CHAPTER 1

INTRODUCTION

The practice of genetic counselling is burgeoning (Biesecker et al.1993, p.213). This is the result of an increased public awareness of genetic problems (Partington 1986, p.63) and rapid developments in human molecular genetics.

Molecular geneticists across the world are racing to map the 50,000 to 100,000 genes contained in each human somatic cell (Modell & Modell 1992,p.24). The mapping of new disease causing genes makes genetic diagnosis, carrier testing and prenatal diagnosis possible for those diseases. These technologies are discussed as part of genetic counselling.

Genetic counselling itself has attracted considerable interest from researchers. Particular attention has been given to the measurement of outcomes of genetic counselling, generally in the areas of reproductive decision making (Wertz & Sorenson 1986a; Sissine et al.1981; Sorenson et al.1987) and recall of information (Seidenfeld & Antley 1981; Sorenson, Kavanah & Mucatel 1981; Rowley, Lipkin & Fischer 1984). Some researchers (Chan et al.1993) have observed changes in the incidence of birth defects following the introduction of technologies frequently discussed in genetic counselling, and some have examined genetic counsellee satisfaction levels (Shiloh & Berkenstadt 1990). Despite the extent of research into genetic counselling, and the growth and apparent increase in sophistication of the practice, relatively little attention is paid to understanding the process of genetic counselling.

Kessler (1992, p.6) highlighted the lack of understanding of the process of genetic counselling by describing it as a 'mysterious black box'. He (Kessler 1992, p.8) suggested that the way to achieve the best, most effective, informative and helpful genetic counselling possible is through process studies and the elucidation of what really happens during the course of genetic counselling.

A relatively small number of authors have examined process issues in genetic counselling. Partington (1986) described the stages of genetic counselling. These were the stages from the genetic counsellor's perspective. For example, defining the genetic counsellee's question, diagnosing, and constructing the pedigree. Lippman-Hand and Fraser (1979) explored the structure of the genetic counselling session and Kessler (1982) examined the interactions between genetic counsellees and genetic counsellors. Little, if any, research has concentrated on the experiences of the genetic counsellees. This thesis is concerned with process issues in genetic counselling from the genetic counsellee's perspective.

Some authors, for example Lipkin et al. (1986, p.115), have used the term *education* to describe the process of genetic counselling. However, there appears to be no reference in the literature made to learning processes in genetic counselling. This thesis is written from the standpoint of a practising genetic counsellor who views genetic counselling as a process of teaching and learning. Since this thesis is concerned with the experiences of genetic counsellees, not genetic counsellors, the emphasis is on **learning**, not teaching or education.

Genetic counselling as a profession is in its infancy and does not have its own theoretical framework in the same way nursing, medicine and social work have a theoretical framework to guide practitioners. The lack of a theoretical framework invites the application of models from other disciplines such as adult learning. This thesis is an exploration of the applicability of an adult learning approach to genetic counselling. The intention is to use this approach to identify the learning activities of genetic counsellees through the genetic counselling process.

The organisation of this thesis is as follows. Chapter two is dedicated to describing the purposes and characteristics of genetic counselling. To help accomplish this, a brief case example is given. Chapter three is a review of adult learning theory and its applicability to genetic counselling. Particular attention is paid to the selection of a model of adult learning relevant to the present study. The research methodology and procedures used to collect and explore the data, in the form of transcripts of genetic counselling sessions, are discussed in Chapter four. Ethical issues arising from the present study are also discussed in Chapter four. Four selected transcripts of genetic counselling sessions are explored in Chapter five. The conclusions and recommendations arising from this exploration are discussed in Chapter six.

CHAPTER 2

THE PURPOSES AND CHARACTERISTICS OF GENETIC COUNSELLING

The following case example is intended to provide the reader with an understanding of the purposes and characteristics of genetic counselling. It also serves as a point of reference for the thesis. The case involves a genetic counsellee whom the writer had seen for genetic counselling on several occasions. The genetic counsellee, referred to here by the pseudonym Meryl, had an induction of labour at eighteen weeks of pregnancy because her baby had anencephaly. In anencephaly, the brain is severely underdeveloped and the baby is usually stillborn or short-lived (Buyse 1990. p.139).

Meryl worked as an intensive care nurse in a relatively large rural hospital. A colleague of hers suggested that she seek genetic counselling. That colleague, and one other, had been through a similar experience and felt assisted by genetic counselling.

Meryl was not referred by a medical practitioner, the usual way of entering genetic counselling. She self-referred, but not immediately. It took Meryl a period of emotional preparation before she could sit down with the writer and talk about her son who died from anencephaly. This was Meryl's first pregnancy and she wanted a large family. The whole experience had affected her self esteem and in particular her perception of her ability to care for a family.

Meryl had a number of questions which are typically addressed in genetic counselling. She wanted to know the chance of a similar problem recurring in any future children, if

that could be prevented, and if not, the possibility of detecting a similar problem early in the next pregnancy.

The questions Meryl had were elicited during an intake session. An intake session is considered to be an important part of genetic counselling. It is where the genetic counsellor contacts the genetic counsellee prior to the more definitive genetic counselling session, principally to take an history and construct a family tree (pedigree). In Meryl's case, the intake session was conducted over the telephone and also included discussion about how accurate was the diagnosis of anencephaly. As would be usual in such a situation, permission was given by Meryl for the writer to obtain copies of any medical reports which would confirm that diagnosis.

This is the way genetic counselling usually commences. The next session occurs in person and involves the genetic counsellor giving information which may answer the genetic counsellee's questions. Meryl attended this session alone, her husband was encouraged to attend but he did not feel that it was necessary for him. The genetic counselling occurred in a counselling room at the local Community Health Centre. Meryl's questions were able to be answered. However, in a proportion of cases, the information cannot be provided because there is uncertainty about the diagnosis, or perhaps the problem for which genetic counselling had been sought is rare and there are no data available on the disorder.

Following a genetic counselling session, the usual practice is for the genetic counsellor to write to the genetic counsellee. This is a letter which summarises the information that had been discussed during the genetic counselling. In some cases, a follow-up appointment is made or the genetic counsellee is referred to another health professional or to a support group.

To the naive observer, a genetic counselling session would appear to involve lengthy, serious and personal discussion. The genetic counsellor usually does most of the talking. The genetic counsellor has the agenda, the training, and has experienced the process many times before. The genetic counsellor understands the processes he or

she is undergoing. What is less clear is the process that the genetic counsellee undergoes.

Some specific genetic counselling issues in Meryl's case are now discussed. Meryl had no clear expectations of genetic counselling. Her main issue was her intense sense of loss. Her bereavement meant that, although she was asking the usual questions about recurrence, prevention and prenatal testing, she was preoccupied with her emotions. Thus, Meryl proceeded to reflect on and discuss her loss and this was facilitated by the writer. Meryl started her narrative at the time anencephaly was diagnosed by a routine ultrasound. She discussed the medical details with the writer as well as the difficulty she and her husband had had in deciding if they would continue with the pregnancy or opt for termination of pregnancy.

Meryl was receiving support from her family, particularly from her husband and mother. However, Meryl's father failed to understand the magnitude of her loss. That was because the baby was born well before term and had not grown and developed fully. To Meryl's father, the loss was not tangible. The result of this for Meryl was that her feelings of grief were minimalised, not considered legitimate.

Meryl retold her story several times over the following year. She developed an understanding of the medical and genetic facts involved. Perhaps her nursing experience contributed to this. Many people in Meryl's position would have been less well informed about medical genetics. Another difference between Meryl's case and what often occurs in genetic counselling is that generally there are fewer genetic counselling sessions scheduled, in many cases there is only one.

Meryl achieved another pregnancy and so the risk of recurrence became a reality. There was a one in twenty chance that anencephaly or a related problem would recur (Harper,1993, p.177). Meryl and her husband had to decide if they would have prenatal testing to detect or exclude anencephaly in the pregnancy. They received advice from a clinical geneticist, who is a medical practitioner expert in genetic disorders, and an obstetrician who performs prenatal testing. The writer was concerned more with Meryl's

anxiety about the chance of the next baby having anencephaly, and with her decision making concerning prenatal testing. Since genetic counselling requires a collaborative effort, the writer, the clinical geneticist and the obstetrician met for a case conference about Meryl. This provided an opportunity to review Meryl's situation and coordinate future management strategies.

Meryl wanted to make her own decisions about prenatal diagnosis. She did not want to be directed by the health professionals involved in her care. Meryl was pleased to be pregnant and decided to undertake prenatal testing in the form of a series of ultrasounds to assess the baby's brain development.

No abnormalities were detected by the ultrasounds. The pregnancy was uneventful and Meryl's second son was born healthy. Meryl eventually adjusted to the loss of her first son and came to learn that her grief response was normal. Therefore, Meryl exited genetic counselling changed. She had undergone a long process which commenced prior to genetic counselling and may have continued beyond it. One might consider this process a learning process.

To further enhance the reader's understanding of the process of genetic counselling, its history, goals and definitions are discussed. Where possible, the case example of Meryl is referred to.

The history of genetic counselling has been described by Kessler (1980) as comprising three different paradigms - eugenics, preventative medicine and psychologic medicine. According to Kessler:

> Each paradigm is based on a differing set of beliefs and assumptions regarding the goals, principles, and practices of genetic counselling (Kessler,1980, p.167).

The three paradigms outlined by Kessler (1980) are reviewed here, starting with eugenics. The eugenics paradigm stemmed from the intellectual excitement generated by evolutionary theory and the possibilities of managing and improving our genetic heritage

(Kessler 1980, p.168). The following statement made in 1865 by Sir Frances Galton illustrates the beliefs underpinning the eugenics paradigm.

> ...if a twentieth part of the costs and pains were spent in measures for the improvement of the human race that are spent in measures for the improvement of the breeds of horses and cattle, what a galaxy of genius might not we create (cited in Reed 1974, p.333).

The above quotation represents positive eugenics which is aimed at increasing the propagation of so called desirable traits. Some community leaders, such as the Bishop of Ripon, also supported positive eugenics and urged procreation among the fit in the 'imperial interest' (Kevles 1985, p.85). Genetic counselling focused on the gene pool rather than on individual needs. The genetic counsellee was little more than a means for improving the lot of subsequent generations. Little, if any, attention was paid to how the genetic counsellee experienced their genetic situation or genetic counselling. The genetic counselling was directive (Kessler 1980, p.168) and the genetic counsellee's task was to comply with the genetic advice given.

Tage Kemp offered an approach to medical genetics which was different from that of Galton (1865) and the other supporters of positive eugenics. The translated closing sentence of Kemp's 1943 text, *Arvelighedslaere,* reads:

> Medical genetics in connection with the associated advice and registration create the necessary scientific foundation for carrying out measures aimed at preventing hereditary diseases (Reed 1974, p.334).

The difference between the approaches of Galton (1865) and Kemp (1943) is that Kemp (1943) advocated the prevention of hereditary disease, not the propagation of desirable traits. The prevention of genetic disease is termed negative eugenics. This approach was the foundation on which genetic counselling clinics were established in North America and the United Kingdom in the 1940s (Headings 1975, p.297). By the 1950s, the preventative medicine paradigm had become established in major medical centres around the world. The importance of accurate diagnoses and the need for contributions by the medical profession were hallmarks of this period. The characteristics of this type of

genetic counselling were described by Kessler.

> The traditional doctor-patient relationship with its stress on professional advice giving, became a major role of service delivery. The counsellor was expected to take the lead in pointing out the necessity of counselling and in providing genetic education as well as advice regarding reproductive decisions.(1980, p.168)

Genetic counsellees were not the centre of the preventative genetic counselling encounter. They '...were expected to take an overall passive and compliant role...'(Kessler,1980, p.169). In fact, there was considerable interest in the degree of compliance to genetic counselling and this was measured and reported in the literature. For example, the first studies into reproductive outcomes following genetic counselling were published at this time. Such papers included those by Carter et al.(1971) and Antley (1976). These papers also dealt with the question of how much information genetic counsellees remembered following genetic counselling. The conduct of such research is likely to have been a reflection of the belief that if genetic counsellees remembered the genetic facts accurately, they would make decisions against taking high risks and so the birth of children with genetic problems would be prevented.

During this period of medicalisation of genetic counselling, genetic counsellors moved away from direct advice giving and the notion of nondirectiveness became one of its tenets. Nondirectiveness involved giving genetic information and presenting options in an unbiased way, and permitting genetic counsellees to make their own decisions. This principle was widely accepted. According to a study by Wertz and Fletcher (1988), greater than ninety percent of six hundred and seventy seven clinical geneticists across eighteen nations regarded nondirectiveness as appropriate in genetic counselling.

Only recently was the nondirectiveness of genetic counsellors tested. Michie et al.(1997, p.40) analysed one hundred and thirty one transcripts of genetic counselling sessions, interviewed genetic counsellees and genetic counsellors and showed that genetic counselling was not characterised as uniformly nondirective. In each transcript there was an average of five point eight genetic counsellor advice statements (when direct advice was given to the genetic counsellee by the genetic counsellor), plus five point eight evaluative statements (when the genetic counsellor gave their own interpretation of the

genetic counsellee's situation - 'That is what we would consider quite a high risk') and one point seven reinforcement statements (when the genetic counsellor reflects or affirms the genetic counsellee's behaviour). These findings support an earlier suggestion by Clarke (1991) that, although nondirectiveness in genetic counselling may be desirable, it may not be possible.

Despite the likely unachievable nature of nondirectiveness, the pursuit of it meant that more attention was being paid to the point of view of the genetic counsellee. Their decisions came to be considered most important. However, the role of the genetic counsellor continued to dominate in actual genetic counselling sessions because the process involved predominantly the transmission of genetic information from the genetic counsellor to the genetic counsellee.

Recently, the usefulness of nondirectiveness, not just its achievability, was challenged (Kessler 1996; White 1996). Kessler (1996) suggested that genetic counsellees may be poorly served by mere provision of information in the absence of help and guidance, especially if the genetic counsellor does not demonstrate empathy for the genetic counsellee. Comments like these point up the importance of attending to the affective domain in genetic counselling. They highlight the limitations of the eugenics and preventative medicine paradigm and provide an argument in favour of the psychologic medicine paradigm which is discussed below.

The need for a more psychologically oriented genetic counselling was first raised in the 1970s by writers such as Fraser (1974, p.637) and there has been a shift towards this (Kessler 1980, p.169). The psychologic medicine paradigm embraces the belief that genetic counselling deals with human thinking, feeling and actions (Kessler 1980, p.170). The focus is on the genetic counsellee, not the genetic counsellor. As a result of the process, the genetic counsellee exits genetic counselling changed. This was the case with Meryl in the case example. Meryl was empowered to incorporate information about recurrence risks and prenatal testing into her plans for having another child. She accepted and dealt with her feelings of loss and so exited genetic counselling changed. Advocates of the preventative medicine paradigm would look towards Meryl's subsequent normal

child as the outcome of genetic counselling. However, proponents of the psychologic medicine paradigm would concentrate on Meryl's adjustment to her loss and improved coping. They might go a step further and say that this enhanced her confidence in reproductive decision making.

The degree to which genetic counsellors have embraced the psychologic paradigm is unclear. In 1980, Kessler (p.170) suggested that all three paradigms are reflected in modern practice, with the modal approach being a combination of the eugenics and preventative medicine paradigms. In 1997, it may be difficult to find evidence of the eugenics paradigm. It would appear that the preventative medicine and psychologic medicine paradigms are the usual forms of practice and this was illustrated in the case example of Meryl.

In Australia, increasing attention is being paid to the affective domain in genetic counselling, suggesting a move towards the psychologic medicine paradigm. For example, at conferences there is a trickle of papers and posters being presented by genetic counsellors who have studied affective domain issues. A reason for this may be that Australian genetic counsellors come from a variety of professional backgrounds including psychology, social work, education and nursing as well as science. Furthermore, all Australian genetic counselling training programs include courses in general counselling skills. This is a requirement of the professional accrediting body, the Human Genetics Society of Australasia (1997).

The paradigm under which genetic counselling operates is reflected in its goals. The goal of the eugenics paradigm was described earlier (Chapter two, p.8) as the propagation of desirable traits. During the 1960s and 1970s when genetic counselling operated on the principle that it should promote rational decision making, the goal was to deter further child-bearing in high risk genetic situations and encourage it in low risk situations (Palmer & Sainfort 1993). This is different from the psychologic medicine paradigm which promotes goals similar to those of Headings (1975, p.300) as follows.

1. The counsellee feels affirmed as being the most significant person involved in the counselling process and as the principal decision maker concerning the task jointly entered into with the counsellor.

2. The counsellee acquires an accurate concept of the inherited entity, its biological basis and prognosis, and the psychosocial adjustments which may have occurred as a consequence of the disorder.

3. Misconceptions held by the counsellee or in his/her social grouping are corrected.

4. The counsellee's anxiety is brought under control. In some instances this is a consequence of correcting misconceptions; in others, it involves a conscious assessment of anxiety-provoking facts and perceiving them as a realistic component of personal experience.

5. The counsellee develops confidence in his/her coping skills, which may be called for in adapting to the biological and psychosocial properties that characterise his/her situation.

Headings' (1975, p.300) goals emphasise the genetic counsellee as being the focus of genetic counselling. Bernhardt also reported a genetic counsellee centred goal - '...the patient and family become experts in their diagnosis and knowledgeable health consumers' (1989, p.954). The goals of both Bernhardt (1989, p.954) and Headings (1975, p.300) are related to change *in* the genetic counsellee, in order that they are able to exert control over their genetic situation.

Since genetic counselling is moving towards the psychologic medicine paradigm, and this is characterised by genetic counsellee centredness, it becomes important to ask how genetic counsellees perceive their own goals in seeking genetic counselling. To answer this question, Wertz, Sorenson and Heeren (1984, p.79) surveyed eight hundred and thirty six women seeking genetic counselling. Five hundred and forty four (sixty five

percent) reported that their major reason for seeking genetic counselling was to obtain information to help them decide if they should have a child. The authors concluded: 'A main goal of genetic counselling is to provide information that clients can use in making decisions about whether or not to have children' (Wertz, Sorenson & Heeren 1984, p.79), but that other goals should include:

> ...the reduction of guilt and anxiety, helping families to adjust to the presence of the genetic disorder, and providing information, possible treatment, or prenatal diagnosis. These are complex and difficult topics to discuss in and of themselves and warrant careful attention by genetic counsellors'(Wertz, Sorenson & Heeren 1984, p.79).

In some cases, genetic counsellees enter genetic counselling with unrealistic or no goals. Hsia confirmed this.

> People coming for genetic counselling often expect an absolute answer; many counsellees expect to have a single course of action recommended to them, with certainty of a happy outcome....It is not usual for people to be referred for genetic counselling without any realization of what genetic counselling can offer. An expected nondirective explanation of risks and options can be confusing to them (1979, p.174).

The work by Lippman-Hand and Fraser (1979, p.120) also suggests that some genetic counsellees have unrealistic expectations. They surveyed thirty couples and of the nineteen for whom childbearing was salient, six asked the genetic counsellor for guidance about what choices were appropriate for their situation. Presumably, the others were either satisfied with a nondirective approach or did not verbalise their need or desire for guidance.

Kessler (1992, p.6) reported that the agendas and goals of genetic counsellors and genetic counsellees may be discordant. Illustrating this, Wertz, Sorenson and Heeren (1986, p.253) showed that at the end of genetic counselling in almost nine hundred cases, fifty eight percent of genetic counsellors were not aware of the topic the genetic counsellees most wanted to discuss.

The discrepancy between the agendas and goals of genetic counsellors and genetic

counsellees raises the question of how well do genetic counsellors understand the experiences of genetic counsellees as they enter and participate in genetic counselling. What model might help explain that process?

The paradigm upon which genetic counselling is based not only influences its goals, but also its definition. The following definition, written in the 1970s, is referred to frequently in the genetic counselling literature.

> Genetic counselling is a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family:
>
> 1. comprehend the medical facts, including the diagnosis, the probable course of the disorder, and the available management;
>
> 2. appreciate the way heredity contributes to the disorder, and the risk of recurrence in specific relatives;
>
> 3. understand the options for dealing with the risk of recurrence;
>
> 4. choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and
>
> 5. make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder (Fraser 1974, p.637).

This definition is genetic counsellee centred and outlines certain tasks to be undertaken by the genetic counsellees themselves. It hints at a process in which the genetic counsellee moves from a position of comprehending medical facts, through to making choices and adjusting to the genetic situation. This concept of adjustment puts Fraser's (1974, p.637) definition within the realm of the psychologic medicine paradigm. However, there appears to be an assumption that the genetic counsellee's movement through the five steps listed in the definition leads to 'rational' decision making. If this were the case, the definition would be aligned more with the preventative medicine paradigm. Therefore, Fraser's (1974, p.637) definition could be described as having characteristics of both the preventative medicine and psychologic medicine paradigms.

Another frequently quoted definition of genetic counselling is that of Harper.

> Genetic counselling is the process by which patients or relatives at risk of a disorder which may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting and of the ways in which this may be prevented or ameliorated (1993, p.3).

The above definition is one of two definitions in Harper's (1993) text: *Practical Genetic Counselling*. It is not genetic counsellee centred and does not place any importance on the affective domain. Given the emphasis on preventing or ameliorating genetic disease, the definition is compatible with the preventative medicine paradigm.

Other definitions of genetic counselling require the genetic counsellor to attend to both the cognitive and affective domain needs of genetic counsellees. One such definition is that of Headings:

> In brief, the objective of genetic counselling is to provide accurate information in a manner enabling individuals or families to make decisions that optimize their sense of well-being in relation to the occurrence or potential occurrence of an inherited disorder (Headings 1975, p.298).

The term '...accurate information...' relates to the cognitive domain and '...optimise their sense of well-being...' relates to the affective domain. Similarly, Bernhardt (1989, p.952) described genetic counselling as both an educational and supportive process, and makes the point that most genetic counsellors recognise that the educational value of genetic counselling is maximised only after the psychological impact of genetic disease on the family is considered. These definitions by Headings (1975, p.298) and Bernhardt (1989, p.952) have characteristics of the psychologic medicine paradigm.

There are significant differences between many of the definitions of genetic counselling. There are also areas of commonality and these have been summarised by writers on genetic counselling as follows. Every definition of genetic counselling mentions the need to give genetic counsellees an accurate recurrence rate for the condition of concern (Lippman-Hand & Fraser 1979, p.117). Providing people with an understanding of their genetic problem has been described as the primary function of genetic counselling (Reed

1980, p.10) and the actual communication between genetic counsellors and genetic counsellees has been described as the "core" of genetic counselling (Shiloh 1992, p.191). Kessler wrote that at the heart of the genetic counselling encounter is the counsellee-counsellor relationship (Kessler 1979, p.53).

In some of the definitions of genetic counselling, for example that of Bernhardt's (1989, p.952) the term education is used. However, neither the term nor the concept of learning is present. What process lead Meryl in the case example to change as a result of genetic counselling? Could this process be conceptualised as learning, and if so, could an adult learning approach be used to explore and discuss what occurs in genetic counselling?

CHAPTER 3

ADULT LEARNING THEORY APPLIED TO GENETIC COUNSELLING

Chapter three discusses the relationship between adult learning theory and genetic counselling. The characteristics of adult learning are described and then related to the activities which occur in genetic counselling and which were discussed in Chapter two. The purpose is to show that adult learning theory is an appropriate means of exploring and discussing the practice of genetic counselling. From this position, discussion focuses on specific adult learning theorists in order to elucidate a model of adult learning relevant to the present study. Criteria for selecting the model are presented and justified. The chosen model is then discussed.

Chapter three is concerned with learning, not education. These are related but different concepts. Education is the structure which facilitates learning, or as Jarvis noted, education is '...the institutionalisation of learning'(1987, p.8). The concept of learning is more relevant to the present study than the concept of education. As discussed in Chapter one (p.2), this is because the focus of the present study is on the process the genetic counsellee undergoes (learning), rather than the task of the genetic counsellor (teaching or education).

The case example of Meryl is typical of genetic counselling in that most genetic counsellees are adults. A minority are not adult in the sense of their chronological age, but their goals in seeking genetic counselling are related to adult themes. For example, optimising one's sense of well-being in relation to the occurrence or potential occurrence

of an inherited disorder (Headings 1975, p.298) is an issue requiring the maturity of adulthood to be addressed fully. A more specific and very common theme in genetic counselling is that of reproduction. This is considered by most to lie within the realm of adulthood.

Since genetic counsellees are adult, and the focus of Chapter three is on learning, it is instructive to review Knowles' (1978, p 55-59) assumptions about adult learning in the light of what occurs in genetic counselling. Knowles' (1978, p.55-59) assumptions hold that the adult's self concept is important for learning, adults have a resource of experience they can draw upon, they are ready to learn and have a problem centred approach to learning (Knowles 1978, p.59). These assumptions can be applied to the case example of Meryl. Meryl had a self-concept which was related to the theme of motherhood. Indeed, that may have been one of the factors exacerbating her sense of loss. Meryl's resource of experience included familiarity with loss by observing and feeling for her colleagues' similar loss some time earlier. She had previously learnt, possibly as part of her professional life as a nurse, a repertoire of coping strategies for dealing with loss. Meryl came to genetic counselling actively seeking change in herself: she was ready to learn. Meryl learnt by reflecting on her genetic situation and by problem solving. For example, Meryl entered genetic counselling to choose whether to pursue another pregnancy or not, given her goal of being a good mother, but being mindful of her emotional state and the risk of recurrence of anencephaly. After her learning, Meryl was able to accept a plan of action which hinged on prenatal diagnosis.

Knowles' (1978, p.77-79) conditions of learning can also be applied to genetic counselling. These conditions are: the learner feels a need to learn, the learning environment is characterised by physical comfort, mutual trust and respect, mutual helpfulness, freedom of expression and acceptance of differences, the learner perceives the goals of the learning experience to be their goals, the learner accepts a share of the responsibility for planning and operating a learning experience and therefore having a feeling of commitment toward it, the learner participates actively in the learning process, the learning process is related to, and makes use of, the experience of the learner and the learner has a sense of progress toward their goals. Some of these conditions of learning

can also be used as a framework to examine the experiences of Meryl in the case example. Meryl's learning environment was '...characterised by mutual trust and respect, mutual helpfulness, freedom of expression and acceptance of differences'(Knowles 1978, p.77). Such an environment was essential because of Meryl's grief reaction and her genetic counselling would not have been as productive without it. Meryl also accepted her share of the responsibility for planning and directing the learning experience. The writer recalls that Meryl set the agenda for each genetic counselling session and controlled the timing and frequency of each session. The decision of when to terminate genetic counselling lay in Meryl's hands also.

The above account of Meryl's genetic counselling in terms of Knowles' assumptions of learning (1978, p.55-59) and conditions of learning (1978, p.77-79) suggests that there is a relationship between adult learning and genetic counselling. Therefore, adult learning theory may provide a means of exploring and discussing the process genetic counsellees experience in genetic counselling.

The question of which adult learning theory is most relevant to the present study is addressed by reviewing the work of three important adult learning writers - Gagne (1985), Mezirow (1991) and Jarvis (1987). They were chosen because they represent distinct approaches to adult learning. The examination of different adult learning theorists was considered more useful than looking at different 'schools' of adult learning. What is required for the present study is a specific model of adult learning which is relevant to genetic counselling and also applicable to the type of data likely to be available in genetic counselling. These data take the form of transcripts of genetic counselling sessions.

Criteria were developed to explore the three adult learning approaches and select a relevant model. These criteria are set out below. A description of the rationale for their selection is then presented.

1. The model should allow for learning to be inferred from behaviour (and not be restricted to the behaviourist approach).

2. The model should account for learning in the affective domain as well as the cognitive domain.

3. The model should have a social dimension.

4. The model should include experience as an integral part of the learning process.

5. The model should be suitable for the analysis of transcript material.

The first criterion, that the model of adult learning should allow for learning to be inferred from behaviour, is required because of the nature of the genetic counselling data. The data are transcriptions of the verbal behaviour of genetic counsellees during genetic counselling. From these relatively brief windows into the lives of people confronted by a genetic situation, illustrations of adult learning processes are sought.

Learning arising from genetic counselling can occur without any behavioural outcome. Meryl's adjustment to her loss serves as an example of this. As Howe (1977, p.xi) wrote, not only are human actions and habits largely the outcome of learning, so too are thoughts, beliefs, attitudes and prejudices. Howe (1977, p.xiii) argued that there is a difference between change or learning done *by* the learner and change or learning *in* the learner. A change *by* the learner is expressed in behavioural terms and is not part of the learner in the same way that change *in* the learner is. Change *in* the learner can only be inferred from behaviour.

If the case example of Meryl is considered illustrative of genetic counselling, the search for behavioural outcomes would be limited to the birth of subsequent children. However, Meryl's change extended beyond that, it also occurred *in* her. Therefore, the model of adult learning selected for the present study should allow for learning to be inferred from behaviour.

The relevance of the second criterion, the model of adult learning should account for learning in the affective domain as well as the cognitive domain, is supported by the shift

towards the psychologic medicine paradigm and by writers in genetic counselling. For example, Kessler (1984, p.674) reported that the genetic counsellor is often confronted with the need to help clients cope with feelings of guilt and shame. Many of the definitions and goals of genetic counselling put emphasis on both the cognitive and affective domains. In Fraser's (1974, p.637) definition, genetic counsellees are required to 'comprehend' the medical facts as well as 'make the best possible adjustment to the disorder'. This is what occurred in Meryl's case. She had to either accept or reject prenatal testing (cognitive domain or perhaps a mixture of both cognitive and affective domains) as well make an adjustment to her loss (affective domain). The research findings of Lippman-Hand and Fraser highlight the importance of the affective domain in reproductive decision making. '...factual information alone will be of only limited use as a basis for their (genetic counsellees) subsequent decisions (1979, p.124). This is supported by the comments of Kessler.

> Traditional genetic counselling places a strong emphasis on the rational aspects of decision-making regarding abortion, procreation, child rearing, and family planning. However, it is doubtful that decisions concerning these emotionally-laden issues are or can be made in an entirely rational way. Nonrational and unconscious motives and needs play a major role in determining the decisions made about these aspects of human life (1979, p.192).

Therefore, to represent genetic counsellee learning adequately, the model of adult learning must address the affective domain as well as the cognitive domain. Not doing so would limit the scope and relevance of the learning in genetic counselling.

The consideration of the social dimension of learning, the third criterion, is also of relevance to genetic counselling. Referring again to Meryl in the case example, her social setting had both positive and negative effects on her. Her father's negative response to her grief made it difficult for her to normalise her feelings of loss. Meryl was lead to believe that her reaction was psychologically abnormal, which of course it was not. On the other hand, Meryl's workmates, because they had been through a similar situation themselves, served to reinforce that her grief response was normal and this may have helped her to progress and eventually achieve positive change.

The experiences Meryl had had with others contributed towards her learning. The genetic counsellee brings to genetic counselling a whole range of experiences related directly and indirectly to their genetic problem. It is likely that what occurs during the genetic counselling session represents only part of what happens to a genetic counsellee as a result of their genetic situation. The fact that Meryl entered genetic counselling having had the powerful experience of preparing for the birth of a child not meant to survive, may have somehow contributed to her learning. So may have the fact that Meryl would have interacted with a range of health professionals during the initial period of her loss. The genetic counselling session can be viewed as merely part of a much broader learning experience. For these reasons, the model of adult learning selected for the present study should include experience as an integral part of the learning process.

Since the accessible data of genetic counselling is likely to comprise transcripts of genetic counselling sessions, the model of adult learning which is selected should be applicable to them - the fifth criterion. The complexity of the model will be an important consideration here. It should account for learning processes adequately, but not be too complex to apply to transcript material.

The writings of the adult learning theorists, Gagne (1985), Mezirow (1991) and Jarvis (1987) are now discussed. This discussion centres on the extent to which each meets the criteria for selecting the model of adult learning relevant to the present study.

Gagne described learning as a '... change in performance...'(1985, p.4). He (Gagne 1985) favoured an objective, cause and effect approach to learning. For example, Gagne (1985, p.2) affirmed that learning conditions can be observed and described, and relationships between behaviour change and these conditions can be detected. From such observations, writes Gagne, inferences can be made about what has been learned (1985, p.2). Although Gagne (1985, p.2) wrote about inferring learning from behaviour, there is the requirement of an observable behaviour at the end of the learning process. Since this is not always possible or relevant in genetic counselling, Gagne's (1985) approach does not meet the first criterion.

Gagne accounted for learning in the affective domain, describing it as '...an altered disposition of the sort called attitude or interest or value' (1985, p.2). An attitude, according to Gagne, is where the '...learner acquires mental states that influence the choices of personal actions' (1985, p.48). This suggests that, even within the affective domain, there is a need for a behavioural outcome of learning. Later in the same text Gagne commented that attitudes generally have behavioural consequences (Gagne 1985, p.63) and '...attitudes must have some behavioural means of expression...(1985, p.65). Gagne (1985) satisfies the requirements of the second criterion concerning accounting for learning in the affective domain as well as the cognitive domain. However, the fact Gagne (1985) requires a behavioural outcome of learning within the affective domain limits the application of his (Gagne 1985) model to the present study.

Gagne recognised experience as being ...the great teacher...(1985, p.1) and:

> ...the events the developing person lives through - at home, in the geographical environment, in school, and in various other social environments - will determine what is learned and therefore to a large extent what kind of person he or she becomes (1985, p.1).

In this regard, Gagne (1985) meets the fourth criterion concerning the inclusion of experience as an integral part of the learning process.

Although Gagne (1985, p.1) refers to the social environment in the above quotation, there is little other reference made to the social dimension in learning in that text. This suggests that Gagne (1985) does not place a great deal of importance on the social aspect of learning. Therefore, Gagne's (1985) model does not meet the third criterion.

The thrust of Gagne's (1985) work is on the individual. The elements which comprise the process leading to learning, according to Gagne (1985, p.3), include the learner, in possession of their sense organs and their brain, through which they receive stimulation and transform them, and neural activity, some of which is stored in the learner's memory and recovered and translated into action. The use of this model in the analysis of transcripts would be problematic. Internal processing, to use Gagne's (1985,p.4) own words to describe neural activity, cannot be observed in transcript material. Attempts at

making inferences about the presence of such physiological processes would be beyond the scope of the present study.

The manner in which Gagne (1985) included experience in his theory of adult learning meets one of the criteria for selecting a model of adult learning for the present study. The relevance of Gagne's (1985) theory is otherwise limited because of its narrow interpretation of both the social dimension in learning and learning within the affective domain. In addition, it would be difficult to apply a physiologically based model such as Gagne's (1985) to transcript material. The fact that Gagne's (1985) model requires a behavioural outcome of learning is a further and major drawback. Therefore, Gagne's (1985) approach is not relevant to the present study.

The next part of this discussion of the work of adult learning theorists includes a review of Mezirow's (1991) theory. Mezirow has 'meaning' as a central theme in his theory (1991, p.11). He described learning as a '...process of using a prior interpretation to construe a new or a revised interpretation of the meaning of one's experience in order to guide future action' (Mezirow 1991, p.12). This statement introduces Mezirow's (1991) view that people participate in the construction of their own reality (Mezirow 1991, p.xiii). It also introduces Mezirow's (1991) views on 'action' as an outcome of learning and the importance of experience in adult learning. These later two points are now discussed.

Mezirow's statement about adult learning serving to: '...guide future action.'(1991, p.12) relates to the first criterion developed in order to select a model of adult learning for the present study. That is, the model should allow for learning to be inferred from behaviour but not be restricted to the behaviourist approach. Mezirow addressed the question of inferring learning from behaviour briefly when he wrote: '...action in transformation theory is not only behaviour, the effect of a cause, but rather "praxis", the creative implementation of a purpose'(1991, p.12). In other words, the result of learning is more than behaviour: it is something which is exemplified by a behavioural outcome. In this regard, Mezirow's (1991) theory meets the first criterion.

Mezirow (1991, p.12) included 'experience' in his description of adult learning and appears to have placed significance on this. This and other references that Mezirow (1991, p. 5 & 146) made to experience meets the fourth criterion for the selection of a model of adult learning for the present study.

Mezirow wrote of attitudinal change: 'The learning process may be understood as the extension of our ability to...change an attitude'(1991, p.11). The following statement also relates to the second criterion concerning the need to account for learning within the affective domain.

> Remembering involves an object or event that usually has been associated with an emotion influential in our initial learning. How well we remember depends upon the strength of this emotion.(Mezirow 1991, p.29)

These quotations show that Mezirow's (1991) model gives some attention to the affective domain in the adult learning process. However, the model does not go beyond this and so its use in the present study is limited.

Mezirow accounted for the social dimension in adult learning. He (Mezirow 1991, p.1) wrote that parents and mentors define a person's reality and this is so strong that people can never be totally free of their past because of this. He also wrote '...learning is best understood as an activity resulting from social interaction...' (Mezirow 1991, p.13). Mezirow's (1991) model of adult learning satisfies the third criterion and in this regard is relevant to the present study.

The actual models which Mezirow (1991) reported in his text 'Transformative Dimensions of Adult Learning' are complex. One of these models is that of interpretation.

Mezirow's description of this model is:

> We project symbolic models (outer area) as we perceive objects or events by scanning and then construing. We resort first to presentational construal and then, if necessary, to propositional construal. Meaning is made both perceptually and cognitively. To move from a perceptual interpretation to a cognitive interpretation requires propositional construal (monitored by presentational awareness) and an imaginative insight. Propositional (cognitive) construal may give coherence to either a new experience or an old one as it becomes validated through reflective assessment.(1991, p.33)

Furthermore, Mezirow (1991, p.32) noted that the progression towards cognitive interpretation is influenced by meaning perspectives, sociolinguistics, and epistemic and psychological factors.

Mezirow's (1991) model does not meet the fifth criterion. It would be difficult to apply such a complex model to transcripts of genetic counselling sessions. These are records of what transpired within the space of approximately forty five minutes to one hour, which is too short a period of time to apply Mezirow's (1991) model. Mezirow's (1991) model stems from cognitive psychology and its application requires an understanding of the learners' perceptions, cognition and meaning schemes. It would be difficult to gain this understanding from transcripts of genetic counselling sessions. Mezirow (1991) acknowledged such difficulties himself:

> The problem facing the researcher who wishes to study transformative learning is finding a way to gain access to the meaning schemes and perspectives of the subjects of the research.(1991, p.221)

Mezirow's model of validation of learning (1991, p.67), problem solving (1991, p.95) and reflective action (1991, p.109) are similarly limited in their applicability to the present study.

Mezirow's (1991) theory meets more criteria for selecting a model of adult learning for the present study than does Gagne's (1985). Its relevance is limited by the complexity of the model and the difficulties one would have in finding evidence of cognitive

processes such as meaning schemes from transcript material. Mezirow's (1991) attention to the affective domain is also a limiting factor. The model would not be appropriate for examining specific genetic counselling sessions.

The third adult learning theorist discussed here is Jarvis (1987). Jarvis (1987, p.3) disputed the purely behavioural approach, arguing that it is possible to undergo a learning process but not demonstrate a behavioural outcome. In Jarvis' (1987, p.3) illustration of this, a learner knows and wishes to change a behaviour as a result of a learning process but does not initiate any change because management or the learner's peer group would frown on such behaviour. In this example, there had been no behavioural change but learning had occurred. Learning might be inferred from comments made by the learner about knowing and wishing to change. There is a parallel with genetic counselling. A couple who learn they have the emotional strength to pursue a pregnancy despite the chance of having a baby with Down syndrome may decide against that choice because their family would disapprove of such a decision. The couple might tell the genetic counsellor of the change *in* them, new found strength, but that the influences of their family had affected their decision. Thus, learning could be inferred from their behaviour but there had been no behavioural outcome. The way in which Jarvis' (1987) model allows for this situation meets the first criterion for selecting a model of adult learning for the present study.

The above example from Jarvis (1987, p.3) about knowing and wishing to change a behaviour suggests that Jarvis' (1987) theory of adult learning accounts for learning in both the cognitive and affective domains. Knowing occurs within the cognitive domain and wishing occurs within the affective domain. Jarvis (1987, p.24) also wrote about the outcome of learning being new knowledge, a different attitude or a changed self concept. Therefore, Jarvis'(1987) model meets the second criterion.

Jarvis (1987, p.11) placed a great deal of importance on the social dimension in adult learning - the third criterion. According to Jarvis (1987, p.13), individuals learn through interacting with other individuals who make up their society and comprise sub-cultures. Society and the subcultures are changing. The learner develops impressions about their

culture, learns, and that learning is lifelong. Jarvis' (1987) model meets the third criterion.

To Jarvis (1987, p.63), experience constitutes the basis from which learning emerges. As such, the fourth criterion, concerning the inclusion of experience as an integral part of the adult leaning process, is met by Jarvis' (1987) model.

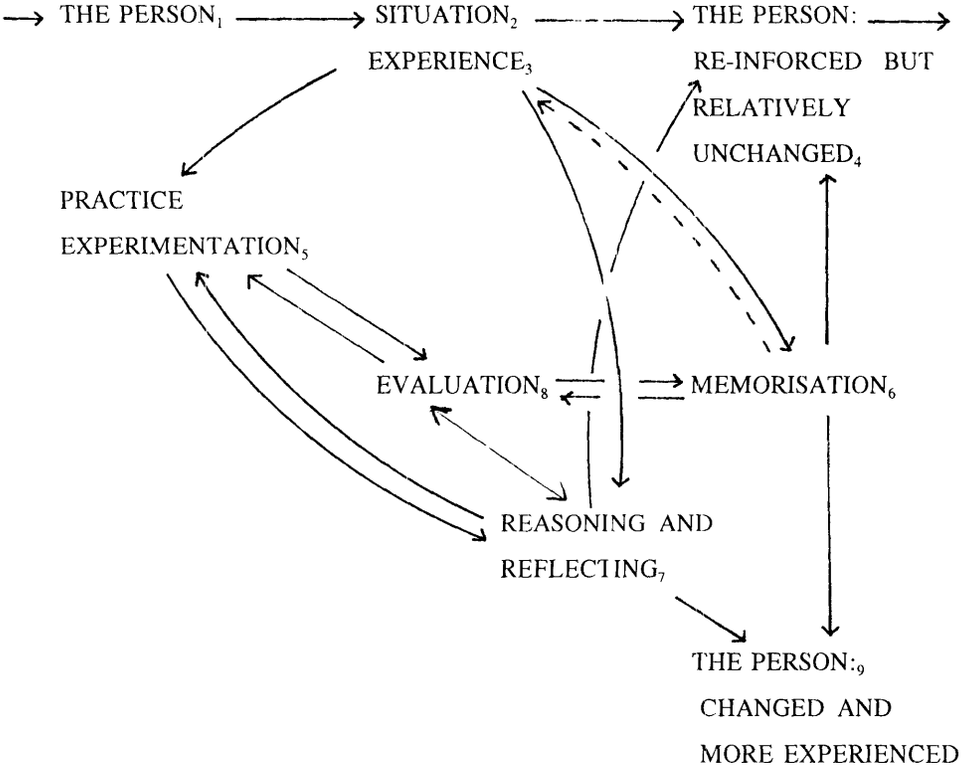
Jarvis' (1979) model of adult learning meets the first four criteria for selecting the most relevant model of adult learning for genetic counselling and the present study. That is, Jarvis' (1987) model allows learning to be inferred from behaviour and is not restricted to the behaviourist approach, it accounts for learning in the affective domain as well as the cognitive domain, and it has a social dimension and includes experience as an integral part of the learning process. In addition, the model appears to have a natural applicability to the events which transpire in a genetic counselling session and which are recorded on transcripts. This may be because the model is relatively simple and because it accounts for different types of adult learning. One type of adult learning encompassed by Jarvis' (1987) model is contemplation. Contemplation, writes Jarvis (1987, p.34), relates to both logical knowledge and belief - two points of great relevance to genetic counselling. Definitions of contemporary genetic counselling refer to logic and belief. Fraser's (1974, p.637) definition has the genetic counsellee appreciating the way heredity contributes to the disorder (a logical phenomenon in most cases) and choosing '... the course of action which seems appropriate to them in view of their risk and their family goals...'(something which is often based on beliefs).

The relevance of Jarvis' (1987) contemplation learning model was trialed by applying it to Kessler's (1981) transcript of a genetic counselling session (Rae et al.1995). The transcript involved a couple who sought genetic counselling because the wife was in her mid-thirties and therefore at increased risk of having a baby with a chromosomal abnormality such as Down syndrome. Events in the transcript fitted well with the elements of the contemplation type of learning and the model provided a means of analysing and discussing the genetic counselling session.

Given that Jarvis' (1987) model meets all five criteria for selecting a model of adult learning relevant to the present study, whereas the models of Gagne (1985) and Mezirow (1991) do not, it is the model of choice. The manner in which the model evolved is now discussed, an overview of the model is presented and the type of learning which Jarvis (1987) called contemplation is discussed in more detail.

Jarvis' model evolved from a series of workshops in which adult educators put forward their own views about learning processes and compared them with Kolb's (1984, p.30) learning cycle. The model which emerged was more complex than Kolb's and is reproduced below.

Figure 1 Jarvis'(1987) model of adult learning processes



The beginning of the model represents the person entering the learning situation. In this case the learner represents the genetic counsellee, and the situation and experience represent the genetic counsellee's genetic situation as well as genetic counselling. The learner moves through one or more routes described by the model and exits the learning experience either changed and more experienced, or reinforced but relatively unchanged. The change in the learner is greater knowledge, the possession of a new skill, attitude or self concept (Jarvis 1987, p.24).

There are nine paths the learner can take through the model. These are named: presumption, non-consideration, rejection, pre-conscious, practice, memorisation, contemplation, reflective practice and experiential learning. They represent different types of learning. A person may learn by practice in response to a particular experience but by contemplation in response to another. Practice usually occurs in training for a manual task. Contemplation, on the other hand, is described as reflective learning (Jarvis 1987, p.27). It is an higher form of learning, concerned with pure thought (Jarvis 1987, p.34). According to Jarvis (1987, p.34), contemplation requires the learner to consider a learning situation and make an intellectual decision about it. This decision may be stored until a future social situation stimulates its recall and some form of action.

In contemplation, the learner moves through steps one to three to seven to eight to six to nine. In other words, the learner enters the learning situation and after that experience, reasons and reflects before making an evaluation, committing the learning to memory and exiting the learning situation changed and more experienced.

Since the publication of his model, Jarvis' views on adult learning have developed and culminated in his 1992 text: *'Paradoxes of Learning : On Becoming an Individual in Society'*. Nonetheless, the integrity of his 1987 model remains intact and relevant to the present study.

Jarvis' (1987) contemplation learning model is used to explore transcripts of genetic counselling sessions in Chapter four. Before that, the methods which will guide this exploration are established in Chapter three.

CHAPTER FOUR

RESEARCH METHODOLOGY

Chapter four describes the research methodology used in the present study. The research question is presented and this is followed by discussion of the manner in which the data were collected and the characteristics of the data. The ethical considerations of the present study are discussed also.

The relationship between adult learning theory and genetic counselling was established in Chapter three (pp.17-19). It was first suggested at the end of Chapter two (p.16) after the change experienced by Meryl in the case example had been noted and a question about conceptualising, examining and discussing that process as adult learning was raised. That question can be elaborated and framed for the present study as: Does an adult learning approach provide a means of exploring and discussing genetic counselling?

The research question of the present study is not an either/or question which would be typical of quantitative research (Leedy 1993, p.142). Rather, it requires an exploration of the relationship between adult learning theory and genetic counselling. A search for meaningful relationships and the discovery of their consequences for action requires qualitative research methodology (Cohen & Manion 1994, p.10). Therefore, qualitative research methodology is used in the present study.

Most research on genetic counselling has been quantitative. However, there has been a move towards phenomenology (Kessler 1980, p.171). Since the use of qualitative research methodology in the study of genetic counselling is a relatively novel approach, it provides a window of opportunity for a better understanding of the practice. Jarvis

(1987, p.16), whose model of adult learning was selected as relevant to the present study, suggested that phenomenology has a great deal to contribute to the understanding of adult learning processes. This is because adult learning processes are complex and rich in both cognitive and affective content, and qualitative methodology is more likely to lead to an understanding of these (Rubinson & Neutens 1978, p.119).

A description of the qualitative research methodology applied to the present study follows. This starts with data collection, progressing to a description of the characteristics of the data, an overview of the research methods used, and finally a more detailed description of those research methods.

One hundred and thirty seven transcripts of genetic counselling sessions had been tape recorded and transcribed for research purposes by a regional medical genetics unit in London, United Kingdom. Of these, twenty one (twenty three percent) relate to genetic counselling for a particular type of genetic disorder, chromosomal abnormalities. Chromosomal abnormalities involve a change in the number, or a rearrangement, of the chromosomes contained in each cell. For example, a chromosomal abnormality may arise from an extra chromosome, number twenty one in the case of Down syndrome, or from the joining of one chromosome with another, called a translocation.

At the request of the writer and following a lengthy period of negotiation with the holder of the transcripts, the twenty one transcripts of genetic counselling sessions for chromosomal abnormalities were mailed to Australia on floppy disc. Transcripts involving genetic counselling for chromosomal abnormalities were requested because the genetic counsellors would not be preoccupied with making or confirming genetic diagnoses. The diagnosis of a chromosomal abnormality is a more straightforward process than it is for many other genetic disorders. It was anticipated that this would allow for the possibility of more transcript space for the elucidation of learning processes. Furthermore, chromosomal abnormalities are relatively common and it was thought that this would enhance the relevance of the present study to everyday genetic counselling.

From the twenty one transcripts of genetic counselling sessions for chromosomal abnormalities, four have been selected for exploration. After preliminary reading, these four appeared to provide the best illustration of adult learning processes, in particular, Jarvis' (1987) contemplation learning. The four transcripts (Appendices A to D) show different learning outcomes: grief (Transcript 1), reproductive decision making (Transcript 2), learning from reviewing the family history (Transcript 3), and learning about prognosis (Transcript 4). It was considered that the selection of transcripts with different learning outcomes would be useful in testing the application of Jarvis' (1987) model. They are also outcomes which are encountered by genetic counsellees frequently. In Transcripts 1, 2 and 3, the genetic counsellees were couples, in Transcript 4 there was one genetic counsellee - the father of a boy with a chromosomal problem.

The four selected transcripts contain the word for word dialogue of both the genetic counsellor and genetic counsellee (or genetic counsellees) for the entire genetic counselling session. Genetic counsellee dialogue represents the data in the present study. It is typical of the data of qualitative research (Cohen & Manion 1994, p.7). In all transcripts except Transcript 3, transcript space is numbered, commencing at zero and increasing in multiples of five every two point five centimetres. This allows genetic counsellee dialogue to be located within the transcript. For Transcript 3, estimations were made about the location of genetic counsellee dialogue within the transcript. Genetic counsellor dialogue is depicted by a 'c' in the left hand column of the transcript and the dialogue of a female genetic counsellee and male genetic counsellee is depicted as 'fp' and 'mp' (standing for female patient and male patient) respectively. If only one genetic counsellee was present, this is depicted as 'p' (patient) in the left hand column. The dialogue of each person participating in the genetic counselling session commences on a new line. Where, for example, the genetic counsellee became upset and cried, this is indicated as such on the transcript. Nonverbal behaviour such as gestures, body positioning and facial expressions could not be recorded. If there was a problem in the tape recording, for example, the genetic counsellees were speaking in a soft voice and their words could not be understood, this is also indicated as such on the transcript. Each genetic counselling session lasted approximately forty five minutes to one hour.

Analysis of the four selected transcripts occurs in two phases. Firstly, Jarvis' (1987) contemplation learning model is used as a means of exploring the transcripts and plotting the process of adult learning. The second phase includes the use of another analytical tool which is consistent with, but not stressed by Jarvis'(1987) model. Since the affective domain is assuming greater importance in genetic counselling, this other analytical tool involves examining the transcripts for evidence of affective versus cognitive domain genetic counsellee dialogue. Although it had been noted earlier (Chapter four, p. 26) that Jarvis' (1987) contemplation learning model does account for learning in both these domains, its ability to do so within the context of genetic counselling has not been established and it was considered important to do so. The second phase of analysis also involves a line by line exploration of the transcripts. It was assumed that learners do not follow Jarvis'(1987) contemplation learning model in any sequential order. The line by line analysis is intended to explore this aspect of the model and glean information about the extent to which the genetic counsellees deviate from the sequence of the model.

The above discussion was intended to provide an overview of the research methods used in the present study. The details of these methods are now described.

Jarvis' (1987) model of adult learning is applied to the four selected transcripts by categorising genetic counsellee dialogue according to the elements of Jarvis'(1987) contemplation learning model. That is, genetic counsellee dialogue is categorised as follows: the person entering the learning situation (the genetic counsellee), reasoning and reflection, evaluation, and the person exiting the learning situation changed and more experienced.

The element of memorisation, which is part of Jarvis' (1987) contemplation learning model, cannot be illustrated by reviewing transcripts; memorisation being an internal process and in some cases a subconscious one. Jarvis (1987) included the element of memorisation in all learning responses encompassed by his model. Therefore, if Jarvis' model is being referred to, and if there is evidence that learning has occurred, it is assumed that memorisation was part of that process also.

The elements of Jarvis' (1987) contemplation learning model referred to as the 'situation' and 'experience' are not considered separately in the analysis of the transcripts. This is because these elements represent the whole of the genetic counsellees' experience with their genetic situation and genetic counselling, not just part of it.

The four selected transcripts are searched for illustrations of how the genetic counsellees entered genetic counselling. An example of this, taken from Transcript 1 after preliminary reading, has the genetic counsellee entering genetic counselling saying:

> "Now the good thing is that we know this is the kind of thing that tends not to recur to the same couple...."

It is not assumed that the learning process commences as the genetic counsellees enter the genetic counselling session. Rather, learning is considered to have commenced when the genetic counsellees first experience their genetic situation. This was the case for Meryl in the case example (Chapter two, p.22). However, in the short space of the transcripts, it may not be possible to find examples of this. In such cases, genetic counsellee dialogue showing how they entered genetic counselling is used as the best example of how they entered the learning process.

Illustrations of reflection are searched for also. Jarvis' description of reflection, reproduced below, is used as a guide for this.

> ...the relevant biographical knowledge/memory of previous experiences is brought together with the perception of the experience under review, so that, analysis, synthesis and evaluation can occur. (1987, p.87)

It was anticipated that in some cases it would be difficult to know if genetic counsellee dialogue should be categorised as illustrative of how the genetic counsellee entered genetic counselling, or as reflection. For example, a genetic counsellee might speak of the event which caused them to seek genetic counselling. This provides information about how they entered genetic counselling. However, if they speak at length and with insight

about this event, it may be illustrative of reflection also. According to Jarvis (1987, p.87), reflection means a process of deep thought. Therefore, the apparent depth of thought behind the comment is used to distinguish between the two. Since reflection is a process which includes reasoning (Jarvis 1987, p.87), reasoning and reflection are not differentiated in the present study, only reflection is referred to.

An example of reflection taken from Transcript 1 during preliminary reading is:

> "Yes...it's amazing how many people told me they have had miscarriages...and when we lost the baby people came forward and said they'd had something similar...we couldn't believe..."

According to Jarvis (1987, p.118), evaluation is a process where, in both the cognitive and psycho-motor domains, learners consider the outcomes of their thought and action and decide whether they have achieved an end product. The four selected transcripts are searched for illustrations of this.

An example of evaluation taken from Transcript 1 is:

> "In some ways Down's Syndrome made it (the death of the baby) a real reason (for the baby dying)...."

The transcripts are also examined for illustrations of the genetic counsellees changing as a result of their genetic situation and genetic counselling. An example taken from the end of Transcript 1 follows.

> "We just learn to carry on...."

As part of the second phase of analysis, the genetic counsellee dialogue which is categorised into the four elements of Jarvis' (1987) contemplation learning model is sub-categorised as being either cognitive or affective domain based. The amount of cognitive versus affective domain genetic counsellee dialogue from each of the elements of Jarvis'

(1987) contemplation learning model is then compared.

Examples of genetic counsellee dialogue coming from the cognitive domain are:

"Does it (Down syndrome) occur more on your first try...?" (Transcript 1)

"So do I just go to the GP and ask (for prenatal diagnosis)...?" (Transcript 1)

Examples of affective domain dialogue are:

"I'm a bit worried about the future..." (Transcript 1)

"...it's (prenatal diagnosis) taken all the excitement (of pregnancy) off now..." (Transcript 1)

Where genetic counsellee dialogue appears to contain a mixture of cognitive and affective domain material, it is categorised as affective domain. This is because the presence or absence of affective domain material is considered to be more important to know than if the genetic counsellee dialogue is purely cognitive or affective domain based.

Phase two of the analysis also includes the line by line analysis. This commences at the beginning of each of the four selected transcripts and progresses to the end of each. It was anticipated that the story of the genetic counsellees would thus unfold and show if Jarvis' (1987) contemplation learning model was followed sequentially, and if not, how the genetic counsellees' path deviated from that. The significance of this is that if the model is followed sequentially, there is the potential for it to be applied during the genetic counselling session to determine the progress of the genetic counsellee's learning and to predict the path they are likely to take. If the model is not followed sequentially, it may be most usefully applied after the genetic counselling session to gain a better understanding of what has occurred.

Throughout analysis, only genetic counsellee dialogue is examined, not genetic counsellor

dialogue. This is because the focus of the present study is on learning, and therefore on the genetic counsellees' experiences. Genetic counsellor dialogue is only referred to if that is necessary to better understand the experiences of the genetic counsellees.

For transcripts containing dialogue of two genetic counsellees, their dialogue is treated as a whole. When the three transcripts involving two genetic counsellees were read as a preliminary to analysis, there was no suggestion that the genetic counsellees were not undergoing the process together.

The manner in which the data are manipulated is by word processor. Genetic counsellee dialogue is cut and pasted into the categories described above.

Since the transcripts of genetic counselling sessions contain personal and sensitive information, genetic counsellee anonymity is maintained throughout the study and in the writing of this thesis. Any identifying characteristics of the genetic counsellees and genetic counsellors has been deleted and only pseudonyms have been used. The question of informed consent has been dealt with to the extent that the researcher who collected the transcripts in the first instance provided a testimony (Appendix E) that consent had been given by the genetic counsellees for the transcripts to be used in the manner in which they have in the present study.

The question of unethical application of any findings which might arise from the present study is of particular importance. For example, it is conceivable that a better understanding of learning processes in genetic counselling might allow genetic counsellors to use that information to influence reproductive behaviour. Although the non-directiveness of genetic counsellors was questioned in Chapter two (p.9), there is no evidence to suggest that genetic counsellor directiveness is overt. In fact, the findings of Wertz and Fletcher (1988), also referred to in Chapter two (p.9), showed that the vast majority of clinical geneticists across eighteen nations regarded nondirectiveness in genetic counselling as appropriate.

Cohen and Manion (1994, p.384) examined ethical issues in research from the

perspective of cost/benefit ratio. In the present study, concern about any cost to genetic counsellees whose genetic counselling sessions were recorded and later transcribed outweigh the potential benefits arising from the study. The costs include the intrusion some genetic counsellees might have experienced as a result of having what is often very private communication tape recorded. Potential benefits include what Kessler (1992, p.8) suggested is required, a better understanding of genetic counselling in order that genetic counsellors can offer a more flexible, creative, and dynamic way of providing it.

The present study has been proposed to the Advisory Committee on Human Experimentation, The University of New England, and is being conducted with that committee's approval. Approval was awarded after the writer declared that mentally ill or disabled subjects were not used, the study does not involve invasive procedures, confidentiality of records would be maintained and that the Statement on Human Experimentation by the National Health and Medical Research Council would be conformed to.