around lack of preparation for the physical and psychosocial implications of a TOP for FA, lack of information on where to get help, on their status regarding post-natal care, on what was precisely wrong with the fetus and the implications of this for a future pregnancy. There was lack of understanding of the turmoil, ambiguity and reticence which couples feel, and the extra tensions in subsequent pregnancies together with a lack of communication between the hospital and; the primary care team, the couple, and the medical team.

In view of this, special attention should be given to the vulnerable groups. Young, immature couples may need special care, women with secondary post-TOP infertility may need extra understanding, pre-TOP vulnerable personalities and those who are totally unsupported require early identification and support; and those with reproductive conflict need recognition.

Thus the two main improvements in the management of TOP for FA are; improved understanding of the total sequelae and its consequences, and greatly improved communication. Within the context of medical on-going care, professionals have the responsibility to become knowledgeable about this new kind of grief. Education programmes should enable:- provision of information about procedure and sequelae; offering emotional support and bereavement counselling; and recognition (keeping the patients' reticence in mind) of the signs that may signal a need for professional mental health

intervention. Education should underline knowledge about both lay and professional community resources to which the couples can be referred as appropriate and desired. Self-help groups should be encouraged to partake of this education and may in turn make the general public aware of the implications of a TOP for FA via newspapers, books and television (see Appendix IX about "CARE").

Communication must be improved at all levels between the health professionals in hospital and those in the community. The aims are; to avoid duplication of information and care by health-care professionals, and to avoid inadequate care being given. In the communication between patient and health professionals it should be realized that the reply "I am alright" could mean in these patients just the opposite. A summary, by letter to the patient, of information given in counselling sessions may encourage further questions and prevent misconceptions. A hospital policy, as used after perinatal mortality would be helpful after TOP for FA.

This study underlines the importance of frequent medical audit to promote the continuation of good care in our hospitals together with the evaluation of screening and prenatal diagnosis programmes. Research and development are required, not only for the technical advances of more effective screening and prenatal diagnosis, but also to identify and assess the nature and adequacy of the counselling and support services; in particular with regard to the CVS procedure and the Down's screening programme. Further prospective and retrospective research is needed to identify vulnerable groups and find the most beneficial intervention programme for adversely affected couples.

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APPENDIX I Questionnaire 1 - Management after detection and termination of Neural Tube Defect

Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospitals
G3 8SJ

MANAGEMENT AFTER TOP FOR NTD

PATIENT'S NUMBER:	:						
Date of Termination	:						
Date of Completion Questionnaire	:						

This questionnaire is confidential

MANAGEMENT AROUND TOP FOR NTD 1983-85

001 Patient's number: □□□

002 Patient's Date of Birth □□□□□□ □□

003 Husband's Date of Birth □□□□□□ □□

004 Hospital ____________ □□□

Obstetrician ____________

006 Para □□ + □□ □□□□

007 Type of NTD ____________ □

008 Which number of pregnancy is the NTD □□ □□

009 Open or closed lesion ? □ Open □ Closed □

SCREENING

010 Did patient receive MS-AFP screening? [1] Yes [2] No [3] Do not know □

011 Was screening offered and accepted? [1] Yes [2] No □

012 Was the purpose of the bloodtest explained? [1] Yes [2] No □

(If patient did not receive MS-AFP screening)

013 Was screening offered ? [1] Yes [2] No [3] Do not know □

014 Reason for not being screened : ____________

____

____

015 Last menstrual Period.

016 Dates: [1] Certain [2] Uncertain □

017 Bleeding during pregnancy? [1] Yes [2] No □

018 Gestation at booking □□ □□

If late for booking visit why? ____________

____

019 Elevated MSAFP

1 First □□□□□□

2 Second □□□□□□ □ □

MANAGEMENT AROUND TOP FOR NTD 1983-85 PRENATAL DIAGNOSIS

Amniocentesis

020 Amniocentesis offered [1] Yes [2] No

Reason for Amniocentesis? ____________________

____

021 First Amniocentesis
Gestation dates U/S Dates:

022 Second Amniocentesis
Gestation dates: U/S dates:

Ultrasound:

023 Routine scan [1] Lesion seen [2] Lesion not seen

024 Detailed scan [1] Lesion seen [2] Lesion not seen

Reasons for detailed scan ____________________

____

025 NTD suspected after [1] Raised MSAFP [2] Raised amniotic AFP [3] Abnormal Scan

026 How and by whom was the patient told that all as not well with the pregnancy?

____

____

027 Was husband present? [1] Yes [2] No [3] Other

____

028 What were they told: ____________________

____

MANAGEMENT AROUND TOP FOR NTD PRENATAL DIAGNOSIS

029 Was the need for further tests explained? [1] Yes [2] No

If not, Why not? ____________________

030 Were the words Spinabifida or Anencephaly mentioned? [1] Yes [2] No

031 What was the couples existing understanding of these conditions?

____

____

MANAGEMENT AROUND TOP FOR NTD 1983-85 -PRENATAL DIAGNOSIS

032 Were they given more information, and if so what?

____

______________________________ [ ]

034 If further tests declined by patient why?

____

______________________________ [ ]

035 NTD confirmed by [1] Amniocentesis [2] Detailed scan [ ]

036 Period between being given an indication that all was not well and confirmation of the NTD?(in weeks [ ][ ] [ ][ ]

PATIENT'S OVERALL PERCEPTION OF CARE DURING PRENATAL DIAGNOSIS

[1] BAD [2] POOR [3] AVERAGE [4] GOOD [5] EXCELLENT [ ]

HOW WAS THE ABNORMALITY EXPLAINED?

---

037 How and by whom was the patient told that the fetus had NTD?

[1] Obstetrician [2] Ultrasonographer
[3] GP [4] Others [ ]

038 Who was accompanying the patient at the time ?
[1] Husband [2] Relative
[3] Friend [4] Other [5] None [ ]

039 What were they told; ______________________________

______________________________ [ ]

040 With whom did they discuss this?
[1] Obstetrician [2] Husband [2] Relatives
[3] Friends [4] Clergy [4] Others [5] None [ ]

041 Was adequate counselling given about the abnormality and the options? [1] Yes [2] No
If not, why not? ______________________________

______________________________ [ ]

042 When the decision to terminate the pregnancy was made, was the TOP procedure explained and the time factor mentioned before admission?
[1] Yes [2] No [3] Partly [ ]

043 What was the waiting time between admission to hospital and the decision to TOP?(days) [ ][ ] [ ][ ]

044 Was this what they wanted at the time? [1] Yes [2] No

MANAGEMENT AROUND TOP FOR NTD 1983-85 ABNORMALITY EXPLAINED

PATIENT'S OVERALL PERCEPTION OF HOW THE ABNORMALITY WAS EXPLAINED.

[1] BAD [2] POOR [3] AVERAGE [4] GOOD [5] EXCELLENT [ ]

CARE DURING TERMINATION.

045 Where did the TOP take Place?
Hospital: ______________________
Ward : ______________________ [ ]

046 What pain controle was offered during the TOP?
[1] Analgesisc [2] Epidural
[3] Inhalation [4] Other [ ]

047 Attitude of staff? ______________________
______________________ [ ]

048 Duration of TOP (in hours) [ ][ ] [ ][ ]

PATIENT'S OVERALL PERCEPTION OF CARE DURING TOP.

[1] BAD [2] POOR [3] AVERAGE [4] GOOD [5] EXCELLENT [ ]

POST-TERMINATION CARE IN HOSPITAL

049 WHere was the patient nursed after the TOP?
[1] Postnatal W [2] Antenatal W
[3] Gyne W [4] Labour R [5] Other
[6] Main ward [7] Side ward. [ ]

050 Length of stay in hospital (in nights) [ ][ ] [ ][ ]

051 Attitude staff ______________________ [ ]

052 Were medical and emotional implications discussed before leavinghospital?
[1] Yes [2] No [3] Partly
Explain: ______________________ [ ]

PATIENT'S OVERALL PERCEPTION OF CARE DURING TOP.

[1] BAD [2] POOR [3] AVERAGE [4] GOOD [5] EXCELLENT [ ]

MANAGEMENT AROUND TOP FOR NTD 1983-85 POST-TERMINATION CARE IN THE COMMUNITY

053 Did the patient have a post-natal appointments?
[1] Yes [2] No [3] Other

054 With whom .... [1] Obstetrician [2] GP
[3] Pre-conception C [4] Other

055 Was proffesional Post TOP support given?
[1] GP [2] Midwife
[3] HV [4] Others

056 Was the GP awere that the TOP for NTD had taken place? [1] Yes [2] No [3] Do not know

057 Was counselling given regarding NTD and the implications for further pregnancies?
[1] Yes [2] No [3] Do not know

058 By whom ____________________

059 Was the counselling, [1] Adequate [2] Inadequate

Please explain, ____________________

____

060 What is your present understanding of the recurrence risk [ ] 1 :

PATIENT'S OVERALL PERCEPTION OF POST TOP COMMUNITY CARE.

[1] BAD [2] POOR [3] AVERAGE [4] GOOD [5] EXCELLENT

What was good about the care you received ?

____

____

____

What was bad about the care you received ?

____

____

____

How could we improve care ?

____

____

____

APPENDIX IIa Request to obstetrician for medical record

Dear Dr ,

Re: Mrs Hospital number:

We are conducting research into the medical and psychosocial sequelae of a termination of pregnancy for foetal abnormality.

Over the years a great deal of effort has gone into improving antenatal care and the availability of prenatal diagnosis: consequently the discovery of severe abnormality in the foetus and the option of termination of a wanted pregnancy is becoming more common.

Little has been published in this country about the sequelae of this intervention and it is thus difficult to prevent medical and psychosocial complications and to provide appropriate aftercare for these patients.

We are therefore approaching patients in the West of Scotland who have had a termination of pregnancy for foetal abnormality during 1986.

We would like to study the patients' records for obstetric complications during and after the termination to determine the implications of these for subsequent pregnancies.

We would be most grateful if you could send the case-sheets for the patients on the enclosed list to Margaretha White at the above address.

Alternatively, arrangements can be made to examine the notes in your department if that is preferred.

Please do not hesitate to get in touch if we can provide you with further information.

Thank You,

Yours Faithfully,

Margaretha White,
Research Coordinator

Professor M.A. Ferguson-Smith.

Copy to medical record officer.

APPENDIX IIb Request to General Practitioner for permission to approach patient.

Date

Re: ______________________________________.

Dear Dr.

We are conducting research into the medical and psycho-social sequelae of a termination of pregnancy for fetal abnormality, and note from our records that this lady has had such an experience.

Over the years, a great deal of effort has gone into improving antenatal care and the availability of prenatal diagnosis; consequently the discovery of severe abnormality in the fetus and the option of termination of a wanted pregnancy is becoming more common.

Little has been published about the sequelae of this intervention and it is thus difficult to provide appropriate after-care to these couples.

We are approaching patients in the West of Scotland who have had a termination of pregnancy for fetal abnormality in 1986 to complete, with us, a questionnaire.

This could be done during a pre-arranged home visit or at a visit to the Department of Medical Genetics, whichever is more convenient for the patient.

At the same time there will be an opportunity for the patient to ask questions and give suggestions for improvements to the present system.

Please let us know if you would rather not have us contact your patient by returning the enclosed slip in the S.A.E provided. If we do not hear from you , we will assume that you have no objection.

For further questions please do not hesitate to get in touch with Margaretha White, who is conducting this research, at the above address or telephone 041-339 8888 extension 7175.

Thank You for your attention.
Yours Faithfully,

Margaretha White
Research Coordinator

Professor J.M. Connor

Re: Mrs

Address

I give/do not give my consent for you to approach Mrs.

Please delete where inapplicable.
If consent is refused, we would be most grateful for your reasons.

From: Dr.

APPENDIX IIc Request to patient prior to visit.

Dear Mrs

Over the years, a great deal of effort has gone into improving the availability of antenatal care and prenatal diagnosis; this means that the finding of a severe abnormality in the unborn baby and the termination of a wanted pregnancy is becoming more common.

Our records show that you have experienced a termination of pregnancy for fetal abnormality. We now wonder if the medical and supportive care provided after such a termination meets the needs of patients.

We are therefore conducting a research programme involving patients in the West of Scotland who have had a termination of pregnancy for fetal abnormality in the last few years. We hope to discover the difficulties most commonly experienced by couples.

You are in the special position of being able to help us to improve the care given to patients who will share this sad experience with you in the future.

The research only involves completing one questionnaire with us, either at a home visit or at an arranged visit to our department in Yorkhill hospitals. And there will be an oppertunity to ask questions and get information

If you have any questions please do not hesitate to get in touch with Margaretha White, who is conducting this research, at the above address or telephone 041-339 8888 extension 7175.

All information will be treated in the strictest confidence.

Please return the tear-off slip in the enclosed S.A.E.

Yours sincerely

Margaretha White
Researcher

Professor J M Connor

____________________TEAR HERE____________________

Mrs

Postcode Telephone

I would like to help you with this research. YES NO

(If you answer NO please give your reasons on the back of this slip)

I would be happy to come to Yorkhill if you could arrange an appointment YES NO

I would prefer you to make an appointment to visit us at home YES NO

APPENDIX IId Request for return of husband's questionnaire

Date

Dear Mr.

Last year your wife helped me with a research which aimed to discover the needs of couples who had a termination for fetal abnormality in 1986 in an effort to improve aftercare.

In order to understand the reactions of both parents, I left a short questionnaire for you to complete.

On completion of the research I noticed that your copy is still missing.

If you have mislaid your copy, I have been so free to enclose a new one. Would it be possible for you to return the completed, or if you object, uncompleted questionnaire to me as soon as possible in the enclosed stamped addressed envelope?

In case of the latter, I would appreciate it if you would write your reasons for objecting on the frontpage. For the sake of confidentiality please **do not mention your name on the questionnaire.**

Thank you for your help

Margaretha White
Researcher

APPENDIX III Questionnaire 2 Sequelae of termination of pregnancy for various Fetal Abnormalities

THE DUNCAN GUTHRIE INSTITUTE OF MEDICAL GENETICS

YORKHILL HOSPITALS

GLASGOW G3 8SJ

The Sequelae of Termination of Pregnancy for Fetal Abnormality in 1986

Patient Number __________

THIS QUESTIONNAIRE IS CONFIDENTIAL
(Please do not mention your name)

TOP SEQUELAE STUDY 1986-88 HOSPITAL RECORDS INFORMATION

Number

Code

Item	Field	Code
		[1]
1001	Study number	1-3
1002	Hospital code	4-5
	OBSTETRICIAN: ______ GP: ______	
1003	Para: .... ☐☐ + ☐☐	6-9
1004	Prenatal diagnosis: 1 MS-AFP; 2 2nd MS-AFP; 3 Amnio; 4 U/S; 5 Second opinion U/S; 6 Others	10-13
1005	Indication for TOP : ______	14-15
1006	Duration of pregnancy: by U/S ☐☐ by Dates ☐☐	16-21
	Date of TOP:	
1007	Method of TOP ______	22
1007b	Routine D / C. 1 Yes 2 No	23
1008	Duration of TOP (hours) (from cath or urea to placenta)	24-25
1009	Complications: ______	26
1010	Analgesia: 1 ______ 2 ______ Times; ☐☐ ☐☐	27-32
1011	Bloodloss: (mls)	33-36
1012	Confirmed FetaL Condition: ______ 1 Confirmed . 2 Added complications 3 Not confirmed.	37
1013	Confirmed by : 1 Medical Genetics No: .... 2 Post Mortem No:	38-39
1014	Fetal weight:	40-43
1015	Fetal gestation:	44-45
1016	Post-TOP complications: 1 ______ 2 ______	46
1017	How many days after TOP	47-48
1018	Drugs given in hospital. (post termination) 1 ______ 2 ______	49-51

TOP SEQUELAE STUDY 1986-88 HOSPITAL RECORDS INFORMATION Code

			Code
1019	Time in hospital (nights)	☐☐	52-53
1020	Post termination visit:	1 No 2 GP 3 Obst 4 PreCon	54
1021	Letter sent to GP?	1 Yes 2 No 3 ?	55
1021b	After how many daysS	☐☐	56-57
1022	Seen in special clinic?	1 Medical genetics 2 Pre-Pregnancy Cl 3 NTD Research 4 OTHER ________	58
			2
1023	Subsequent pregnancy:	1 Yes 2 No	4
1024	Antenatal complications.	________	5
1025	Pre-natal diagnosis	1 MSAFP 2nd MSAFP 3 Amnio 4 Det US 5 Other	6-9
1026	Mode of delivery	________	10
1027	Outcome	________	11
1028	Gestation at delivery (weeks)	☐☐	12-13
1029	Outcome, how many months after TOP ..	☐☐☐	14-15
1030	Weight (grammes)	☐☐☐☐	16-19
1031	Placental weight(grammes)	☐☐☐☐	20-23
1032	Bloodloss (ml)	☐☐☐☐	24-27
1033	Postnatal complications	1 ________ 2 ________	28
1034	Family planning 0 Not in records:	1 Yes 2 No	29

TOP SEQUELAE STUDY 1986-88 _ Consultand's History Code

3

2001 Consultand's age at TOP .... ☐☐ 4-5

2002 Husband's age at TOP .... ☐☐ 6-7

2003 Marital status: 1 Single 2 Married 3 Separated 8

2004 How long married or cohabiting?(yrs)......... ☐☐ 9-10

2005 Consultands occupation ________ 11-13

2006 Husband's/ partner's occupation ________ 14-16

2007 Patients religion ________ 17-18

2007B 1 practising 2 none practicing

2008 Husband's/partner's religion ________

2008B 1 practising 2 non-practising 19-20

2009 Handicapped Children Alive ☐ Deceased ☐ 21

OBSTETRIC BACKGROUND

2010 Pregnancies

	Before/		After Termination		Code
1 Livebirth normal	at ☐ wk	12	at ☐ wks		22-43
2 Livebirth abnormal	at ☐ wk	13	at ☐ wks		
3 Miscarriage <28wk	at ☐ wk	14	at ☐ wks		
4 Stillbirth >28wk	at ☐ wk	15	at ☐ wks		
6 Intra-uterine death	at ☐ wk	16	at ☐ wks		
7 Termination	at ☐ wk	17	at ☐ wks		
8 Ectopic pregnancy	at ☐ wk	18	at ☐ wks		
9 Premature birth	at ☐ wk	19	at ☐ wks		
10 Sons	☐	21	☐		
11 Daughters	☐	20	☐		

2011 Outcome of last pregnancy before termination ________ 44-45

2012 How long had you been trying for a baby (months) ☐☐ 46-47

MEDICAL BACKGROUND

2013 Current major illness
1 No
2 Diabetes
3 Epilepsy
4 Crohn's disease
5 Heart disease
6 Kidney disease
7 Clinical Depression
8 Other ________ 48-49

2014 Major operations in past 30 months 1 Yes 2 No 50
(Please give details) ________

2015 Before or after the termination
1 Yes 2 No 3 Both 51

2016 How did you experience the termination
1 Coped
2 Painful (physically)
3 Painful (emotionally)
4 Frightening
5 Other ______ 52-55

SOCIAL BACKGROUND

2017 Any other stressful events in last 30 months

1 No				
2 Bereavement	1	2	3	56-61
3 Loss of job	1	2	3	
4 Finance	1	2	3	
5 Separation	1	2	3	
6 Divorce	1	2	3	
7 Other ______	1	2	3	

(Code 1 =Before TOP. 2 =After TOP. 3 =Both)

MEDICAL SEQUELAE

4

2018 Relevant medical complications post TOP
(after discharge from hospital)
1 No
2 Heavy bleeding
3 Retained placenta
4 Discharge
5 Fever
6 Other ______ 4-5

2019 After how many days? ☐☐ 6-7

2020 Were you readmitted to hospital 1 Yes 2 No 8

2021 Were you given drugs,(on return from hospital)?
1 Yes 2 No 3 ?
(If yes please specify) ______ 9

2022 Who prescribed the drugs?
1 GP
2 Obstetrician
3 Others ______ 10

2023 Who was first home visit from ?
(In first three weeks)
1 GP
2 Health Visitor
4 Midwife
3 Medical Genetics Sister
4 Midwife
5 None
6 OTHER ______ 11

		Code
2024	Why did they visit? (Referred by) 1 Hospital 2 GP 3 Requested by patient 4 Routine visit 5 Other ______	12
2025	How long from leaving hospital to home visitor? (days) .... ☐☐	13-14
2026	Did you want,or would you have liked, an earlier home visit to allow you to ask questions and/or support ? 1 Yes 2 No 3 Other ______	15
2027	Did you go and visit your GP? 1 Yes 2 No 3 Other	16
2028	Was he/she aware of the termination? 1 Yes 2 No 3 Other	17
2029	Did you have a post-natal appointment? 1 Yes 2 No 3 other	18
2030	With whom? 1 GP 2 Obstetrician 3 Other hospital doctor 4 Pre-conception clinic	19
2031	Were you invited to attend this appointment? 1 Yes 2 Yes but did not go 3 No 4 No but made own arrangements	20
2032	Was the baby's condition discussed with you? 1 Yes 2 No 3 Other	21
2033	Who discussed the baby's condition with you? 1. G.P. 2. Obstetrician 3. Midwife 4. Other hospital doctor 5. Preconception clinic 6. NTD researcher	22-24
2034	How long did discharge/bleeding lasts?(days) ☐☐	25-26
2035	When did you periods return to normal? (weeks) ☐☐	27-28
2036	Were your breasts sore? 1 Yes 2 No 3 Other	29
2037	For how long?(days) .... ☐☐	30-31
2038	What kind of help were you given 1 None 2 Advice 3 Drugs	32
2039	By whom? 1 Professionals 2 Friends/relatives	33

2040 On return from hospital did you experience any of the following ? (lasting up to what time in months)

		CODE	<3M	3m	6m	12m	18m	Now	Code
1	None	☐							34
2	Sleeplessness	☐	<3	3m	6m	12m	18m	Now	35-36
3	Listlessness	☐	<3	3m	6m	12m	18m	Now	37-38
4	Depression	☐	<3	3m	6m	12m	18m	Now	39-40
5	Crying	☐	<3	3m	6m	12m	18m	Now	41-42
6	Nervous stomach ache	☐	<3	3m	6m	12m	18m	Now	43-44
7	Loss of appetite	☐	<3	3m	6m	12m	18m	Now	45-46
8	Loss of Concentration	☐	<3	3m	6m	12m	18m	Now	47-48
9	Irritability	☐	<3	3m	6m	12m	18m	Now	49-50
10	Tiredness	☐	<3	3m	6m	12m	18m	Now	51-52
11	Headaches	☐	<3	3m	6m	12m	18m	Now	53-54
12	Palpitations	☐	<3	3m	6m	12m	18m	Now	55-56
13	Nightmares	☐	<3	3m	6m	12m	18m	Now	57-58
14	________	☐	<3	3m	6m	12m	18m	Now	59-60

CODE: 0= Not at all 2= Rather more then usual
1= No more then usual 3= Much more then usual

2041 With whom have you discussed these complaints?
1 With no one 2 GP
3 Obstetrician 4 Other professionals
5 Others ________ 61

2042 Were you given help? 1 Yes 2 No 3 Other 62

2043 How? 1 Counselling
2 Drugs
3 Other ________ 63

2044 For how long were you treated.(weeks) ☐☐ 64-65

2045 Are you still on treatment?
1 Yes 2 No 3 Other
(please explain) ________ 66

2046 If you did not ask for help,why not?
1 I did not want to bother anyone
2 I was frightened that anyone would think that i was "going crazy"
3 I did not think it a medical problem
4 I did not know what to say
5 I don't know
6 Other ________ 67

2047 Was family planning discussed ?
1 Yes 2 No 3 Other 68

		Code
2048	With whom 1. G.P. 2. Family planning clinic 3. Obstetrician 4. Genetic clinic 5. ____________	69

PSYCHOLOGICAL SEQUELAE

5

		Code
2049	How did you feel about the pregnancy 1 Planned and welcome — 3 Not planned, unsure 2 Not planned but welcom — 4 Do not know	4
2050	Did you feel movement 1 Yes 2 No 3 Do not know	5
2051	How did you feel about the fetus ____________	6
2052	Did you feel sure or unsure about the decision to terminate 1 Sure 2 Unsure 3 Do not know	7
2053	If unsure why 1 ____________ 2 ____________ 3 ____________	8

2054 After the termination did you feel any of the following emotions? For how long ?(up to what time in months)

		Code							
1	No	☐							9
2	Anger	☐	<3m	3m	6m	12m	18m	Now	10-11
3	Guilt	☐	<3m	3m	6m	12m	18m	Now	12-13
4	Shame	☐	<3m	3m	6m	12m	18m	Now	14-15
5	Fear	☐	<3m	3m	6m	12m	18m	Now	16-17
6	Sadness	☐	<3m	3m	6m	12m	18m	Now	18-19
7	Relief	☐	<3m	3m	6m	12m	18m	Now	20-21
8	Failure	☐	<3m	3m	6m	12m	18m	Now	22-23
9	Panic spells	☐	<3m	3m	6m	12m	18m	Now	24-25
10	Vulnerable	☐	<3m	3m	6m	12m	18m	Now	26-27
11	Isolated	☐	<3m	3m	6m	12m	18m	Now	28-29
12	"Emotional"	☐	<3m	3m	6m	12m	18m	Now	30-31
13	Numb	☐	<3M	3M	6M	12M	18M	NOW	32-33
14	____________	☐	<3m	3m	6m	12m	18m	Now	34-35
15	____________	☐	<3m	3m	6m	12m	18m	Now	36-37

CODE: 0= Not at alL — 3= Rather more then usual
2= No more then usual — 4= Much more then usual

6

2055 Who gave support? (most important aspect in box)

	Code
1 Relatives	4-5
2 Family doctor	6-7
3 HV/ Midwife/District Nurse	8-9
4 Religious Group/Church	10-11
5 Friends	12-13
6 Other women who have experienced a termination	14-15
7 Colleagues	16-17
8 Neighbours	18-19
9 No one	20-21
10 ____________	22-23
11 ____________	24-25

What was the most important aspect of the support

1 understanding 4 close contact
2 good listening 5 practical help
3 spiritual support 6 thoughtfulness
7 ____________

2056 Did the termination and the reaction to it upset the following relationships (most important aspect in box)

	Code
1 Relatives	26-27
2 Family Doctor	28-29
3 HV/Midwife/District Nurse	30-31
4 Relgious Group/Church	32-33
5 Friends	34-35
6 Colleague	36-37
7 Neighbours	38-39
8 None	40-41
9 ____________	42-43

What was the main cause of the upset in the relationships?

1 disapproval 2 indifference
3 suggestion of blame 4 silence about the subject
5 lack of understanding 6 impatience with physicaL and emotional after affects
7 distance 8 envy of other mothers
9 insensitivity 10 ____________

MARRIAGE AND PARTNERSHIP

2057 Did the termination change your relationship with your husband (or Partner)? 1 Yes 2 No 3 Do not know — 44

2058 In what way did it change?

	Code
1. Closer together	45-46
2. Further apart	47-48
3. Increased quarrelling	49-50
4. Considering separation	51-52
5. Separated	53-54
6. Divorced	55-56
7 ____________	57-58

2059 When did this occur?(code box)
1 first three months 2 six months
3 twelve months 4 eighteen months
5 now

2060 How is the situation now?
1 Back to normal 2 Improved
3 Unchanged 4 Grown worse
5 Other ______________________ 59

2061 Did your sexual relationship change after TOP ?
1 Yes 2 No 3 Do not know 60

2062 How did this affect you ?
1 Made love more frequently than before termination
2 Made love less frequently then before
3 Rarely make love now
4 Stopped making love
5 Other ______________________ 61

2063 Which of you experienced most difficulty?
1 Husband/Partner 2 You 62

2064 Did you ask for help/counselling?
1 Yes 2 No 3 Do not know 63

2065 From whom? 1. GP
2. Special clinic
3. Other 64

2066 How long did these difficulties last ?
(in months) ☐☐ 65

2067 How is the situation now?
1 Back to normal 2 Improved
3 Unchanged 4 Grown worse
5 OTHER ______________________ 67

CHILDREN IN THE FAMILY

2068 Did the relationships with your other children change?
1 Yes 2 No 3 Do not know 68

2069 How did this affect you?
1 Feel closer to the chiLd 2 Overprotective
3 Overanxious 4 Indifferent
5 Impatient 6 Children disapprόved
7 Other ______________________ 69-70

If there were difficulties, for how long did they last?
1 <Than 3 months 2 Three months
3 Six months 4 Twelve months
5 To present
(specify) ______________________ 71-72

7

2070 Did you discuss the termination with a religious leader?
1 Yes 2 No 3 Do not know — 4

2071 Before or after the termination?
1 Before 2 After — 5

2072 Did you find this helpful?
1 Yes 2 No 3 Do not know — 6

2073 Did you receive a homevisit after the termination?
1 Yes 2 No 3 Do not know — 7

2074 How many days after the termination?
(Days) ☐☐ — 8-9

2075 Did you request the visit?
1 Yes 2 No 3 Do not know — 10

2076 Did the termination influence your faith?
1 Loss of faith 2 Growth of faith
3 Indifference 4 No change
5 Angry with God 6 Increased need for religion — 11

2077 How is the situation now?
1 Loss of faith 2 Growth of faith
3 Indifference 4 No changes
5 As before 6 ____________ — 12

SEEING THE BABY

2078 Did you see the baby? 1 Yes 2 No 3 Do not know — 13

2079 Was this what you wanted at the time?
1 Yes 2 No 3 Do not know — 14

2080 If you did not see the baby, why not?
1 Advised not to 2 Did not want to see
3 Too frightened 4 Too drowsy to look
5 Afraid to ask
6 Easier to come to terms with it
7 No suggestions made about seeing the baby — 15

2081 Did you regret your decision?
1 Yes 2 No 3 Do not know — 16

2082 Did your husband/partner see the baby?
1 Yes 2 No 3 Do not know — 17

2083 Did you get a photograph
1 Yes 2 No 3 Do not know — 18

2084 Would you have wanted one
1 No 2 Yes - at the time
3 Yes - in the medical record — 19

2085 Who counselled you about the recurrence risk of the fetal abnormality or the genetic implications for future pregnancies?
1 Obstetrician 2 GP
3 Other hospital doctor 4 Genetic advisory centre
5 N.T.D. RESEARCHER 6 ______ 20

2086 Did you find this counselling helpful, and how?
1 Not helpful 2 Detailed information
3 Reassurance 4 Information about recurrence risk
5 Information for management next pregnancy
6 ______ 21

2087 Were you given enough time to ask questions
1 Yes 2 No 3 Do not know 22

2088 Was the counselling followed up by letter?
1 Yes 2 No 3 Do not know 23

2089 If yes did you find this helpful?
1 Yes 2 No 3 Do not know 24

2090 Were you offered genetic counselling in a "genetic clinic"? 1 Yes 2 No 3 Do not know 25

2091 If not, would you have wanted to be referred
1 Yes 2 No 3 Do not know 26

2092 How long after the termination were did you receive counselling? (weeks) ☐☐ 27-29

2093 Did the counselling influence your plans for your family 1 Yes 2 No 3 Do not know 29

2094 Did the recurrence risk influence your decisions about further pregnancies 1 Yes 2 No 3 Do not know 30

FAMILY PLANNING AND ATTITUDES

8

2095 Have you had another pregnancy since the termination?
1 Yes 2 No 4

2096 What was the outcome
1 Livebirth normal 5
2 Livebirth abnormal 6
3 Miscarriage Less than 28wks at wks ☐ 7-9
4 Stillbirth More than 28wks at wks ☐ 10-12
5 Intra-uterine death at wks ☐ 13-15
6 Termination at wks ☐ 16-18
7 Ectopic pregnancy at wks ☐ 19
8 Premature birth at wks ☐ 20-22

 Code

2097 If live birth what kind of labour ______ 23

2098 Birthweight baby (g) [ ][ ][ ][ ] 24-27

2099 Time between TOP and next outcome of pregnancy [ ][ ] 28-29

2100 Were there any problems after the birth? ______ 30

2101 Did you have pre-natal diagnosis in this pregnancy
1 CVS 2 MS-AFP
3 Detailed scan 4 Amniocentesis
5 Fetoscopy 6 Other ______ 31

2102 What is your present situation
1 Pregnant 2 Trying to conceive
3 Undecided 4 No further pregnancy
5 Wait [ ][ ] Months to conceive
6 Others ______ 32-34

2103 If you are not pregnant, what family planning do you use
1 Pill 2 Cap
3 Condom 4 Female sterilisation
5 Natural method 6 Abstinence
7 Vasectomy 8 Coil(IUCD)
9 Other ______ 35

2104 If you are trying to conceive how long have you been trying? (Months) [ ][ ] 36-37

2105 In case of infertility is there a known reason
1 No 2 Blocked fallopian tubes
3 Hormonal imbalance 4 Sexual difficulties
5 Low sperm count 6 Do not know
7 Other ______ 38

2106 If you are not planning a further pregnancy what is the reason for this
1 Completed family 2 ADopted
3 No partner 4 Ill-health
5 Recurrence risk 6 No further termination
7 Other ______ 39

2107 Have you reached the family size you originally wanted?
1 I now want a bigger family
2 No
3 Yes
4 Other ______ 40

2108 Would you have appropriate pre-natal diagnosis?
1 Yes 2 No 3 Do not know 41

2109 If not, why not? Specify ______ 42

2110 Did you, considering the circumstances, regret the termination? 1 Yes 2 No 3 Do not know 43

	Code
2111 Would you take the same decision, for a similar abnormality, in a subsequent pregnancy? 1 Yes 2 No 3 Do not know	44
2112 How did you feel on the expected date of delivery of the terminated baby 1 Sad but resigned 2 Very distressed 3 Do not remember 4 Other ________	45
2113 Were you pregnant at the time 1 Yes 2 No	46
2116 Which events made the time after the termination difficult for you? ________ ________ ________ ________	49-53
2117 Which special events helped you come to terms more quickly with the termination? ________ ________ ________ ________	54-58
2118 How can the after-care service be improved for couples like you? ________ ________ ________ ________	59-64

THE DUNCAN GUTHRIE INSTITUTE OF MEDICAL GENETICS

YORKHILL HOSPITALS

GLASGOW G3 8SJ

The Sequelae of Termination of Pregnancy for Fetal Abnormality
in 1986

Patient Number H______

THIS QUESTIONNAIRE IS CONFIDENTIAL
(Please do not mention your name)

9

Please circle the appropriate number

3001 Who explained the abnormality of the baby to you before the termination?
1 Obstetrician 2 Family doctor
3 My wife/partner 4 Other ________ 4

3002 Did you get enough information at the time?
1 Yes 2 No 3 Do not know? 5

3003 Who took the final decision to terminate the pregnancy?
1 Together 2 WIFE/PARTNER
3 I decided
4 I did not agree but felt it was my wife's/partner's decision
5 Was unsure but supported wife's decision
6 Other ________ 6

3004 Were you with your wife/partner during the termination?
1 Yes
2 No, I thought it better not to be present
3 No, I wanted to be there, but was not able to be
4 Other ________ 7

3005 Did you see the baby after the termination?
1 Yes 2 No 3 Do not know? 8

3006 Did you regret this decision?
1 Yes 2 No 3 Do not know? 9

3007 After the termination did you feel any of the following strong emotions and until what time?
(Please circle the appropriate number and period)

e.g. (2) Anger	<3m	3m	(6m)	12m	18m	NOW	
1 None							10
2 Anger	<3m	3m	6m	12m	18m	NOW	11-12
3 Guilt	<3m	3m	6m	12m	18m	NOW	13-14
4 Shame	<3m	3m	6m	12m	18m	NOW	15-16
5 Fear	<3m	3m	6m	12m	18m	NOW	17-18
6 Sadness	<3m	3m	6m	12m	18m	NOW	19-20
7 Relief	<3m	3m	6m	12m	18m	NOW	21-22
8 Failure	<3m	3m	6m	12m	12m	NOW	23-24
9 Withdrawn	<3m	3m	6m	12m	18m	NOW	25-26
10 Feeling left out	<3m	3m	6m	12m	18m	NOW	27-28
11 Overanxious for your other children	<3m	3m	6m	12m	18m	NOW	29-30
12 "Emotional"	<3m	3m	6m	12m	18m	NOW	31-32
13 Other ________	<3m	3m	6m	12m	18m	NOW	33-40

TOP SEQUELAE STUDY 1986-1988 HUSBAND/PARTNER QUESTIONNAIRE Code

3008 After the termination, did you experience any of the following symptoms, and up to what time did these complaints last ? to answer: please circle two answers for each symptom where appropriate — Code: 10

FOR EXAMPLE:

2.SLEEPLESSNESS	No	No more than usual	(More than usual)	Much more than usual
LASTING UP TO:	<3M	(3 Mth)	6 Mths	12 Mths	24 Mths

1 None — 4

Symptom						Code
2 Sleeplessness	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	5-6
3 Listlessness	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	7-8
4 Depression	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	9-10
5 Weeping spells	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	11-12
6 Stomach pain	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	13-14
7 Loss of appetite	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	15-16
8 Loss of concentration	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24M	17-18
9 Irritability	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	19-20
10 Tiredness	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	21-22
11 Headaches	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	23-24
12 Nightmares	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	25-26
13 Other ____________	No	No more than usual		More than usual	Much more than usual	
LASTING UP TO:	<3M	3 M	6 M	12 M	24 M	27-28

3009 With whom have you discussed these complaints?
1 With no one 2 Wife/partner
3 Family doctor 4 Friends
5 Relations 6 Others ________ 36

3010 Did you receive help?
1 YeS 2 No 3 Do not know 37

3011 Did you receive any medical treatment?
1 Drugs (Name please) ________ 38
2 Counselling

3012 If you did not ask for help, why not?
1 I did not consider it a medical problem
2 I did not want to bother anyone
3 I did not need help
4 I do not know
5 I did not think any one was interested
6 Other ________ 39

3013 Were you able to understand your wife's reaction after termination? 1 Yes 2 No 3 Do not know? 40
Please explain:

____

____

3014 Have you reached the family size you originally hoped for? 1 I now plan a bigger family
2 NO
3 YES
4 Other ________ 41

3015 Was your wife/partner unhappy on the day that the baby would have been due?
1 Yes 2 No 3 Do not know? 42

3016 Do you regret terminating the pregnancy, considering the circumstances ?
1 Yes 2 No 3 Do not know? 43

3017 Would you take the same decision for a similar abnormality in a subsequent pregnancy?
1 Yes 2 No 3 Do not know? 44

3018 Are there any ways in which we could have helped you and your wife/partner up till now?

Please Explain, using as much detail as you wish (using page opposite if necessary) 45-49

APPENDIX IV Twenty key questions used in cross-correlation of responses to questionnaire 2

QUESTIONS TO BE ASKED ABOUT THE FREQUENCIES OF THE RECORDED RESULTS OF SECOND STUDY.

Compare the following four variables in turn with the 20 questions?

1. Age groups: a) 16-20 versus (F 2001)
b) 21-35 "
c) 35-39 "
d) 40+ "

2. Social class: 1-2 " (M 2006A and B)
3-3M (=9) "
4-5 "

3 Religion: 1 Ch o Sc (1) F2007A
2 RC (2) M2008A
3 Mixed marriages were 2007A and 2008A are different.

4 Indication of detection:
1 Patients who opted for prenatal diagnosis for anxiety , maternal age or previous history of FA or family history of FA. (considered FA to a certain extent)
(9 previous NTD, 4 maternal age, 6 other known at risk factors)

2 Patients who had prenatal diagnosis after screening or ultrasound detection of abnormality.(unprepa red for FA)

TWENTY KEY QUESTIONS:

1 Stressful life events in the six months preceding the termination and the two years after the TOP. (2017A, 2017C)

2 Pregnancy preceeding TOP (2011)

3 How long had they been trying for the terminated pregnancy?

4 Sure or unsure about TOP (after their decision) ? (2052)

5 How did you experience the TOP 2016 A,B,C,D,

6 Did you see the baby F=2078 M=3005
Did you regret this F=2081 M=3006

7 Psychosomatic symptom Sleeplessness F 2040 2A 2B M= 3008 2A 2B
Listlessness F 2040 3A 3B M= 3008 3A 3B
Depression F 2040 4A 4B M= 3008 4A 4B
Crying F 2040 5A 5B M= 3008 5A 5B
Loss of concentration F 2040 8A 8B M= 3008 8A 8B
Irritability F 2040 9A 9B M= 3008 9A 9B
Palpitations F 2040 12A 12B
Nightmares F 2040 13A 13B

APPENDIX IV Twenty key questions (Continued)

8 Discussed with anyone? F=2041 M=3009

9 If not discussed, why not? F=2046 M=3012

10 Strong emotional feelings after TOP

	F	M
Anger	F 2054 2A 2B	M= 3007 2A 2B
Guilt	F 2054 3A 3B	M= 3007 3A 3B
Shame	F 2054 4A 4B	M= 3007 4A 4B
Relief	F 2054 7A 7B	M= 3007 7A 7B
Failure	F 2054 8A 8B	M= 3007 8A 8B
Isolation	F 205411A11B	M= 300711A11B
Withdrawn	-----------	M= 300713A13B

11 Discussed with anyone? (2054, 3009)

12 Social positive support.

Social positive support.	Relatives	2055 1A
	Family doctor	2055 2A
	Friends	2055 5A
	Colleagues	2055 7A
	Neighbours	2055 8A
	No one	2055 9A
Negative social contacts	Relatives	2056 1A
	Family doctor	2056 2A
	Friends	2056 5A
	Colleagues	2056 6A
	Neighbours	2056 7A
	No one	2056 8A

13 Effect of TOP on marriage and duration in months

Effect of TOP on marriage and duration in months	Closer together	2058 01A
	Further apart	2058 02A
	Increased Quarrels	2058 03A
	Separation	2058 05A
	Divorce	2058 06A

14 Changes in sexual behaviour (2062)

15 How is the situation now (2060)

16 Time between TOP and next pregnancy outcome? 2099

17 Another pregnancy and outcome? (2096)
1, 2, 3, 3A, 3B, 4A, 4B, 5, 5B, 6, 6B, 7, 8B

18 If not planning another pregnancy why not? v 2106

19 If you planned a pregnancy would you have prenatal diagnosis in your next pregnancy? 2108

20 Would you terminate again under the same circumstances in a subsequent pregnancy? F=2111 M=3017

APPENDIX V The Self-Help Group - "CARE" - conception and implementation

Formal Title 1987-1989:

THE SCOTTISH ASSOCIATION FOR CARE & SUPPORT
AFTER TERMINATION FOR FETAL ABNORMALITY

From June 1989:

THE SCOTTISH ASSOCIATION FOR CARE & SUPPORT
AFTER DIAGNOSIS OF FETAL ABNORMALITY

The idea that there is a need for a support group for couples who have had a termination for fetal abnormality came after interviewing women post-termination for NTD during 1983 to 1986. However, it was not until 1987 that Mrs Janice Moreland came forward to help start the association. Shortly after this, Mrs Morag Wilson (from the East Coast of Scotland) joined, bringing her secretarial and organisational skills. Following the design and legal approval of a constitution, "CARE" received Scottish Charity Registration. Meanwhile a similar association had been started in England and Wales (Support After Termination For Abnormality - SATFA), but thoughts of combining the two organisations were abandoned after obtaining legal advice and consulting the membership of "CARE". Leaflets explaining the aims of "CARE" were printed and distributed to hospitals, health centres and libraries. Free publicity for the new organisation was given by Scottish Television's Community Service programme, women magazines and newspapers.

Members representing "CARE" were invited to Health Visitors and Midwifery conferences and many of our members have been asked to talk to staff in maternity hospitals and at Round Table meetings about their experiences with prenatal diagnosis and termination. Representatives of "CARE" expressed the views of the membership to the Kings Fund Forum on Screening and Prenatal Diagnosis (1987). In 1988, David Alton tried, via a private members bill, to reduce the latest abortion time to 18 weeks gestation. Members of "CARE" and SATFA encouraged their members to write to their Members of

Parliament with their personal stories. This resulted in representatives being invited to the Houses of Parliament to explain their points of view regarding prenatal diagnosis and the choice of termination.

Many couples felt the need for some positive action after they had been confronted with fetal abnormality. For this reason a separate research fund (The Daisy Fund) was started and members vote annually on which research, into the prevention of fetal abnormality, the yearly proceeds will be donated.

Three-monthly news letters keep the membership in touch with each other. These provide an opportunity to share their experiences and often include articles by Scottish medical staff about e.g. prenatal diagnostic procedures, pre-conception clinics and genetic counselling.

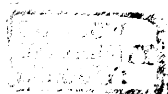
Based on some of the findings of this study, two booklets containing information relevant to termination for fetal abnormality were produced. The co-operation of all maternity hospitals in Scotland has enabled most mothers in this situation to have access to this information.

Following representation at the First European Conference on the Psycho-social Aspects of Genetics, in the Netherlands 1988, these booklets were requested by, and sold to, delegates from several countries in Europe.

Demand from mothers who had been given equivocal or abnormal diagnosis led to the change of emphasis evident in the title of the Association. Under the chairmanship of Eileen McKenzie, the main purpose of the association is to give care and support after diagnosis of fetal abnormality, and for as long as is necessary for those who undergo termination of pregnancy. However added to this is the aim to increase professional and public awereness of the psycho-social aspects and consequences of this intervention and thus to give impetus for improved services.

Included in this section are:

1 Leaflet One - The aims of "CARE" 1987
2 Booklet One "On hearing the news"
3 Booklet Two "Coming to terms"
4 Leaflet Two - The aims of "CARE" 1989



Scottish Association for Care & Support
after Termination for Fetal Abnormality

ON HEARING THE NEWS

CARE BOOKLET 1

Charity Reg. No. ED 588/87

his is the first of two booklets intended mainly to help parents who have been told that a severe abnormality has been found in heir unborn baby. However, we hope that it will be of use, as well, to all those who care for the parents; their relatives, friends and professional medical staff. There is a lot of information designed to answer some of the many questions which are to be faced. For this reason, the booklets are divided into sections. here is no need to read it all at once.

he headings are: Page

INTRODUCTION 2

HEARING THE NEWS 2

MAKING A DECISION 3

LABOUR 3

WHAT TO PACK FOR HOSPITAL 4

SEEING AND HOLDING YOUR BABY 4

AND WHAT ABOUT THE FATHER 5

RELIGION 6

POST-MORTEM 6

BURIAL 6

POST-TERMINATION HOSPITAL CARE 7

FEELINGS 7

GOING HOME 8

CARE (SEEKING HELP) ..... 8 & 9

YOUR OWN NOTES & QUESTIONS 10

his book is free to all parents who may be faced with the cision of terminating a pregnancy, but the Association must ke a charge, to cover printing costs, to any other interested rties)

[M]AKING A DECISION

Once you are sure of all the relevant facts concerning your baby, take time to consider what to do. Your obstetrician may give some guidance, but you may also find it helpful to discuss this information with friends, relatives your family doctor or a member of the clergy. Ultimately, only you can decide what is the best in the long run, for you, your family and the unborn baby.

If you decide to continue the pregnancy, "CARE" can refer you to the appropriate organisation so that you can prepare yourself for the birth of your baby.

If you feel that a termination is the best thing for your family and unborn baby, the members of "CARE" will try to provide the support you need.

[LA]BOUR

If you decide to end the pregnancy after the 12th week (three months) you will have to go through labour. It is important that you know as much as you can about the delivery, so please ask questions!

It will usually be possible for your husband, a relative or a friend to be present during some, or all, stages of the labour. The termination will take place in either the labour room or a side ward (depending on the hospital).

The delivery will be induced by one of several methods and you should not hesitate to ask how, in your particular hospital. It could be painful, but adequate relief is available in the form of pain-killing injections and, in some hospitals, epidurals may be available. There is no need to suffer quietly and you must keep telling the staff if you are in pain.

Depending on your hospital, you may be given a D & C routinely. Elsewhere, you will only have your womb cleared if the afterbirth is incomplete.

HAT TO PACK FOR HOSPITAL

You can expect to be in hospital for two to three days. Hospital requirements may vary a little, but you are likely to need:

2 Nightdresses
2 Comfortable bra's
1 Dressing-gown
1 Pair of slippers

Toilet requisites: Face flannel, a towel, soap, toothpaste and toothbrush, hairbrush, makeup and tissues.

Optional

A bottle of squash or fruit juice
A few favourite magazines
A pen and writing paper
Some hospitals allow you to take in your own portable radio or television.

EING AND HOLDING YOUR BABY

Should you see and hold your baby?

This is not an easy decision. Many people feel too upset to think about this before the termination. Please try to consider this because many parents feel later that holding their baby (however small) helped them to come to terms with their loss. Some are frightened to look because they do not know what to expect. In this case, ask your midwife to give you a gentle wordpicture.

Many parents would not consider seeing or holding their baby and have not regretted their decision.

It may be helpful to seek guidance from you midwife and/ or obstetrician.

An alternative might be to ask for your baby to be photographed. The pictures would be kept in your file, available for you a week, a month or even several years later.

ND WHAT ABOUT THE FATHER?

One of the comments made by our male members in "CARE" was 'I felt so helpless during the termination'.

It is hard to advise how best you can help your wife/ partner at this time as, obviously, you know your wife/ partner better than we do, but here are a few points you may consider.

Most couples find it helpful to be together during the termination. For the woman it is a stabilising influence to have someone who is so closely involved with the unborn baby with her during this confusing time.

She may feel too drowsy or tired to consider seeing the baby and the husband/partner may want to do this instead and if she wishes, discuss this with her later.

The man, too, may find it easier to understand his wife/ partner's feelings after the termination if he has been with her at the time.

If ever there was a time for mutual support - this is it.

ELIGION

Even if you are not religious, you may find it helpful to talk with a member of the Clergy or a religious leader; the hospital Chaplain should be available.

If you wish to have a blessing or a small service for your baby, please consider this before (or during) the termination so that special arrangements can be made.

OST-MORTEM

A detailed post-mortem examination is invaluable in providing information about your baby's condition and is, in some cases, vital for informing you about the risk of abnormality in future pregnancies. At all times your baby will be treated with respect. Your obstetrician will be notified when the results are available and you will be able to discuss them during the six-week post-termination visit.

URIAL

There is no legal requirement for burial or official cremation if the pregnancy has not gone beyond 27 weeks and the death does not have to be registered.

After thorough examination, the baby is usually "cremated" in the hospital. No ashes will be available. If you feel strongly that your baby should have a funeral and a religious service, this may be arranged. There is no death grant available for this and no financial assistance can be given. Detailed information concerning funerals can be obtained from CARE.

OST-TERMINATION HOSPITAL CARE

You may be nursed in the postnatal, antenatal or gynaecological ward; in the main area or in a side room. Do not be afraid to tell the staff if you are unhappy about your care. Some women prefer to be alone; others prefer to be amongst other women. Depending on the accommodation available, the midwives will be happy to consider your request. Unless there are special circumstances, the average hospital stay is 2 to 3 days. Do not hesitate to ask questions and do ask for further information if you do not understand the answers. It may help if you write your questions down as you think of them.

ELINGS

The feelings after a termination are often compared with the grief which one feels after a bereavement. It starts with shock and numbness. The numbness can last for a very long time and some women are unable to show any emotions.

There may be feelings of anger, guilt and sadness; sometimes it is helpful to talk about them or to write your feelings down on paper. Feelings are, however, very individual emotions and vary from person to person.

For many people, crying is more helpful than trying to control your emotions; it is almost always better, if you can, to express your feelings.

GOING HOME

Most mothers prefer to go home as soon as possible, but some will need to stay a bit longer for medical reasons. Before your discharge from hospital, it may be helpful to check up on a few points.

Have arrangements been made for your post-termination visit or will you be given an appointment by post?

Does your family doctor know about your termination? It would be helpful to tell the sister or midwife on duty if you would like a midwife or health visitor to visit you at home. The District nursing staff do not visit routinely after a termination for fetal abnormality, but this can easily be arranged.

Ask about breast care and how long you can expect to have a discharge.

Ask the staff to give you CARE Booklet 2, which deals with the post-termination period at home, or send a large stamped addressed envelope to us so that we can send one to you.

CARE (SEEKING HELP)

However helpful and understanding your family and friends may be, you may wish to talk with other couples who have had similar experiences. CARE can introduce you to people who have volunteered to help in this way.

If you prefer it, support can be given by correspondence or telephone and CARE has a list of people in your own area. For further details, please contact either:

Janice Moreland
790 Crookston Road
GLASGOW G35 7TT
Tel: 041-882-6080

or

Morag Wilson
11 Balmanno Green
Stenton, Glenrothes
Fife, KY7 4TD
Tel: 0592-775240

On request, you will receive a three monthly newsletter and have a vote in the decisions made in the Association.

If you feel that we have left out important information in this booklet, we would be very pleased to hear from you.

All information is free of charge, but if you feel you would like to make a contribution, this would be gratefully received.

M.C.A. White

Revised: November 1988

knowledgements and thanks for information and ideas from members of CARE, SATFA and the SANDS group.

YOUR OWN NOTES AND QUESTIONS

Scottish Association for Care & Support after Termination for Fetal Abnormality

COMING TO TERMS

CARE BOOKLET 2

Charity Reg. No. ED 588/87

This is the second of two booklets intended mainly to help arents who have had a termination for fetal abnormality. We ope, however, that it will be of use as well to all those who care r the parents; their relatives, friends and professional medical aff.

There is a lot of information, designed to answer some of e many questions which are to be faced. For this reason, the ooklet is divided into sections so that there is no need to read em all at once.

(This booklet is free to all parents who have just had a rmination of pregnancy, but to cover printing costs, the Assoation must make a charge to any other interested parties)

he sections are;

INTRODUCTION 3

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YOUR BODY AFTER TERMINATION OF PREGNANCY 4

FEELINGS 4

CHILDREN 5

YOUR PARENTS 6

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OUR BODY AFTER TERMINATION OF REGNANCY

Mothers who have had a termination after 18 weeks gestation often produce milk. This happens between two and five days after the termination. The feeling of the milk coming in varies from a mild discomfort to actual pain. The breasts may become hard, hot and sore. This can be a distressing experience. Drugs are sometimes prescribed, but the milk will, anyway, dry up after no more than one week. Try to resist the urge to express (or squeeze out) the milk as this will only produce more. To make yourself more comfortable, wear a tight-fitting bra by day and by night, and avoid excess fluid intake. Cold flannels on the breasts and showering the breasts with cold water may bring some relief while others find warm baths helpful and paracetamol is a useful pain-killer.

There will be some bleeding and discharge for a few weeks. If you feel very uncomfortable or the discharge becomes foul smelling or if you are bleeding heavily, it is very important that you contact your G.P. immediately.

Normal periods usually restart after 6 - 8 weeks, but sometimes take 3 - 4 months and may be irregular for some time.

If you have not received an appointment for a post-termination visit, get in touch with the hospital or your family doctor.

ELINGS

As discussed in CARE Booklet 1, the feelings after a termination are often compared with the emotions after a bereavement. For some, the feeling of shock and numbness persist after coming home. Others feel anger, guilt

and sadness. Feelings, however, are very individual and vary greatly from person to person. Some may wish to discuss the event all the time while others may feel withdrawn, isolated and unable to talk.

A sense of failure may be experienced by one or both partners. The man often feels that he is expected to be stronger and better able to cope, but if he pretends that nothing has happened and refuses to discuss the incident, this can isolate his partner. It is important that you both respect and understand each others feelings. If discussion is difficult you could involve a mutual friend or a professional person. This is not a sign of failure.

For many people, crying is more helpful than trying to control their emotions. It is almost always better, if you can, to express your feelings. Some people come to terms with the termination much more quickly than others. In general, you cannot expect to get over the loss in a few days or weeks, even if well-meaning people make you believe that you should. It may be difficult to carry on as normal.

In the beginning, the baby may occupy your thoughts most of the time, but other aspects of your life will gradually interest you again.

Time should slowly take the edge off your pain.

CARE will provide help and further information when required.

HILDREN

If you have other children, it will help them if you talk honestly about your experience and do not try to pretend that nothing has happened. Older children will need an explanation and further discussion.

internal movement? Even couples who lose an advanced pregnancy often receive a strong message from society that their loss is not very important. Sad, but not really a tragedy.

Yet, it is at this time that the couple need support, comfort and understanding. They need to feel that others are sensitive to their anguish and share the feeling of loss. The expression "You can always have more children" is of no comfort at that time. They need to be able to discuss their feelings, which can include anger, guilt and a sense of failure. And they need to know that these feelings are normal parts of the grieving process.

They need someone who will listen to the same details again and again. Friends and relatives who listen and react with understanding, who console and care and who realise that the need for support may last for a long time, are the greatest help to couples who have made one of the most difficult and distressing decisions of their lives.

ARE (SEEKING HELP)

However helpful and understanding your family and friends may be, you may wish to talk with other couples who have had similar experiences. CARE can introduce you to people who have volunteered to help in this way. If you prefer it, support can be given by telephone. For further details, please contact:-

Janice Moreland	or	Morag Wilson
790 Crookstone Road		11 Balmanno Green
GLASGOW		Stenton, GLENROTHES
G35 7TT		Fife, KY7 4TF
Telephone 041-882-6080		Telephone 0592-775240
(Organiser & Treasurer)		*(Secretary)*

or Margaretha White
Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospital, Yorkhill
GLASGOW G3 8SJ
Telephone 041-339-8888 Ext 7175
(Co-organiser)

;ENETIC COUNSELLING

After termination for fetal abnormality, it is advisable that you receive genetic counselling. This will provide you with information about the condition of the fetus, the risk of the abnormality happening again and any test available to you during your next pregnancy.

Genetic counselling may be given by your obstetrician and/or following referral to a specialised clinic. If no-one mentions counselling to you, and you would like to visit the specialised clinic, then you should ask your obstetrician or G.P. to refer you to a clinic.

In a Genetics Clinic you will be seen by a person with a medical background and specialised training in genetics. They will look into your medical and family history. There will be plenty of time for you to discuss all your relevant problems, worries and doubts with the counsellor.

A list of Scottish Genetic Advisory Centres is included at the end of this booklet.

ETURNING TO WORK

There is no entitlement to maternity allowance/benefit or maternity leave for a pregnancy terminated before 28 weeks. You may (and should) take some sick leave. If you have received an Exemption Certificate, you must return

this to the Department of Health and Social Security explaining the change in circumstances.

How much time is spent at home varies from person to person. Some want to get back to a normal routine as soon as possible, others will need a little longer to collect themselves and face working conditions.

If it was well known that you were pregnant, broaching the news of your loss might be a painful experience. It may help you to ask a friend at work to prepare your colleagues for your return.

EX

For a while you may not feel like making love. This is quite normal. However, the time will come when both of you are ready to restart a sexual relationship.

Friction occurs when one partner needs to demonstrate or regain closeness by making love and the other cannot separate lovemaking from the memory of the previous pregnancy. If you disagree strongly about this and feel that your relationship is under pressure, then you should consult your GP or family planning clinic.

They may refer you for specialised counselling.

LANNING THE NEXT PREGNANCY

Although, just after the termination, you may feel that you would not like another pregnancy, your opinions are likely to change as your emotions and your body return to normal. Friends and colleagues will have various ideas about the wisdom of another pregnancy, but you and your husband are the only ones who can decide when you can cope with the strain and excitement imposed by the new

conception. It is advisable to use some form of contraception for at least three months to allow normal periods to restart. In some cases, tests will have been carried out on other members of your family and it is wise in these circumstances, to await the results of these tests before contemplating another pregnancy.

It is quite natural for you to wonder if there is a link between what you did, or did not do during your pregnancy, and the abnormality. In practically all cases, there is no connection.

It is often forgotten that the time immediately before becoming pregnant is as important as during pregnancy. For your own peace of mind you may like to provide the new baby with the best possible start. Perhaps you should ask yourself whether you are both taking a good and varied food intake or are smoking or drinking too much? In case of illness, you should mention to your family doctor that you are planning another pregnancy so that he or she can prescribe medicine which would not be harmful to the developing fetus.

'RE-CONCEPTION CLINIC

Some hospitals now hold regular pre-conception clinics which you can attend by referral from your own doctor or by just making an appointment yourself. These clinics not only give you a further opportunity to discuss your recent pregnancy, but also allow you to prepare yourself for the next one. Diet, smoking and drinking patterns will be advised upon. You will be given information on the availability and timing of tests to make sure that your next baby is normal and doing well. Any need for further specialist advice will be discussed.

IST OF PRE-CONCEPTION CLINICS

Dr E SUTHERLAND Aberdeen Maternity Hospital ABERDEEN AB9 2ZA	0224 - 681818 Ext. 52072
Dr I GREER / Dr F JOHNSTONE Edinburgh Royal Infirmary EDINBURGH	031 - 229- 2477 Ext. 2266
Dr J WALKER Glasgow Royal Maternity Hospital Rottenrow, GLASGOW G4	041 - 552 - 3400 Ext. 236
Dr M WHITTLE The Queen Mother's Hospital GLASGOW G3 8SJ	041 - 339 - 8888 Ext. 301

REGNANT AGAIN

As soon as you suspect that you are pregnant, go and see your family doctor. This will enable him or her to confirm the pregnancy and arrange for you to have the tests appropriate to your medical history. In some cases, pre-natal diagnosis may be offered as early as 8 to 10 weeks into your pregnancy, so it is very important to see your doctor in good time.

People will tell you, "Try not to worry", but that can be easier said than done. It can be hard to let events run their course and to wait for the results of tests, but there are some things you can do. Talking to another mother in CARE may help. Practising relaxation on a regular basis

THE ASSOCIATION - CARE

The Scottish Association for **CARE** and Support after Termination for Fetal Abnormality:

CARE was started to offer support and help to parents who have been told that their unborn baby has a severe abnormality or serious genetic disease.

It is run on a voluntary basis, by parents for parents. All members have experienced a termination for fetal abnormality - professionals and other interested parties are welcomed as associate members.

The aims are:-

To provide a 'link' service between parents where this is requested.

To produce written information about termination, the post-termination care and support, fetal abnormality and pre-natal diagnosis.

To support research into ways for improving the services provided within the N.H.S.

To raise funds in order to contribute towards research into the causes of the fetal disorders which lead to termination of pregnancy. A separate account for this purpose has been set up and is called 'The Daisy Fund'.

To educate all medical staff, who are in daily contact with parents facing a termination, of the needs of these parents.

To represent our members at meetings and conferences where their interests are likely to be discussed.

Members will receive a regular newsletter and have the right to vote when financial and other decisions are made.

Membership is free and a registration form is included at the end of this booklet.

Contributions, donations or fund-raising offers are all very welcome!!

Cheques can be made payable to CARE and should be forwarded to:

The Treasurer
CARE
790 Crookston Road
GLASGOW G35 7TT

CARE's Charity Registration Number is ED 588/87

I.C.A. White *Revised: November 1988*

cknowledgements and thanks for information and ideas from members of CARE, SATFA and the SANDS group.

URTHER INFORMATION

If you would like more detailed information about any of the topics discussed, the following books and leaflets are available via your local library, **CARE** or other Associations.

TITLE	AUTHOR ; PUBLISHER RELEVANT PORTION
Pregnancy	Gordon Bourne ; Pan Chapter 36 The Abortion Act of 1967 and Chapter 44 The abnormal baby.
When Pregnancy Fails	Susan Borg & Judith Lasker Routledge; Kegan & Paul. Chapter 3 Prenatal Diagnosis and Unwanted Abortion.

Preconception Care, *Preparing for your Next Baby,* *Neural Tube Defects*	Stillbirth and Neonatal Death Socy. Argyle House 29 - 31 Euston Road LONDON NW1 2SD
Stress and Relaxation	Jane Madders, Martin Dunitz - 1979 Price: £3.95
Eating for Health	Christopher Robins Granada Publishing 1985 - Price: £4.95
Systematic Relaxation Pack	Write to Systematic Relaxation at Telford Road, Bicester, Oxon OX6 0TS - Price: £9.95
Wellwoman	Scottish Health Education Group, Woodburn House, Canaan Lane, Edinburgh EH10 4SG. (no charge)
Health Choices (Book and Audio Tape on Relaxation)	Scottish Health Education Group, c/o CARE, 11 Balmanno Green, Stenton, Glenrothes KY7 4TD.

ȷSEFUL ADDRESSES

Foresight Association
The Old Vicarage
Church Lane
Godalming, Surrey GU8 5PN Tel: 042879 4500

his Association has a wide range of booklets on pre-conception care, e.g. *Guidelines for Future Pregnancies* Price £2.00 plus S.A.E.

ASH (Action on Smoking and Health)
6 Castle Street
Edinburgh Tel: 031 - 225 - 4725

his group gives information on the hazards of smoking and advice on how to give up smoking.

Relaxation for Living
29 Burwood Park Road
Walton-on-Thames
Surrey Tel: 0932 227826

his group supplies relaxation tapes and cassettes.

Family Planning Association
4 Clifton Street
Glasgow G3 Tel; 041 - 333 - 9696

;ENETIC ADVISORY CENTRES IN SCOTLAND

Dr A W Johnston
Department of Genetics
University of Aberdeen Medical School, Foresterhill,
ABERDEEN AB9 2ZD Telephone: 0224-681818, Extension 2120

Cytogenetics Laboratory
Department of Pathology
Ninewells Hospital and Medical School
DUNDEE DD1 9SY Telephone: 0382-60111, Ext. 2680

Dr A Raeburn
University Department of Human Genetics
Western General Hospital
Crewe Road,
EDINBURGH EH4 2XU Telephone: 031 - 332 - 2525, Ext. 4534

Peripheral Clinics (contact the above department) at
Dunfermline and Kirkcaldy

Professor J M Connor
West of Scotland Regional Genetic Service
Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospitals
GLASGOW G3 8SJ Telephone: 041 - 339 - 8888, Ext. 7117

Peripheral Clinics (contact the above department) at
Alexandria, Bellshill, Dumfries, Falkirk, Greenock, Irvine,
Paisley, Stirling and Stranraer

The Paediatric Unit
Raigmore General Hospital
INVERNESS Telephone: 0463 - 234151

'OUR OWN NOTES AND QUESTIONS

DONATION TO "CARE"

To: Mrs Janice Moreland
Treasurer
CARE
790 Crookston Road
Glasgow G35 7TT

From:

Name:..

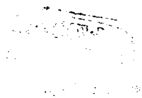
Address:...

....

....

....

The Scottish Association for Care and Support
After Termination for Fetal Abnormality.



find enclosed a small donation to help "CARE" in its hroughout Scotland.

Amount: £ __________

d like my donation to go towards the everyday work of , i.e. the printing of booklets, leaflets and the quarterly tter, postage, etc.

Please tick here ☐

ld like my donation to go towards research into the of fetal abnormality.

Please tick here ☐

d like my donation divided equally between the two mentioned accounts.

Please tick here ☐

require a receipt / I shall not require a receipt.

Please delete as appropriate

RE's account is with the Bank of Scotland, Glasgow

RE's Research account is with the Gateway Building Society under the name of "The Daisy Fund".

If you would like further information about CARE and a copy of our booklet and latest Newsletter, please send a large stamped addressed envelope to the Secretary at 11 Balmanno Green, Stenton, Glenrothes, Fife KY7 4TD or telephone Glenrothes (0592) 775240.

As with any self-help group, funds are badly needed and if you think that you could help, in any way, donations made payable to CARE can be forwarded to The Treasurer at 790 C[illegible] G53 7TT.

ORGANISER & TREASURER
Mrs Janice Moreland
32 Linkwood Place
Lawthorn
Irvine, Ayrshire
Tel : 0294 218839

We would like to extend our sincere thanks to:
Boehringer Corporation (London) Ltd.,
for their Sponsorship of this leaflet.

ORGANISER & TREASURER
Mrs Janice Moreland
790 Crookston Road
GLASGOW, G53 7TT
Telephone: 041 882 6080

or

ASSOCIATION SECRETARY
Mrs Morag A Wilson
11 Balmanno Green
Stenton
GLENROTHES, Fife, KY7 4TD
Telephone: 0592 775240

or

CHAIRPERSON
Mrs Eileen Mackenzie
48 Duncan Avenue
Scotstown
GLASGOW G14
Telephone: 041 954 4442

or

CO-ORGANISER & ADVISER ON MEDICAL MATTERS
Mrs Margaretha White
Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospital
Yorkhill
GLASGOW
Telephone: 041 339 8888, Ext. 4365

THE SCOTTISH ASSOCIATION FOR CARE AND SUPPORT AFTER DIAGNOSIS OF FETAL ABNORMALITY

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Charity Registration No. ED588/87

WHAT IS CARE?

CARE is a Scottish Association whose full title is: "The Scottish Association for CARE and Support after Diagnosis of Fetal Abnormality".

WHO WILL BENEFIT FROM CARE?

CARE has been set up to offer support and help to parents during the time of prenatal diagnosis, i.e. scanning, waiting for results of amniocentesis and other tests which may lead to the discovery of an abnormality or genetic disease.

These couples are faced with the possibility of terminating the pregnancy of a baby that is both loved and wanted. This is a distressing and confusing experience.

Before CARE was started, no Scottish organisation concentrated on the special problems associated with this decision.

HOW IS CARE ORGANISED?

CARE is run on a voluntary basis, by parents for parents. Every member of CARE has faced a similar situation and has had to decide whether to continue with the pregnancy or to have a termination because of the severity of the abnormality or disease. The organisers, when required, draw on guidance, support and advice from the Department of Medical Genetics at Yorkhill Hospital, Glasgow and other trained professionals.

WHAT ARE THE AIMS OF CARE?

1 To organise a 'link' service between parents faced with the knowledge that their unborn baby has a serious abnormality or genetic disorder.

For parents who request this service, volunteers who have been in a similar situation will listen, support and help couples through this difficult and distressing period in their lives. The volunteers will, in no way, influence the parents in making their decision but will help those couples who decide to continue with the pregnancy by putting them in touch with the appropriate support group for them and their baby. For those couples who decide to have the pregnancy terminated, the parents will know that CARE can refer them to other couples who have, themselves, been in a similar position.

2 To produce literature:

(a) For the parents themselves; because, at present, written information about the options open to parents at this time, is not readily available.

(b) For the families and friends of the parents; to make them more aware of the problems and anxieties which the parents face and how best to help them through this trying time.

(c) For hospital staff, the Primary Care team and others; to raise their awareness of the very special needs of parents prior to and after the decision has been made.

3 To raise funds for the day to day expenses of CARE and to finance the production and distribution of literature.

4 To produce a regular Newsletter, which will be available to anyone on request.

5 To raise money to contribute towards research into the disorders which may lead to fetal abnormality and genetic diseases.

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Although termination for fetal abnormality is still relatively uncommon, improved prenatal diagnostic techniques are increasing the numbers of parents who are told that their unborn baby has a severe abnormality or serious genetic disease and this means that the demand for the services which CARE provides will, inevitably, increase.
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If you would like further information about CARE and a copy of our booklet and Newsletter, please send a large stamped addressed envelope to either of the addresses shown overleaf.

We would also like women who have had a termination to contact us, not only for information, but to assist us at a later stage.

As with any new Association, funds are badly needed and if you would like to help, donations made payable to CARE can be forwarded, likewise, to any of the addresses shown on this leaflet.

ORGANISER
Mrs Janice Moreland
790 Crookson Road
GLASGOW, G35 7TT
Telephone: 041 882 6080

or

ASSOCIATION SECRETARY
Mrs Morag A Wilson
11 Balmanno Green
Stenton
GLENROTHES, Fife, KY7 4TD
Telephone: 0592 775240

or

CO-ORGANISER
Mrs Margaretha White
Duncan Guthrie Institute of Medical Genetics
Yorkhill Hospital,
Yorkhill
GLASGOW
Telephone: 041 339 8888, Ext. 7175

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Charity Registration No. ED588/87

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Before CARE was started, no Scottish organisation concentrated on the special problems associated with this decision.

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1 To organise a 'link' service between parents who have experienced a termination for fetal abnormality. For parents who request this, volunteers who have been in a similar situation will listen, support and help couples through this difficult and distressing period in their lives.

2 To produce literature:

(a) for the parents themselves; because, at present, written information about termination for fetal abnormality is not readily available.

(b) for the families and friends of the parents; to make them more aware of the problems and anxieties which the bereaved parents have and how best to help them through this trying time.

(c) for hospital staff, the Primary Care team and others; to make them aware of the very special needs of parents before, during and after the termination.

3 To raise funds for the day to day expenses of CARE and to finance the production and distribution of literature.

4 To produce a regular Newsletter, which will be available to anyone on request.

5 In the future, CARE will raise money to contribute towards research into the disorders which lead to a termination of pregnancy.

- - - - - - - - - -

Termination for fetal abnormality is still relatively uncommon, but improved pre-natal diagnostic techniques are increasing the numbers of parents who are told that their unborn baby has a severe abnormality or serious genetic disease.

This means that the demand for the services which CARE provides will increase.