CHAPTER 5

EXPLORATION OF SELECTED TRANSCRIPTS OF GENETIC COUNSELLING SESSIONS

Four selected transcripts of genetic counselling sessions for chromosomal abnormalities are analysed. Transcripts 1 to 4 are related to grief, reproductive decision making, learning from reviewing the family history, and learning about prognosis respectively. These are issues encountered by genetic counsellors frequently.

The transcripts are analysed in the above order. As detailed in Chapter four, this exploration occurs in two phases. In the first phase, genetic counsellee dialogue is categorised into the four elements of Jarvis' (1987) contemplation learning model. These elements include: the person (the genetic counsellee) entering the learning situation (genetic counselling), reflection, evaluation, and the person exiting the learning situation changed and more experienced. In the second phase, genetic counsellee dialogue is sub-categorised as either cognitive or affective domain based. The second phase is also a line by line examination of genetic counsellee dialogue. This is intended to provide information on the degree to which the elements of Jarvis' (1987) contemplation are followed sequentially.

GRIEF (TRANSCRIPT 1)

Transcript 1 illustrates that genetic counselling provides learning opportunities for those experiencing grief as a result of their genetic situation. The genetic counsellees are a couple who entered genetic counselling for the first time four weeks after their baby had died with Down syndrome and hydrocephalus. Down syndrome is a chromosomal abnormality in which the affected person receives forty seven chromosomes from both parents instead of the usual forty six. The extra genetic material leads to the characteristics of Down syndrome. These include a typical facial appearance and body habitus, developmental disability, and in many cases, heart defects and other physical disabilities. People with Down syndrome often do not live as long as their non-affected peers. Parents of Down syndrome children often experience grief. This grief may result from the death of the child with Down syndrome or from a sense of loss of the 'normal' child they had expected. Hydrocephalus is an accumulation of cerebrospinal fluid around the brain. If untreated, it can cause neurological damage. Hydrocephalus is occasionally associated with Down syndrome.

For the first phase of the analysis, genetic counsellee dialogue is categorised according to the four elements of Jarvis' (1987) contemplation learning model, starting with illustrations of how the genetic counsellees entered genetic counselling.

THE PERSON ENTERING GENETIC COUNSELLING

As described in Chapter four (p.33), fp represents the female genetic counsellee and mp represents the male genetic counsellee.

fp: It's the fourth week....(since the baby died)

fp: The first week was very hard....wasn't it....?

mp: Yes...(in response to fp)

fp: ...but then you get used to the idea, don't you....that she's gone or whatever...

mp: Yes...(in response to fp)

fp: Because it was a shock that she was Down's Syndrome...

fp: ....and when they said Down's Syndrome it has sort of far reaching consequences, doesn't it...Down's Syndrome, for the future and whatever...

mp: ....complete shock...

fp: Now the good thing is that we know this is the kind of thing that tends not to reoccur to the same couple....

fp: .... I'm a bit worried about the future....

mp: Yes, Hmmmm (in response to fp)

fp: We were wondering if we were incompatible or something...you know...

fp: ....and we were thinking....I've had a bad cold....and I'd bled a little during that....and I'm a keen gardener....and I thought "Was it something I picked up in the garden...?

It had been four weeks since the genetic counsellees first became aware of their genetic situation. The above dialogue suggests that during this time the genetic counsellees had made progress in adapting to their genetic situation and to their loss: "....you get used to the idea....". This adaptation occurred after experiencing, to use mp's words: "....complete shock....".

The genetic counsellees entered genetic counselling perceiving their recurrence risk of Down syndrome as being negligible: "....tends not to reoccur....". In fact, the recurrence

risk is one percent for Down syndrome and related chromosomal abnormalities. This is for the most common form of Down syndrome which occurs in ninety five percent of cases. Of course, genetic counsellees' perceptions of recurrence risk is individual and may be at variance with actual recurrence risk figures. The work of Lippman-Hand and Fraser (1979, p.118) demonstrated this.

The categorisation of genetic counsellee dialogue under the heading of 'The Person Entering Genetic Counselling' allows for these statements to be compared. It highlights what appears to be discordance between the genetic counsellees' perception of their recurrence risk as low and what they say about their future '...I'm a bit worried about the future....'. Assuming that their concern for the future is related to the possible recurrence of Down syndrome, as is likely to be the case, the above suggests that the genetic counsellees were experiencing conflict about the recurrence risk. This was not conflict between the genetic counsellees. Rather, it was conflict caused by each of them being in two minds over the recurrence risk. An explanation for this would be that the genetic counsellees understood that the recurrence risk was low in an intellectual sense, but in an emotional sense, they found this difficult to accept. This concept of genetic counsellees not feeling ready to accept information which intellectually they know must be true has been described by Lubinsky (1994).

The comments about incompatibility and "Was it something I picked up in the garden...?" suggest that the genetic counsellees did not enter genetic counselling with an accurate understanding of the cause of Down syndrome. Genetic compatibility and environmental factors are unrelated to Down syndrome.

REFLECTION

The genetic counsellees reflected on their loss as being part of a life process which others had also had. That is, they brought together their knowledge of previous experiences (the loss experienced by others) with their perception of the experience under review (their own loss)(Jarvis 1987, p.87).

fp: 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...

Entering a period of deep thought, the genetic counsellees reflected on the fact that their loss has an end, again suggesting that their experience was part of a life process.

mp: ...it hits you harder...you won't forget it...it happened....you survive...

fp: It just seems so unfair...I couldn't believe it...I felt really angry....and when I was going to work....I kept saying "I shouldn't be going to work...I should be leaving...." But in the end you just get it into your head...this it's the way it's going to be now...

The genetic counsellees also reflected on their sense of isolation.

fp: In fact one of the worst things was actually leaving (hospital) ...everyone was so nice in there....to step outside....

mp: Yes...when you get in the real world you don't know how people are going to react...

fp: Most people have been very nice....but some people....young people with babies...haven't even mentioned it...I suppose I might be the same if it was the other way around....

Other difficulties the genetic counsellees reflected on was the lack of acknowledgment of their daughter's life and their grief.

fp: It's almost as if they want to dismiss it....it's like saying she wasn't real....but she was a real baby....and she was ours....

fp: I don't think some people understand that....do they...that we consider her as being our daughter....

mp: My mate came to see us in hospital....but it was hard....he couldn't see that I was sick, sort of thing...They said the right things...but....

mp: They kept telling me not to hurry back....but when I did go back the boss started ranting and raving at me saying I was letting them all down...

The genetic counsellees also reflected on sources of strength:

fp: But on the whole people have been really nice....

fp: Yes. Work have been good to me....I was on the list to be made redundant....which I was pleased about at the time...but when I lost the baby they saved my job...

They reflected on issues related to reproduction and what had been explained to them about the cause of Down syndrome.

fp: We were just beginning to wonder what we were going to do if we couldn't have children....

fp: So it could have been either of us, then...? (the origin of the extra chromosome number twenty one)

The above reflective statements have three characteristics. Firstly, they suggest that the genetic counsellees were dealing with their sense of loss by reframing it. That is, by reasoning that their loss is part of a life process which has an end and is experienced by others. This may have allowed the genetic counsellees to normalise their grief response. Secondly, the difficulties experienced by the genetic counsellees, and also their sources of strength, had a social dimension. They originated from their interaction with friends

and colleagues. Thirdly, the genetic counsellees developed more accurate knowledge of the cause of Down syndrome by reflecting on what had been explained to them by the genetic counsellor.

EVALUATION

The genetic counsellees had initially considered that their baby died because they were: "....incompatible or something...." or was due to "....something I picked up in the garden....". The following genetic counsellee statement suggests that they had come to acknowledge that their earlier understanding was inaccurate and that they appreciated the relationship between Down syndrome and the death of their baby. They had evaluated - considered the outcomes of their thought and action and decided if they had achieved an end product (Jarvis,1987, p.118).

fp: In some ways Down's Syndrome made it a real reason....

The genetic counsellees also evaluated their adaptation to their genetic situation.

fp: Some days I don't feel too bad...but when she's going to be due...that's going to be hard...

This evaluation resulted in the genetic counsellees planning a strategy to maximise their coping abilities at a time they could foresee as being more difficult - the date their baby was due.

mp: Yes.... We're going to have time off then...

THE PERSON CHANGED AND MORE EXPERIENCED

Mp exited genetic counselling with a feeling of relief. This is a change from his initial concern about the future.

mp: It's been a relief...

Change in fp is more difficult to infer from the transcript. Her experience with genetic counselling was similarly positive and it may be that her learning progressed beyond the genetic counselling session.

fp: We just learn to carry on....I'm glad at what we've done today....

Using the guidelines established in Chapter four (pp.34-36), and as shown above, genetic counsellee dialogue was able to be categorised according to the elements of Jarvis'(1987) contemplation learning model. This assists in understanding the process the genetic counsellees underwent. The genetic counsellees experienced an initial shock from their genetic situation and this was followed by a period of adaptation around the time they entered genetic counselling. At that time there appeared to be confusion about what they believed was the cause of their baby's death and conflict about the recurrence risk of Down syndrome. During genetic counselling, the genetic counsellees reflected on their experiences, reframed them, and evaluated their understanding of the cause of their baby's death and their progress through the grief process. Most of the reflection was not related directly to 'genetics', but to the genetic counsellees' experience with genetics. This had a significant social dimension. There was no direct evidence within the transcript that the genetic counsellees had resolved the conflict about recurrence risks. However, there was a change in the direction of satisfaction and relief which suggests that there may have been at least some resolution of this conflict. Therefore, it can be assumed that learning had occurred.

There has been a shift in genetic counselling towards the psychologic medicine paradigm. To establish if Jarvis' (1987) contemplation learning model accounts for learning in the affective domain as well as the cognitive domain, phase two of the analysis comprises an examination of genetic counsellee dialogue for each of the four elements of Jarvis' contemplation learning model to see if it comes from the cognitive domain or the affective domain. This was done by referring to the guidelines established in Chapter four (pp.36-37). In Transcript 1, most genetic counsellee dialogue comes from the affective

domain. Almost all statements illustrating how the genetic counsellees entered genetic counselling come from the affective domain. All reflective and evaluative statements come from the affective domain. Both statements illustrating change in the genetic counsellees as they exited genetic counselling come from the affective domain.

Jarvis' (1987) contemplation learning model provided a means of exploring and discussing this transcript, including the large amount of affective domain material contained in it. However, it would be misleading to give the impression that the genetic counsellees progressed through Jarvis' (1987) contemplation learning model sequentially. To examine the extent to which the genetic counsellees deviated from the sequence of the model, a line by line analysis of the transcript follows. Not all genetic counsellee dialogue is presented. It is summarised where appropriate. As described in Chapter four (p.32), transcript space is numbered, commencing at zero and increasing in multiples of five every two point five centimetres. The nearest whole number which corresponds with the commencement of each piece of genetic counsellee dialogue presented in this part of the analysis is shown in brackets after the genetic counseellee dialogue. The genetic counsellee dialogue is introduced by commentary intended to highlight main points and where possible relate the dialogue to the elements of Jarvis' (1987) contemplation learning model. In some cases, comments are made following the genetic counsellee dialogue. Since this is the second review of the transcript, it is likely that there will be some repetition of themes already covered in phase one of the analysis.

The session began with the genetic counsellees answering questions the genetic counsellor asked about their welfare. Their responses give an indication of *how they entered genetic counselling* - in an early stage of the grief response:

fp: It's the fourth week....(20)

The process of adaptation to their genetic situation and the loss of their baby had so far been difficult:

fp: The first week was very hard....wasn't it....?(24)

mp: Yes...(26)

The genetic counsellees had accepted their loss and begun to move on.

fp: ...but then you get used to the idea, don't you....that she's gone or whatever...(28)

mp: Yes...(30)

The genetic counsellees referred to the time when the diagnosis of Down syndrome had been made, and explained the impact of that diagnosis.

fp: Because it was a shock that she was Down's Syndrome...(32)

fp: ....and when they said Down's Syndrome it has sort of far reaching consequences, doesn't it...Down's Syndrome, for the future and whatever...(52)

mp: ....complete shock...(56)

fp: A setback, that was...(61)

Before entering genetic counselling, the genetic counsellees had gained some, albeit limited, knowledge of the cause of Down syndrome. In answering the genetic counsellor's question about their familiarity with chromosomes, the genetic counsellees responded:

fp: We did some...three of one particular one or something...(73)

The genetic counsellees were referring to the fact that in Down syndrome there are three number twenty one chromosomes instead of the usual two.

The genetic counsellor gave an explanation of the genetics of Down syndrome. This was

interspersed by genetic counsellee comments such as 'Right' and 'Yes'. Following the genetic counsellor's explanation, fp commented:

fp: Now the good thing is that we know this is the kind of thing that tends not to reoccur to the same couple....(196)

The genetic counsellor had not spoken about recurrence risks. Therefore, the above comment represents the genetic counsellees' perception of their recurrence risk *as they entered genetic counselling*. They had interpreted their risk as low.

The genetic counsellor then stated that some forms of Down syndrome are inherited. The genetic counsellees *reflected* on this and applied that information to another problem they had had - miscarriage. This was a logical connection because approximately half of miscarriages are the result of a chromosomal abnormality in the fetus.

mp: Can we have problems with our chromosomes though, before...[?] we had a miscarriage as well...(226)

fp: The inherited ones (people with Down syndrome) ...they look different do they...?(253)

The genetic counsellor discussed in some detail the differences between the inherited type Down syndrome and the sporadic type. There was also an explanation about some of the clinical features of Down syndrome. Apart from one or two simple questions, the genetic counsellees responded to the genetic counsellor's explanations with 'Oh', 'Oh right', and similar expressions of understanding.

The genetic counsellees, apparently having developed some rapport with the genetic counsellor, then disclosed a concern with which *they entered genetic counselling*. They asked:

fp: We were wondering if we were incompatible or something...you know...(421)

The genetic counsellor reassured the genetic counsellees about any incompatibility and the genetic counsellees asked their next and unrelated question.

fp: There's something else...if I have another baby would you recommend that I have an amniocentesis...(432)

Since the genetic counsellor had not used the term amniocentesis previously, this statement suggests that the genetic counsellees knew of the availability of prenatal testing *as they entered genetic counselling*. After the genetic counsellor explained prenatal testing, fp indicated that she knew that there was a miscarriage risk associated with the procedure. The genetic counsellor explained that the recurrence risk for Down syndrome was one percent and the genetic counsellees responded by using words such as 'right' to acknowledge what the genetic counsellor was saying.

The genetic counsellor was asked for an opinion about the magnitude of the recurrence risk for Down syndrome. That is, should it be considered high or low.

fp: ....or do I think that 1 in 100 is not really a bad risk...(601)

The genetic counsellor then provided information about perception of the magnitude of risk and how recurrence risk figures are interpreted on an individual basis. The genetic counsellees asked some questions for clarification and then initiated discussion about how to obtain prenatal testing.

fp: So do I just go to the GP and ask.....?(680)

The genetic counsellor described how to obtain prenatal testing and there was agreement between the genetic counsellees and the genetic counsellor that the final decision about prenatal diagnosis is best left until pregnancy. This advice came from the belief that decisions need to based on reality rather than imagined scenarios.

Fp (and confirmed by mp) then disclosed an emotional concern *with which she entered genetic counselling.*

fp: I'm a bit worried about the future....(736)

The genetic counsellor attempted to normalise this concern and spent a considerable amount of time trying to provide reassurance based on his own experience. This elicited responses such as:

mp: Yes, Hmmmm(737)

After the genetic counsellor had offered reassurance, fp sought clarification about the recurrence risk.

fp: Does it occur more on your first try...?(764)

The genetic counsellor gave information to reassure the genetic counsellees again. They responded with single words of affirmation.

Discussion then focused on the frequency of babies born with abnormalities.

fp: 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...(807)

This comment represents the genetic counsellees placing their loss within a broader context and *reflecting* on that.

The genetic counsellees told the genetic counsellor they had a relative with Down syndrome and consequently the genetic counsellor constructed their pedigree. The genetic counsellees did not talk again about the family history of Down syndrome.

In response to a question by the genetic counsellor about wanting to discuss anything further, fp indicated that her main concern was for a future pregnancy and the question of prenatal testing.

fp: No, not really, it's just the future, the tests....(947)

Mp then verbalised his concern about prenatal testing.

mp: Well yes....this has taken all the excitement off now.(969)

This emotional issue was not perused by the genetic counsellor who offered a reassuring statement and changed the subject.

The genetic counsellees were prompted by the genetic counsellor to discuss how their genetic situation had affected them emotionally. This provided further information about *how the genetic counsellees entered genetic counselling*.

fp: In fact one of the worst things was actually leaving (the hospital) ...everyone was so nice in there....to step outside....(984)

mp: Yes...when you get in the real world you don't know how people are going to react...(987)

The genetic counsellees then appeared to enter a period of deeper thought and *reflected* on their experience of loss.

fp: Most people have been very nice... but some people....young people with babies...haven't even mentioned it. .I suppose I might be the same if it was the other way around....(990)

fp: It's almost as if they want to dismiss it....it's like saying she wasn't real....but she was a real baby....and she was ours....(996)

fp: I don't think some people understand that....do they...that we consider her as being our daughter....(1001)

fp: But on the whole people have been really nice....(1004)

fp: So that's really good....the worst thing would have been to be at home in a stew about it...it was quite a while before I went back...but to be with people all the time...(1014)

mp: My mate came to see us in hospital....but it was hard....he couldn't see that I was sick, sort of thing...(1024)

mp: They said the right things...but....(1027)

mp: I would have liked to have stayed with Sarah as much as anything...(1036)

mp: I felt guilty at leaving Sarah....you get to a point where you think "Stuff all this, it isn't important....(1038)

mp: ...but after a while...you've got to go back....(1041)

mp: ...it hits you harder...you won't forget it...it happened....you survive...(1047)

fp: It just seems so unfair...I couldn't believe it...I felt really angry....and when I was going to work....I kept saying "I shouldn't be going to work...I should be leaving...." But in the end you just get it into your head...this it's the way it's going to be now...(1049)

At this point in the genetic counselling session, the genetic counsellees *evaluated* their adaptation to their genetic situation.

fp: Some days I don't feel too bad...but when she's going to be due...that's going to

be hard...(1056)

mp: Yes...(1059)

mp: We're going to have time off then...(1061)

The genetic counselling session appeared to be drawing to a close and the genetic counsellees commented on the usefulness of the session. Inferences about *changes in the genetic counsellees* can be made from these statements.

mp: It's been a relief...(1069)

fp: We just learn to carry on....I'm glad at what we've done today....(1066)

Notwithstanding the genetic counselling session was closing, the genetic counsellees *reflected* again on their concern about future children.

fp: We were just beginning to wonder what we were going to do if we couldn't have children....(1070)

The placement of this statement at the end of the genetic counselling session suggests that the topic was important to them. It may have taken the genetic counsellees the duration of the interview to develop sufficient rapport to disclose such a central concern.

Fp (and confirmed by mp) then made the *evaluative* statement:

fp: In some ways Down's Syndrome made it a real reason....(1079)

mp: Yes....(1081)

The relevance of this statement is highlighted by what fp said subsequently and which illustrates her belief about the cause of their baby's problems *as she entered genetic*

counselling.

fp: If it had only been the water on the brain...and we were thinking....I've had a bad cold...and I'd bled a little bit during that...and I'm a keen gardener...and I thought "Was it something I picked up in the garden...?(1083)

fp: And all those sort of things....I was thinking "What have I done wrong...?(1090)

Then, *reflecting* on what the genetic counsellor explained about the chromosomal basis of Down syndrome, fp asked:

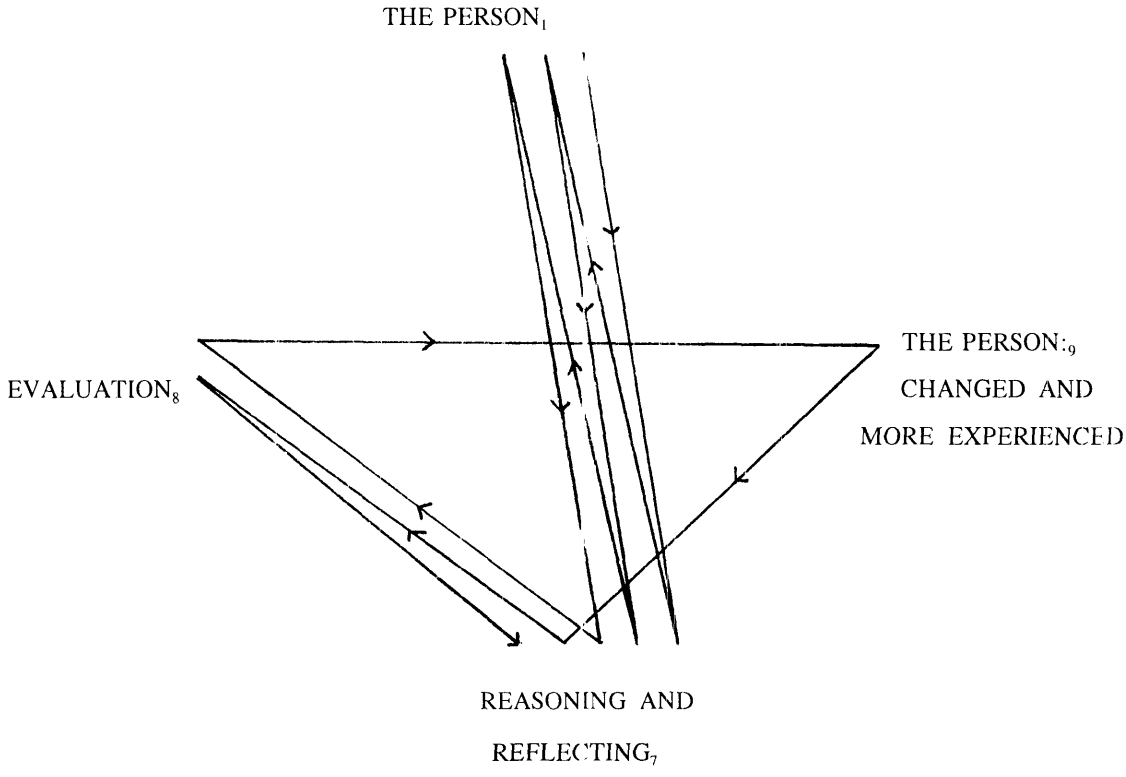
fp: So it could have been either of us, then...?(1096)

The line by line analysis of the transcript can be summarised as follows. There is a relatively long period at the beginning of the transcript when the genetic counsellees gave information about themselves as they entered genetic counselling. For example: "... it was a shock that she was Down syndrome...". The genetic counsellees then reflected on what the genetic counsellor had said about the heritability of Down syndrome. They moved on to another issue they were dealing with as they entered genetic counselling. '...we were wondering if we were incompatible or something...'. The genetic counsellees then asked the genetic counsellor for advice. Their question was about prenatal diagnosis, the genetic counsellor's perception of the recurrence risk, and how to obtain prenatal diagnosis. The genetic counsellees further illustrated their knowledge and experiences as they entered genetic counselling. For example, 'I'm a bit worried about the future...' In fact, this was a recurrent theme in the transcript. Prompted by the genetic counsellor, the genetic counsellees entered another brief period of reflection, this time on the fact that problems such as Down syndrome are common and frequently go unnoticed. After providing further additional information about how they entered genetic counselling, the genetic counsellees reflected for a relatively long period of time on their experience of loss, then an evaluative comment was made. The session appeared to be drawing to a close and the genetic counsellees spoke about how they had changed. "It's been a relief...". The genetic counsellees re-entered the session by reflecting again on their chief

concern: "...We were just beginning to wonder what we were going to do if we couldn't have children..." and made another evaluative comment: "In some ways Down syndrome made it a real reason...". There was a further reflective comment about the cause of Down syndrome and the session ended.

This summary (depicted in Figure 2) illustrates that the four elements of Jarvis'(1987) contemplation learning model did not occur sequentially. The genetic counsellees periodically backtracked to earlier elements of the model such as reflection. As the genetic counsellees developed rapport with the genetic counsellor, they disclosed more and so completed the picture of themselves as they entered genetic counselling. They also appeared to reflect more as they developed confidence with the genetic counsellor.

Figure 2 The progression of the genetic counsellees depicted in Transcript 1 through the learning process.



REPRODUCTIVE DECISION MAKING (TRANSCRIPT 2)

Transcript 2 illustrates the learning processes genetic counsellees undergo when making reproductive decisions. The genetic counsellees had a termination of pregnancy because the fetus had a chromosomal translocation. A chromosomal translocation involves a rearrangement of the chromosomes. In this case, it caused an abnormality of the fetus' brain. The genetic counsellees experienced grief as a result of the loss of their baby.

Analysis of the transcript occurs in the same way as in Transcript 1. Genetic counsellee dialogue is categorised according to the four elements of Jarvis' (1987) contemplation learning model and then sub-categorised as coming from the cognitive or affective domains. This is followed by a line by line analysis of the transcript to determine the degree to which the genetic counselling session varies from the strict sequential pattern of the model.

THE PERSON ENTERING GENETIC COUNSELLING

The two genetic counsellees, fp and mp, entered genetic counselling for the first time with bereavement issues.

fp: OK. I get good days and bad [fp: whispers].

mp: Certain things, sort of, trigger memories and it comes back.

fp: I had to give up work last Friday and, er....

mp: Generally not bad (no). We had lots of calls from friends and family.

fp: Yeah and you, you get back to everyday life, you get back to normality at certain times [inaudible].

They had already been told of the translocation in their baby.

mp: I mean that's what apparently made the blood results (chromosomal analysis) come back. But I said she just said it's bad brain tissue disorder and that's as far as it goes. It would be the best result we could have but a decision we had to make.

This dialogue suggests that the genetic counsellees were in the process of adapting to the loss of their baby, but this was incomplete. When put in the context of the whole transcript, the last statement refers to the fact that a brain abnormality in the fetus had been detected by ultrasound. Its cause had not been established but it had been hypothesised that it was an isolated abnormality. The 'blood results' were an analysis of the fetus' chromosomes, performed on a blood sample collected from the umbilical cord. This showed the translocation, the cause of the brain abnormality. The parents had blood collected also and because their chromosomes were normal, it was presumed that the translocation in the fetus occurred *de novo*.

The genetic counsellees had other explanations for their baby's problems as they entered genetic counselling - all of them inaccurate.

fp: The only thing I can think is that [inaudible]. And the fact that in early pregnancy I smoked [inaudible].

mp: ... At the time I sort of worked for BT and I was considering taking redundancy. I was looking for another job, erm, so we'd just moved and we had all the stress of money and everything as well, so, I mean, I don't know if that would play any part of headaches and stress and everything.

fp: Could it be an external thing? From, sort of, something internal, you just can't.....

mp: Because as I, as I said earlier with my hip disease. I mean up to the age of 12

or 13, I would have at least 1 or 2 X-Rays a month, sort of like, to see the development of my hips - for about 3 or 4 years.

REFLECTION

The genetic counsellees reflected on the time when the brain abnormality was first identified, before its precise cause had been established. They reflected on the uncertainty of the diagnosis and the fact that they had to make a decision concerning termination of pregnancy based on incomplete information

fp: No, we had the first scan and they said, we saw what's it [?] and he said it was strange because there wasn't any one thing that he could say 'well yes, this is definitely this or yes, this is definitely that' he said it was all too.. because the trunk was twisted, the chest was concave, the ventricles in the brain were too prominent, but not (um) seriously so. He just couldn't seem to put his finger on it.

fp: ...And when we went back the following week to have blood tests ourselves, they said had you thought about it. And we'd obviously thought about it. If the baby was brain damaged then, we would terminate, but if it's just bits of [inaudible] we'll carry on with the pregnancy. And they scanned again and found that things had got a lot worse.

The genetic counsellees perceived that they had been given inaccurate information.

fp: He told us it couldn't get worse. It did.

They then reflected on their need for tangible evidence that their baby existed and of their baby's problems.

fp: We went back to Farnborough and they'd lost the results there. We've never been told the results.

fp: I'd like to see it (pathology report).

mp: .... we've got a photograph (of the baby) and we've got like a cot card and other bits and pieces. We weren't going to initially were we? You alright (to fp)? We weren't initially, but we thought it helped to, sort of, like grieve and everything.

The following three genetic counsellee statements suggest that the forthcoming appointment for genetic counselling had caused fp to reflect on the time when they had to make the decision about termination of pregnancy. This genetic counsellee dialogue might have been included as illustrative how the genetic counsellees entered genetic counselling. However, it is a more detailed and deeper review and so has been categorised as reflection.

mp: As I say, this has been worrying A for quite a while, because leading up to it, because she didn't know - it's all been nagging there, sort of brought it all to the fore again.

After the genetic counsellor stated: 'Coming today?', mp replied:

mp: Yeah.

mp: 'Cos the last couple of days it's been, I mean it's always been nagging, all these sort of things trigger it.

The genetic counsellees then reflected on the genetic counsellor's explanation about the chromosomal translocation.

mp: So it had lost some and gained some other (chromosomal material).

They also reflected on some objective signs that their baby would not be born healthy.

mp: She put on literally, well, nothing....(weight)

fp: They showed, Andrea showed us on the graph, sort of 2 points in a week and she showed us where it should have been and where it was.

mp: Yeah, I mean, 2 crosses which were on top of each other, whereas they should have been a couple of inches apart on the graph; they showed us.

The genetic counsellees reflected on their interpretation of the recurrence risk.

fp: No, I know, but - I don't know, you just think - it was a 1 in a million chance and it happened to be this time, whatever. I know that's not [inaudible] it's a 1 in a million chance that I had developed an infection after the baby was born and I had to go back for a second D&C (dilatation and curettage) and, er, that was a 1 in a million as well, so my luck at the moment [laughing] is pretty, erm....

EVALUATION

Fp weighed up her torrid prenatal and intrapartum experiences against the pleasure of being with her dead baby for a short period of time.

fp: Yeah, you accept it. You don't forget it but you accept it. At least I had the baby - that helped.

After reflecting on their experiences and the information presented to them, the genetic counsellees made the following evaluative remark.

fp: We made the right decision (to terminate the pregnancy).

THE PERSON CHANGED AND MORE EXPERIENCED

There are no specific examples in the transcript of how the genetic counsellees exited genetic counselling. However, it can be assumed that they left with less anxiety, or as

mp put it, less 'nagging' about their decision to terminate the pregnancy. The evaluative statement "We made the right decision." supports this.

As shown above, Jarvis' (1987) contemplation learning model, applied by referring to the guidelines established in Chapter four (pp.34-36), provides a means of exploring and discussing this transcript. The process the genetic counsellees underwent began prior to genetic counselling. This is exemplified by the adaptation the genetic counsellees had already made to their loss and by the knowledge with which they entered genetic counselling. In particular, there is evidence that the genetic counsellees had been reflecting on their experiences prior to genetic counselling and this was prompted by the forthcoming genetic counselling appointment. There are several other examples of reflection. These include reflection on what the genetic counsellor had explained to them, the problems their baby had, and the difficult decision they had to make. The evaluative statement: "We made the right decision", shows that the genetic counselling session had reassured the genetic counsellees about their decision to terminate the pregnancy. There is no illustration of how the genetic counsellees exited genetic counselling. This is not a limitation of the application of Jarvis' (1987) contemplation learning model. It suggests that the learning process should be considered as something which progresses beyond the genetic counselling session. This is highlighted by a final comments made by one of the genetic counsellees: "A lot to think about....".

Using the guidelines established in Chapter four (p.36-37), the statements for each of the four elements of Jarvis' contemplation learning model were examined to see if they come from the cognitive domain or the affective domain. Over half the statements illustrating how the genetic counsellee entered genetic counselling come from the affective domain. Approximately half of the reflective statements are affective domain based. The two evaluative statements come from the affective domain. Therefore, Jarvis' (1987) contemplation learning model facilitated the exploration of this transcript in both cognitive and affective domains.

The line by line analysis of the transcript is conducted in the same way as Transcript 1. The aim is to determine if the genetic counsellees progress through Jarvis' (1987)

contemplation learning model sequentially.

The genetic counsellees started by talking about their feelings of grief as they *entered genetic counselling.*

fp: OK. I get good days and bad [fp: whispers].(10)

mp: Certain things, sort of, trigger memories and it comes back.(12)

They related the practicalities of this.

fp: I had to give up work last Friday and, er....(14)

mp: ....We had lots of calls from friends and family.(16)

After a brief attempt by the genetic counsellor to normalise the genetic counsellees' feelings of loss, fp confirmed that normality by responding:

fp: Yeah and you, you get back to everyday life, you get back to normality at certain times [inaudible].(25)

The above statement provides information about how the genetic counsellees had adjusted to their loss *as they entered genetic counselling.*

The genetic counsellees explained their understanding of their genetic problem: "...that's what apparently made the blood results come back..."(44). This suggests that they knew their baby had a chromosomal abnormality *when they entered genetic counselling.*

The genetic counsellees then provided objective information about their family history as the genetic counsellor constructed the pedigree. They commented on their brief and troubled pregnancy.

fp: ...Erm, the home test kits kept coming up positive (yes) and the hospital kits kept coming up negative. Erm, so in the end I paid for a blood test to have the pregnancy confirmed for once and for all. Then I started to lose the baby at 6 weeks.(137)

fp: I had lots of little complaints like, I had indigestion which you don't usually get in the middle of pregnancy. Erm, headaches, I had lots and lots of headaches. I just generally didn't feel.....(145)

The genetic counsellees had an explanation for the threatened miscarriage referred to above. This was:

fp: ..... I just put it down to, you know, this is the first pregnancy, you never know what to expect.(151)

They also had an alternative explanation for the cause of their baby's problems *as they entered genetic counselling.*

mp: ... At the time I sort of worked for BT and I was considering taking redundancy. I was looking for another job, erm, so we'd just moved and we had all the stress of money and everything as well, so, I mean, I don't know if that would play any part of headaches and stress and everything.(154)

That is, the genetic counsellees had not fully accepted that the baby's chromosomal abnormality was the cause of their baby's problems and proposed an environmental cause.

The pregnancy progressed to the twentieth week before a definite abnormality was detected.

fp: Yeah. And the first we knew that there was something wrong was at the 20 week scan, and...(175)

The genetic counsellees *reflected* on information presented to them before genetic counselling.

fp: He told us it couldn't get worse. It did.(192)

fp: No, we had the first scan and they said, we saw what's it [?] and he said it was strange because there wasn't any one thing that he could say 'well yes, this is definitely this or yes, this is definitely that' he said it was all too.. because the trunk was twisted, the chest was concave, the ventricles in the brain were too prominent, but not (um) seriously so. He just couldn't seem to put his finger on it. (196)

The genetic counsellees then *reflected* on their need for tangible evidence of their baby and their baby's problems. At this point fp started to cry and wanted to see the pathology report.

fp: We went back to Farnborough and they'd lost the results there. We've never been told the results.(233)

fp: I'd like to see it.(241)

After the genetic counsellor asked if they had seen their baby, the genetic counsellees *reflected* on their time with their dead baby.

mp: Yes we've got a photograph and we've got like a cot card and other bits and pieces. We weren't going to initially were we? You alright? We weren't initially, but we thought it helped to, sort of, like grieve and everything.(247)

Mp explained how difficult the experience had been for fp, and that it had been hard for her to attend the genetic counselling session. The following statements suggest that the genetic counsellees had been *reflecting* on their experience in preparation for the genetic counselling session.

mp: As I say, this has been worrying A for quite a while, because leading up to it, because she didn't know - it's all been nagging there, sort of brought it all to the fore again.(254)

mp: 'Cos the last couple of days it's been, I mean it's always been nagging, all these sort of things trigger it.(270)

Fp then spoke about not wanting to lose her feelings for her baby.

fp: I hope it (feeling for her baby) never goes away.(278)

fp: Yeah, you accept it. You don't forget it but you accept it. At least I had the baby - that helped.(283)

The above statement is an example of *evaluation*.

At this point, the genetic counsellor changed the subject from the genetic counsellees coping, and discussed the fact that a chromosomal abnormality had been found in the baby. The genetic counsellor then proceeded to explain the translocation.

The genetic counsellees *reflected* on the information the genetic counsellor presented. This was accomplished by providing their interpretation of the information and asking a related question.

mp: So it had lost some and gained some other.(314)

fp: I see. What's the likelihood of it happening again?(326)

mp: Uh huh. You can't trace to where it, yeah, to the origin.(343)

The above statements show that the genetic counsellees had returned to the reflection phase after evaluation. They continued to *reflect* on their experience, this time concerning

the problems their baby had.

mp: She put on literally, well, nothing....(397)

fp: They showed, Andrea showed us on the graph, sort of 2 points in a week and she showed us where it should have been and where it was.(412)

mp: Yeah, I mean, 2 crosses which were on top of each other, whereas they should have been a couple of inches apart on the graph; they showed us.(417)

The genetic counsellees accepted a copy of the pathology report and there was further discussion about the genetics of their situation. Fp then made the short but very significant *evaluative* comment.

fp: We made the right decision.(536)

Put in the context of the whole transcript, this comment points up the fact that the genetic counselling session had reinforced the genetic counsellees' decision to terminate the pregnancy.

The genetic counsellees then *reflected* on what the genetic counsellor had told them about the likelihood of miscarriage in their last pregnancy.

mp: Yeah. I mean you wouldn't say 100%, it is about 80, 80% chance?(539)

They provided more information about *how they entered genetic counselling* by revealing their earlier beliefs about the cause of their baby's problems.

fp: Could it be an external thing? From, sort of, something internal, you just can't.....(556)

mp: Because as I, as I said earlier with my hip disease. I mean up to the age of 12

or 13, I would have at least 1 or 2 X-Rays a month, sort of like, to see the development of my hips - for about 3 or 4 years.(565)

fp: The only thing I can think is that [inaudible]. And the fact that in early pregnancy I smoked [inaudible].(574)

The genetic counsellees raised the question of prenatal diagnosis and explained that they wanted this. The genetic counsellor provided information about prenatal diagnosis and the genetic counsellees occasionally asked questions. This discussion led the genetic counsellees to the realisation that they would have to make another decision. They *reflected*:

fp: It's a horrible decision to have to make.(752)

The genetic counsellees then *reflected* on their recurrence risk.

fp: No, I know, but - I don't know, you just think - it was a 1 in a million chance and it happened to be this time, whatever. I know that's not [inaudible] it's a 1 in a million chance that I had developed an infection after the baby was born and I had to go back for a second D&C and, er, that was a 1 in a million as well, so my luck at the moment [laughing] is pretty, erm....(757)

There was some discussion about the steps to take if fp was to become pregnant again. At the close of the session, fp acknowledged the need for further *reflection.*

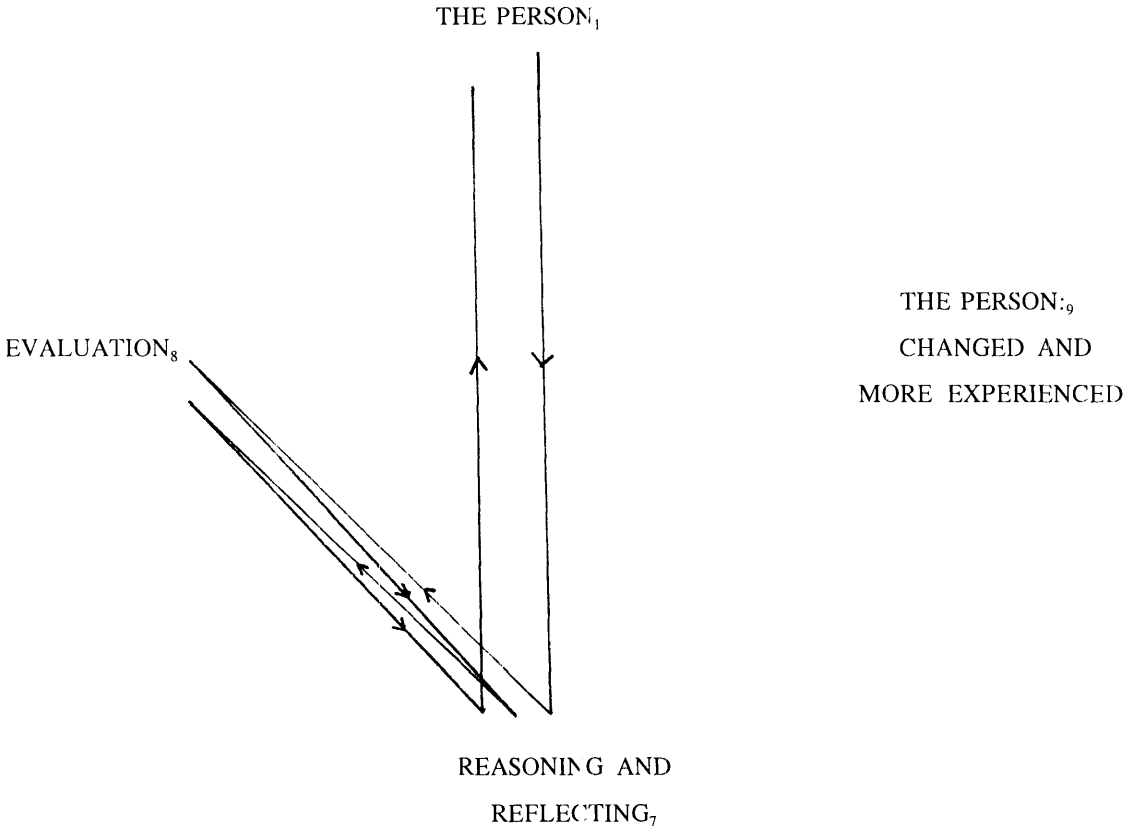
fp: [inaudible] A lot to think about (um). Thank you very much.(865)

The line by line analysis can be summarised as follows. The genetic counsellees entered genetic counselling explaining their sense of loss and how they were coping. They provided information which allowed the genetic counsellor to construct the pedigree and record the prenatal history. The genetic counsellees then spoke about the beliefs with which they entered genetic counselling concerning the cause of their baby's problems.

They reflected on the imprecise information they had been given previously. Fp became upset and the genetic counsellees reflected on their loss. There was evidence that the genetic counsellees had been reflecting on their genetic situation prior to the genetic counselling appointment. This was followed by an evaluative statement about it helping to have had the baby for the short time they did. The genetic counsellees returned to reflection, this time on the information the genetic counsellor had provided. The genetic counsellees reflected again on their experience and the problems their baby had. The evaluative statement: "We made the right decision" was made and the genetic counsellees reflected further on information the genetic counsellor had presented. After this, there were two examples of the genetic counsellees disclosing more about themselves as they entered genetic counselling. The genetic counselling session ended with fp suggesting she will reflect further.

The four elements of Jarvis' (1987) contemplation learning model did not occur sequentially (Figure 3). The genetic counsellees periodically returned to reflection and disclosing how they entered genetic counselling.

Figure 3 The progression of the genetic counsellees depicted in Transcript 2 through the learning process.



LEARNING FROM REVIEWING THE FAMILY HISTORY (TRANSCRIPT 3)

Transcript 3 illustrates the learning processes genetic counsellees undergo as they review their family history. The potential for learning in such situations became apparent after another transcript, Transcript 14, was read as a preliminary to the present study. In Transcript 14, the genetic counsellee sought relationship counselling because her marriage had dissolved. The genetic counsellee related her previous experiences with counselling and commented:

> ....and part of the counselling was actually looking at families....and part of that was looking at families because she does a sort of therapy that includes all deceased members of the family in her work....And we got to talking about the first child that I'd had...that I'd miscarried....Well it was a missed abortion so I had to have it removed, bits were left....and I'd never thought about it any more because it happened, and I put it on a back-burner.....I don't actually feel...I'm slightly tense when I think about it ..I don't think I grieved at the time...(Transcript 14)

This suggests that by reviewing her family history the counsellee learnt that the tense feelings she had been experiencing may have originated from the miscarriage she had some time earlier.

The above quotation occurred in isolation in Transcript 14. It lead to the writer to search for similar learning experiences in other transcripts including Transcript 3.

Analysis of Transcript 3 occurs in the same way as in Transcripts 1 and 2. Genetic counsellee dialogue is categorised according to the four elements of Jarvis' (1987) contemplation learning model and then sub-categorised as coming from either the cognitive or affective domains. This is followed by a line by line analysis of the transcript to determine if Jarvis' (1987) contemplation learning model is followed sequentially.

The transcript involves genetic counselling for a couple (fp and mp) whose relative, Evelyn, had a chromosomal deletion. A chromosomal deletion is where part of one of the chromosomes is missing. The genetic counsellees had received advice from other health professionals that they were not at any increased risk of having a child with a similar problem. This was because Evelyn's parents were found not to have a deletion themselves, thus the deletion occurred *de novo* in Evelyn and was not hereditary.

THE PERSON ENTERING GENETIC COUNSELLING

mp: Well we discussed it briefly with the expert but he said as far as he was concerned it was very unlikely that....it would be, you know....(hereditary)

fp: What we're principally concerned about is that there are so many medical things in Pat's family that...

These comments suggest that the genetic counsellees entered genetic counselling with the knowledge that they were not at risk of having a baby with Evelyn's problems, but they were concerned about other aspects of their family history.

REFLECTION

The transcript contains numerous examples of the genetic counsellees reflecting on their family history. Some of this reflection is related to Evelyn's problems, but most is related to other family characteristics and problems such as cancer, consanguinity, alopecia, eczema and gynaecological problems.

fp: I'm just trying to think....she has an extended family which I really don't see all that much....I'm just trying to think.... one of her brothers is dead...he died of cancer last year.... but he was 75....

fp: (Talking to mp) There's quite a lot of things with your brothers and sisters.....

mp: It's not actually discussed...it's...I don't actually understand... there's no history of it in the extended family...

mp: No she never had children...she actually married a cousin....so whether that was the reason for tha....

fp: Well your Uncle Ivan has three children, one of them has alopecia as well and she's also got hormonal problems the same as Fiona..and incidentally she's also called Fiona...so the alopecia and the hormonal and the gynaecological problems...their situation is very similar, actually....

mp: That's on my father's side...it comes from my father's side...well all...

mp: It's her skin...it's not as bad as I remember it when she was working fulltime as a nurse, but I remember when I was growing up it was very bad....

fp: Well there's bits of eczema....

The counsellees also reflected on the burden of Evelyn's problems.

mp: She's (Evelyn) now able to walk...she has to use the supports....but she's obviously...

fp: She's quite a handful really....

mp: She's quite a handful...she's very headstrong...she's very ...I really don't know what's going to happen there....I don't know what's going to happen long-term....

These periods of reflection can be conceived of as an exploration by the genetic counsellees of possible links between Evelyn's problems and other characteristics and problems in the family.

EVALUATION

The periods of reflection lead the genetic counsellees to make the brief but significant evaluative statement.

fp: And how? Right...OK....so it was just spontaneous then....

This suggests that the genetic counsellees came to accept that their family history did not contribute towards Evelyn's problems.

THE PERSON CHANGED AND MORE EXPERIENCED

The genetic counsellees exited the genetic counselling session reassured that there was no relationship between their family history and Evelyn's problems, and therefore that there was no increased risk to any of their own future children.

fp: ....and I think really we felt.... you know...all these family histories ending up with....

fp: Well so that's great..that's all we need to know...

fp: Thank you for that reassurance...

The application of Jarvis' (1987) contemplation learning model to this transcript, using the guidelines established in Chapter four (pp.34-36), assists in understanding the process the genetic counsellees underwent. Despite having been told previously that Evelyn's problem was not hereditary, the genetic counsellees needed to reflect on their family history in search of evidence of that. They reflected on different characteristics and

problems in the family and also on the problems Evelyn had. This, and no doubt comments made by the genetic counsellor, lead to them accepting that the family history was non-contributory and that the chromosomal deletion was *de novo*. As a result, the genetic counsellees felt reassured.

Using the guidelines established in Chapter four (pp. 36-37), the statements for each of the four elements of Jarvis' contemplation learning model were examined to see if they come from the cognitive domain or the affective domain. Results showed that almost all genetic counsellee statements come from the cognitive domain. The only possible exception was one statement made by fp as she exited genetic counselling: '...we felt...you know...all these family histories ending up with...' This predominance of cognitive domain issues may have arisen because the main concern of the genetic counsellees was their family history, rather than say bereavement as in Transcript 1. Other possible explanations would be that the genetic counsellees may normally resolve issues intellectually, instead of emotionally, or they may have perceived that the genetic counsellor was not open to the discussion of affective domain issues.

The line by line analysis of the transcript follows. The genetic counselling session commenced with the genetic counsellees responding to the genetic counsellor's questions about their health and family history. Their responses are short and objective. For example:

fp: He's got a brother and sister still alive....(111)

Fp then *reflected* on a particular aspect of her family history.

fp: I'm just trying to think....she has an extended family which I
really don't see all that much....I'm just trying to think....
one of her brothers is dead...he died of cancer last year....
but he was 75....(123)

The genetic counsellees continued to answer the genetic counsellor's questions about their

family history and when asked about Evelyn, they *reflected* on her problems.

mp: She's (Evelyn) now able to walk...she has to use the supports....but she's obviously...(164)

fp: She's quite a handful really....(166)

mp: She's quite a handful...she's very headstrong...she's very ...I really don't know what's going to happen there....I don't know what's going to happen long-term....(169)

The genetic counsellees provided further information about Evelyn and their family history. They *reflected* again on their family history.

fp: (Talking to mp) There's quite a lot of things with your brothers and sisters.....(200)

mp: It's not actually discussed...it's...I don't actually understand... there's no history of it in the extended family...(224)

mp: No she never had children...she actually married a cousin....so whether that was the reason for that....(353)

fp: Well your Uncle Ivan has three children, one of them has alopecia as well and she's also got hormonal problems the same as Fiona..and incidentally she's also called Fiona...so the alopecia and the hormonal and the gynaecological problems...their situation is very similar, actually....(372)

mp: That's on my father's side...it comes from my father's side...well all...(392)

mp: It's her skin...it's not as bad as I remember it when she was working fulltime as a nurse, but I remember when I was growing

up it was very bad....(449)

fp: Well there's bits of eczema....(455)

Following this, mp disclosed that they had *entered genetic counselling* with knowledge about the heritability of the chromosomal deletion.

mp: Well we discussed it briefly with the expert but he said as far as he was concerned it was very unlikely that....it would be, you know....(hereditary)(469)

After the genetic counsellor confirmed what the genetic counsellees had been told previously, the following *evaluative* comment was made.

fp: And how? Right...OK....so it was just spontaneous then....(484)

Fp acknowledged that she *entered genetic counselling* because of her concerns about her family history and that these concerns stemmed from Evelyn's problems.

fp: What we're principally concerned about is that there are so many medical things in Pat's family that...(492)

fp: Yes, but Evelyn is the catalyst....(496)

Mp then changed the subject to the question of expressivity. That is, could Evelyn's problems be expressed to a greater or lesser degree in other family members? This was followed by a relatively long period in which the genetic counsellor provided further genetic information. The genetic counsellees responded with acknowledgments such as 'Hmmm' and 'Right'.

The genetic counsellees changed the subject and asked several questions about an unrelated topic, the safety of air travel during pregnancy. The genetic counsellor

answered these questions.

The genetic counsellees thanked the genetic counsellor and made comments which illustrated *how they exited genetic counselling changed.*

fp: ....you've explained everything very well....and I think really we felt.... you know...all these family histories ending up with...(735)

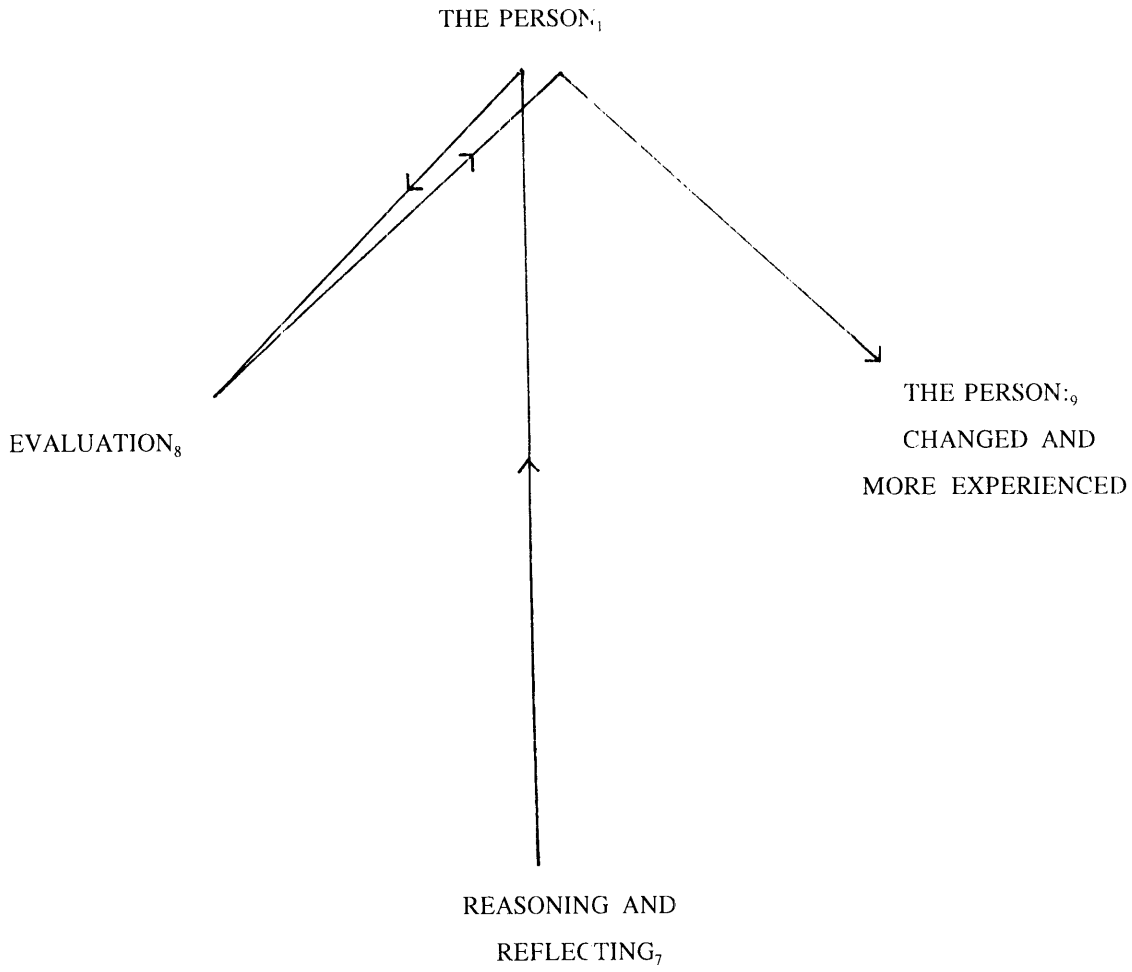
fp: Well so that's great..that's all we need to know...(750)

fp: Thank you for that reassurance...(800)

The line by line analysis can be summarised as follows. After answering questions about their health and family history, the genetic counsellees reflected on particular aspects of their family history and Evelyn's problems. They continued to reflect on their family history, this time in more detail. Information about how the genetic counsellees entered genetic counselling was then disclosed and this was followed by an evaluative comment. The genetic counsellees provided further information about how they entered genetic counselling requiring certain knowledge, and then how they exited genetic counselling satisfied and reassured.

The above summary (depicted in Figure 4) shows that Jarvis' (1987) contemplation learning model was not followed sequentially. Similar to Transcripts 1 and 2, details about how the genetic counsellees entered genetic counselling came later in the transcript. The earlier explanation (Chapter five, p.55) that it takes genetic counsellees a period of time to develop rapport with the genetic counsellor before they will disclose themselves, could be applied here also. The genetic counsellees appeared to have no such difficulty in reflecting, which they did early in the transcript.

Figure 4 The progression of the genetic counsellees depicted in Transcript 3 through the learning process.



LEARNING ABOUT PROGNOSIS (TRANSCRIPT 4)

An expectation that many genetic counsellees have about genetic counselling is that they develop an understanding of the prognosis of the genetic disorder that they have themselves or that a family member has. In this transcript, a single genetic counsellee (p) has a son with Klinefelter syndrome and he learns about the prognosis of that. Klinefelter syndrome is caused by an extra X chromosome in males. It results in the male having a slightly different body habitus, infertility, and often behavioural problems. The genetic counsellee in Transcript 4 does not have custody over his son who is in foster care.

Analysis of the transcript occurs in the same way as in the three previous transcripts. Genetic counsellee dialogue is categorised according to the four elements of Jarvis' (1987) contemplation learning model and then sub-categorised as coming from the cognitive domain or the affective domain. This is followed by a line by line analysis of the transcript to determine if Jarvis' (1987) contemplation learning model is followed sequentially.

THE PERSON ENTERING GENETIC COUNSELLING

The genetic counsellee entered genetic counselling for the first time making clear his lack of knowledge of Klinefelter syndrome. As the session progressed, the genetic counsellee revealed that he had only recently heard of the diagnosis and that it had been causing him anxiety.

p: What I want to know is what is this genetic disorder that he's got, what is it - I don't know anything about it.

p: My social worker told me (about the diagnosis of Klinefelter syndrome) about 2 or 3 weeks ago.

p: Well, I've got Black's medical dictionary at home but it doesn't say a lot about it, you know. There's only a little ....

p: ...they gave me the impression that it was a killer disease that he had, you know. That was the impression I'd got from them. You know, and the way they were talking about the less people know about it the better, you know ....

p: Makes it sound as if the child was going to die within the next 6 or 7 months, you know. They had me really worried.

REFLECTION

The genetic counsellee appeared to reflect by either paraphrasing the genetic counsellor or asking a question related directly to the information provided by the genetic counsellor. To illustrate this, reflective statements of the genetic counsellee are preceded by the genetic counsellor dialogue which prompted the reflection. Genetic counsellor dialogue is in bold print to more easily distinguished it from genetic counsellee dialogue.

c: Well, you don't need to get rid of it and there is no way that you can get rid of it - it is there and it will always be there.

p: So, in other words there's no treatment for it.

c: But he will learn to talk and it will eventually be (yes he is learning to talk at the moment, yeah) fine. That does mean to say, though, that sometimes speech therapy is helpful.

p: Yes, his speech is very late.

p: How long would it take him before he gets his normal speech?

p: Will he ever be able to have kids?

c: That's the one thing that he won't be able to do.
[long pause]

p: Sad. S'life isn't it.

p: So in the long term its not going to affect him?

p: But when he's, when he's growing up is, it's going to affect his speech for a little while isn't it.

c: **We don't know exactly how it happens, we know that at the time he was actually conceived - at the time he was made - he got 1 extra chromosome, and because there was 1 extra chromosome in that initial ball of cells before he developed into a baby, that 1 extra chromosome then occurs in every cell in his body. Because as the cells divide and divide (yeah) and divide, so that extra chromosome gets passed into all the cells in his body. It's just one of those things that happens.**

p: So, in other words, it's a freak mishap of nature.

c: **Um. There's just one thing that I'd like to go back to, and that's the business about C. having children (yeah), perhaps that seems the one thing which is rather negative about Klinefelters, but I do want to tell you that he will be able to get married and have a normal sexual relationship with his wife, and there would be ways, other ways round them having children (yeah) if they wanted to. (Um).**

p: That's all in the future as you say.

p: It's a very long way off. Yeah. That'll be his, it'll be up to him to work out.

EVALUATION

The genetic counsellee appeared to have considered the information the genetic counsellor provided about Klinefelter syndrome and then made judgements about the burden of the

disorder, the credibility of his other sources of information, and the usefulness of the new information.

p: They're not life threatening, but still they're, they're serious because at the moment its affecting his speech and its affecting his co-ordination and lots of other little things like that.

p: That's good. So, I don't think they know what they're doing either, social services they're crap.

p: I think it would be really helpful for them (having the genetic counsellor send the foster parent information about Klinefelter syndrome)

PERSON CHANGED AND MORE EXPERIENCED

The genetic counsellee exited genetic counselling relieved of the anxiety with which he entered genetic counselling. He indicated that there had been a significant change in his outlook on Klinefelter syndrome.

c: Good. OK. Do you feel that the sorts of things that we've talked about have been helpful?

p: Yes, very helpful because when I came.... before I came in here I hadn't a clue ... what this thing was, I hadn't a clue what it was. Because, as I said, when I read up on Black's medical dictionary it was only just about that much, and it just said that it was an extra chromosome and that was all it said, and that it wasn't related to anything else and that's it. that's all I knew. I didn't know anything else. I thought it was something really serious. I was really worried when I came in here. But you've explained it to me.

p: ...the social services don't know anything about it and here's me sure now, from, from the way they described it to me, you know, they never even told me, o'h

it's .... they made a big issue out of it as if the child was going to die within 6 months [inaudible] you know. They really scared me.

p: ... So now that I know more about this, this is great.

p: Well, that's about taken off my heart .....

Some of these statements illustrating how the genetic counsellee exited genetic counselling might have otherwise been categorised as evaluation; they have an evaluative quality about them. However, they provide such a good description of how the genetic counsellee had changed and became more experienced that it seemed appropriate to categorise them as such.

The application of Jarvis' (1987) contemplation learning model to this transcript, according to the guidelines established in Chapter four (pp.34-36), provided a means of plotting the path of the genetic counsellee from anxiety about lack of knowledge of Klinefelter syndrome, through to understanding and relief. The genetic counsellee accomplished this principally by reflecting on the information provided by the genetic counsellor.

Using the guidelines established in Chapter four (p.36-37), the statements for each of the four elements of Jarvis' (1987) contemplation learning model were examined to see if they come from the cognitive domain or the affective domain. Genetic counsellee statements come from both these domains. Approximately half the statements illustrating how the genetic counsellee entered genetic counselling come from the affective domain, almost all reflective statements come from the cognitive domain, two out of the three evaluative statements came from the cognitive domain and half of the statements illustrating how the genetic counsellee had changed on exiting the genetic counselling session come from the affective domain. This illustrates that Jarvis' (1987) contemplation learning model can account for learning in both the cognitive and affective domains in genetic counselling.

The line by line analysis of the transcript follows. The session commenced with the genetic counsellor asking the genetic counsellee for demographic details. Without direct prompting, the genetic counsellee outlined his goals as he *entered genetic counselling*.

p: What I want to know is what is this genetic disorder that he's got, what is it - I don't know anything about it.(46)

The genetic counsellor then asked questions in order to record the family history. Whilst answering these questions, the genetic counsellee explained his estrangement from his son's mother, how often he received access to his son, and how this was unsatisfactory to him. The genetic counsellee also disclosed that the situation was affecting him socially.

p: It does at times, yeah. Because I don't socialise or nothing, I'm a very private person...(193)

In response to the genetic counsellor's questioning, the genetic counsellee explained that he was *entering genetic counselling* having only recently heard of the diagnosis of Klinefelter syndrome.

p: My social worker told me about 2 or 3 weeks ago.(205)

The genetic counsellee then discussed in some detail how his son required spectacles, and that these had improved his son's life.

p: [sounds to be getting more and more irate and frustrated] A massive big difference. When I come out for a walk ... there's ... flowers growing there and he never even bothered with them before (um). Probably couldn't see them. They were about 15 - 20 foot away from the pavement (um) and all of a sudden he let go of my hand he rushed over and said o'h dad flowers (um). Probably never seen them before...(245)

The genetic counsellee displayed anger because others had blamed poor parenting skills

for his son's poor developmental progress. Prompted by this, the genetic counsellor gave an explanation about Klinefelter syndrome. The genetic counsellee *reflected* on this and verbalised his interpretation of the information. For example:

p: So, in other words there's no treatment for it.(308)

The genetic counsellee disclosed that he had searched for information about Klinefelter syndrome *before entering genetic counselling*.

p: Well, I've got Black's medical dictionary at home but it doesn't say a lot about it, you know. There's only a little ....(319)

The genetic counsellee also disclosed an explanation that had been given to him earlier about his son's problems. This explanation was most likely inaccurate.

p: Yes, that's what they're saying you know. That's what they've been saying all along, the social services, been saying all along, before it was found out that he had that kline thing. That he's seen me being stabbed and that was why he wasn't responding and he wasn't talking and that he wasn't developing properly and all this.(349)

As the genetic counsellor provided information about Klinefelter syndrome, for example, that it can cause shyness and speech problems, the genetic counsellor *reflected* on this and related it to his son.

p: Yes, his speech is very late.(338)

p: How long would it take time before he gets his normal speech?(358)

The genetic counsellor raised the matter of some boys with Klinefelter syndrome requiring hormone treatment to help them develop physically. This appeared to prompt the genetic counsellee to *reflect* on his son's reproductive potential.

p: Will he ever be able to have kids?(457)

The answer to the above question is 'no', and after receiving that answer, the genetic counsellee took a long pause (as indicated by the transcriber) before *reflecting*:

p: Sad. S'life isn't it.(463)

The genetic counsellee moved on to *reflect* on other aspects of the prognosis.

p: So in the long term its not going to affect him?(467)

p: But when he's growing up is, it's going to affect his speech for a little while isn't it.(471)

The genetic counsellee changed the subject to the frequency of Klinefelter syndrome, the aetiology of it, the recurrence risk, and asked if the origin of the extra X chromosome was maternal or paternal.

p: How common is it?(479)

p: And how does it happen?(484)

p: Is it ever likely to happen again - suppose I had more kids, would it happen?(494)

p: And is there any way of finding out which of the parents the extra chromosome came from?(497)

p: So, in other words, it's a freak mishap of nature.(502)

The genetic counsellee then requested reading material on Klinefelter syndrome and *reflected* on the long-term problems of the disorder.

p: That's all in the future as you say.(525)

p: It's a very long way off. Yeah. That'll be his, it'll be up to him to work out.(529)

Prompted by the genetic counsellor, the genetic counsellee discussed his family of origin and how he missed his relatives. The genetic counsellor asked if he was missing his son, since he did not have permanent custody of him.

p: Prefer it if I had him back, tell you the truth. I miss him terribly, you know (um). Even though other people say, o'h you never miss a child, you know - but they're wrong, you will. I used to look forward to going to see him on Tuesday and on Thursday.(589)

There was then discussion about informing relevant professionals about the Klinefelter syndrome. The genetic counsellee commented:

p: It is very important....(619)

The genetic counsellee then made an *evaluation* of the prognosis in his son which was based on his understanding of the information presented to him by the genetic counsellor.

p: They're not life threatening, but still they're, they're serious because at the moment its affecting his speech and its affecting his co-ordination and lots of other little things like that.(624)

He requested that his solicitor be provided with information on Klinefelter syndrome in order that this could be used to assist in the custody case.

p: Well, I'd like my solicitor to know and my barrister to know all about this the way they can stand up in court and say, that the social services are building their case wrong that this is why C. is the way he is and that because ....(631)

When an offer for contact with the Klinefelter syndrome support group had been made, the genetic counsellee responded:

p: I think it would be very good to contact this lady because ....(669)

p: I don't really want to read up about it, you know.(673)

The genetic counsellee then reiterated that he had only recently heard of Klinefelter syndrome and had perceived the problem to be worse than what it was. The genetic counselling had been worthwhile to him and he was *exiting it changed.*

p: Yes, very helpful because when I came.... before I came in here I hadn't a clue ... what this thing was, I hadn't a clue what it was. Because, as I said, when I read up on Black's medical dictionary it was only just about that much, and it just said that it was an extra chromosome and that was all it said, and that it wasn't related to anything else and that's it, that's all I knew. I didn't know anything else. I thought it was something really serious. I was really worried when I came in here. But you've explained it to me.(697)

This was followed by an illustration of how the genetic counsellee *entered the genetic counselling session* - with an inaccurate and damaging understanding of Klinefelter syndrome.

p: Because, the way the social services were going on about it, you know, they were saying o'h it's steadily and all this and the other, they gave me the impression that it was a killer disease that he had, you know. That was the impression I'd got from them. You know, and the way they were talking about the less people know about it the better, you know ....(707)

p: Makes it sound as if the child was going to die within the next 6 or 7 months, you know. They had me really worried.(715)

Based on the information he received from the genetic counsellor about Klinefelter syndrome, and his reflection on that, the genetic counsellee made the following *evaluative* comment about some of the professionals he had been in contact with.

p: That's good. So, I don't think they know what they're doing either, social services (um) they're crap.(720)

The conversation moved on to the genetic counsellee describing how his son loves him.

p: Yeah. When they cut down the contact, the foster mother was telling me, I used to go there on Thursday, and on a Friday - sometimes, some Thursday's they'd tell me to come to the office in Grove Park (um), the social services. She says to me, she says, Thursday and Friday he had his chair ready and his coat and he had his wellies put on, he was waiting for you (um). He knew exactly the time when I was going to arrive there. And she said she had an awful time with him (um) crying and shouting and asking for me, you know.(747)

The genetic counsellee then made another *evaluative* statement, this time concerning the value of the information about Klinefelter syndrome to others involved in his son's care.

p: I think it would really help for them (having the genetic counsellor send the foster parent information about Klinefelter syndrome).(776)

The genetic counsellee discussed the problems he had been having with Social Services. Part of this discussion illustrates *how the genetic counsellee exited genetic counselling changed.*

p: Everything they've asked of me, I've done. But everything I've asked of them, they've done nothing for me. They've treated me as if I was the plague, so I just keep quiet, watch what they do and listen, take a few pointers here and there, take them to my solicitor and they'll work for me. They make mistakes, I capitalise on their mistakes - it's as simple as that. *So now that I know more*

about this, this is great. So, I'll write to them. I'll ring her, ring her from the hotel.(819)

The genetic counsellee gave an indication of the relief he had received from the genetic counselling session *as he exited it.*

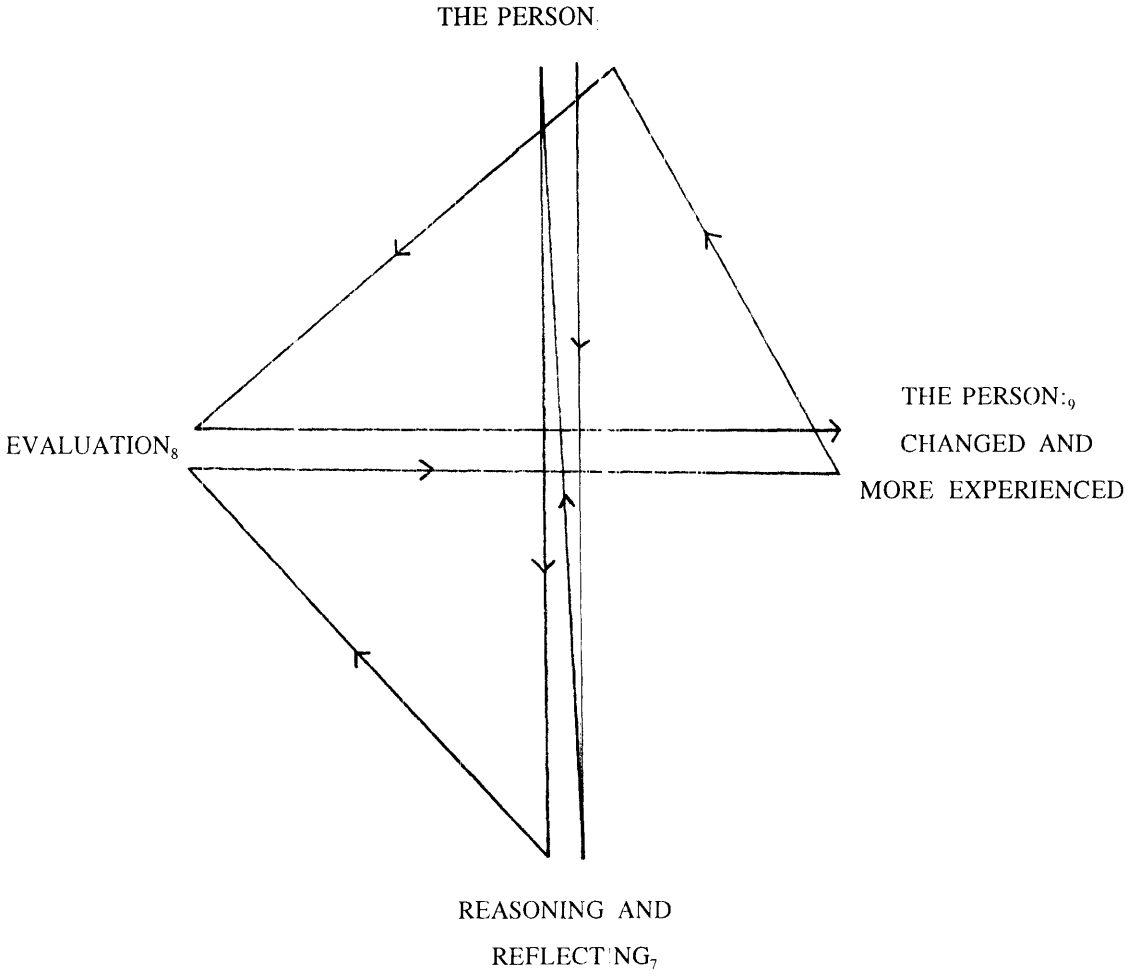
p: Alright. That's great. Well, that's about taken off my heart ....(845)

The line by line analysis can be summarised as follows. The genetic counsellee entered genetic counselling with little knowledge of Klinefelter syndrome and wanted to expand that: "...what is it - I don't know anything about it.". He reflected on what the genetic counsellor explained to him about Klinefelter syndrome before revealing that he had searched for information prior to entering genetic counselling. There was another period of reflection on what the genetic counsellor had explained; this one was much longer. The genetic counsellee then spoke about his family situation and the custody arrangements of his son. These themes were repeated throughout the transcript. The genetic counsellee made an evaluative comment about prognosis and made comments which illustrated how he would exit genetic counselling changed. After providing further information about how he entered genetic counselling, the genetic counsellee made another evaluative comment and provided more evidence of how he would exit genetic counselling changed: "Alright. That's great. Well, that's about taken off my heart ....."

The line by line analysis shows that the genetic counsellee did not progress through the four element of Jarvis' (1987) contemplation learning model sequentially. This is depicted in Figure 5. The line by line analysis also suggests the importance of examining the elements of Jarvis' (1987) contemplation learning model in the context of the entire genetic counselling session. For example, the first phase of analysis showed quite clearly that the genetic counsellee entered genetic counselling wanting to learn information, and that he exited having achieved that goal, feeling reassured as a result. The line by line analysis showed a similar beginning and end of the genetic counselling session, but that the genetic counsellee's family and legal affairs were threaded through the genetic counselling session and had a significant bearing on the process he underwent. Much of

the relief the genetic counsellee experienced as result of the genetic counselling may have stemmed from the fact that, initially, poor parenting had been blamed for his son's problems, and since genetic counselling provided an alternative explanation, this was going to be helpful in custody proceedings. This suggests that a fuller understanding of the process genetic counsellees undergo will come when the application of Jarvis' (1987) contemplation leaning model is supplemented by a line by line analysis of the entire genetic counselling, allowing the nuances of the genetic counsellees' story to unfold.

Figure 5 The progression of the genetic counsellees depicted in Transcript 4 through the learning process.



CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

The applicability of an adult learning approach to genetic counselling was suggested in Chapter three (pp.17-19) where the case example of Meryl was used to show that what occurs in genetic counselling meets Knowles' assumptions (1978, p.55-59) and conditions (1978, p.77-79) of learning. The exploration of the four selected transcripts in Chapter five confirms this suggestion. Genetic counsellee dialogue is easily categorised according to the elements of Jarvis' (1987) contemplation learning model and the model accounts for learning in both the cognitive and affective domains. The application of Jarvis' (1987) contemplation learning model to the four transcripts provides a means for exploring and discussing the processes experienced by the genetic counsellees. However, the analysis shows that the model was not followed sequentially.

Chapter six presents the benefits to be derived from using Jarvis' (1987) contemplation learning model to explore and discuss genetic counselling in clinical practice, and in the education of genetic counsellors. Where possible, and to demonstrate their clinical relevance, these benefits are placed in the context of what is discussed at clinical meetings or case conferences. These meetings and case conferences are where most of the discussion about individual genetic counselling sessions occurs. The limitations of the present study and recommendations for future research are also discussed throughout Chapter six.

As introduced in Chapter two (p.7) and the above paragraph, the exploration and discussion of genetic counselling sessions occurs most often at clinical meetings or case

conferences. These can be held either prior to or following a genetic counselling session. Clinical meetings and case conferences conducted prior to a genetic counselling session serve to prepare the professionals involved, genetic counsellors, clinical geneticists and obstetricians, in order that the best possible service can be provided by them. Clinical meetings and case conferences conducted following genetic counselling session are intended to provide a forum for the review of cases. Comments about how the sessions were conducted are sought and any outcomes are discussed. They also help to meet educational needs of staff. In addition, case conferences are held regularly between trainee genetic counsellors and their supervisors to address the trainee genetic counsellor's clinical performance.

The exploration and discussion of cases at clinical meetings and case conferences does not normally follow any particular model. Kessler and Jacopini (1982) suggested that the Bales system of scoring small group interactions was applicable to genetic counselling, but it has not been taken up by other genetic counsellors. It appears that no model for exploring and discussing genetic counselling cases has been accepted by the profession. This thesis suggests that there are benefits in using Jarvis' (1987) contemplation learning model in such situations. For example, the application of Jarvis' (1987) contemplation learning model offers a broad view of the process genetic counsellees undergo and encourages genetic counsellors to consider that learning commences before the actual genetic counselling session, and may not be complete at the end of it. It also facilitates a more genetic counsellee centred genetic counselling and promotes an understanding of the genetic counsellees. These benefits are now discussed in more detail.

The application of Jarvis' (1987) contemplation learning model in the present study highlights that learning by genetic counsellees should be considered to have begun before the actual genetic counselling session. Such was the case with the genetic counsellees in Transcript 2. The genetic counsellees had made progress in adapting to their loss and gaining genetic knowledge prior to their appointment. It is conceivable that most, if not all, genetic counsellees commence learning from their genetic situation before genetic counselling. In some cases it may be several years from when a genetic situation is first experienced to when genetic counselling is sought. Huntington disease, a degenerative

neurological disorder, would be an example of this. People seeking genetic counselling for Huntington disease often have detailed knowledge and heightened awareness of the disorder and its implications when they enter genetic counselling. This is because they generally have lived with, and even nursed, their affected parent.

Understanding that learning may commence prior to the genetic counselling appointment should prompt genetic counsellors to include discussion about how genetic counsellees enter genetic counselling at clinical meetings and case conferences. This may assist genetic counsellors and others involved in the genetic counselling to understand better the perspective of the genetic counsellees and what they have already accomplished. Shiloh and Berkenstadt (1992, p.191) explained that one of the main tasks of the genetic counsellor is to be sensitive to personal meanings, and to recognise genetic counsellees' points of view and previously determined concepts of the topics being discussed. Without such an understanding of genetic counsellees' points of view and any learning they have already achieved, genetic counsellors cannot as easily demonstrate empathy towards their clients, thus limiting rapport development and honest and open communication. A good understanding of how genetic counsellees enter genetic counselling, including any learning they have already achieved, is also a first step in understanding their goals and knowing how to meet them. Although it may be routine for genetic counsellors to ask genetic counsellees' about their goals, this may not always be adequate. Evidence suggesting that genetic counsellors need to be more aware of the goals of their genetic counsellees has already been discussed (Chapter 2, p.13).

As discussed in Chapter two (p.5), the intake session is an important part of genetic counselling. This is where the genetic counsellor meets with the genetic counsellee prior to the more definitive genetic counselling session, principally to take an history and construct a pedigree. The fact that the work of many genetic counsellors is structured as such, provides an opportunity for them to observe, explore, and report how genetic counsellees enter genetic counselling. Broadening the focus of the intake session and conceptionalising it as part of the learning process, would hopefully allow for a greater awareness amongst all involved in the genetic counselling of what learning has already occurred and what change the genetic counsellee is seeking.

In the same way that the application of Jarvis' (1987) contemplation learning model to the transcripts shows that learning often commences prior to the genetic counselling session, it also suggests that it may not be complete at the end of it. This also was illustrated in Transcript 2. At the end of the genetic counselling session, no learning outcome was observed. In fact, the genetic counsellee commented: "A lot to think about....". At clinical meetings and case conferences conducted after genetic counselling sessions, genetic counsellors should ask if learning is complete and be open to the need for follow-up appointments. In some genetics services these seldom occur; certainly they are not routine. However, if genetic counsellors see their role as facilitating learning, and if in some cases learning appears to be incomplete, the option for one or more follow-up appointments can be justified. Headings (1975, p.825-826) and Antley (1976, p.115) made similar comments about the need for follow-up sessions.

Since learning by genetic counsellees may commence prior to and following a genetic counselling session, or a series of genetic counselling sessions, subsequent studies should include an examination of these periods as well. Such research may provide valuable information about when to initiate genetic counselling and for how long it should be sustained.

It has already been mentioned that a number of professionals participate in genetic counselling sessions (Chapter one, pp.6-7). Often, these professionals are in the one session together. For example, a clinical geneticist makes and presents a genetic diagnosis, and an obstetrician explains a prenatal diagnostic procedure. From the writer's observation of such situations, the preventative medicine paradigm is adopted and the emphasis is on the person providing information, and on the information itself. Affective domain issues are often neglected. If Jarvis' (1987) contemplation learning model is applied to that situation, more attention might be paid to promoting genetic counsellee reflection on the meaning and impact of the information presented to them. Genetic counsellee evaluation might be promoted also. Genetic counsellees might be encouraged to reflect and evaluate on both cognitive and affective domain issues through carefully worded questions or prompts. The end result would be a genetic counsellee centred genetic counselling, more typical of the psychologic medicine paradigm which is where

the profession of genetic counselling appears to be heading.

What is less clear is if encouraging genetic counsellee reflection and evaluation will alter the course of change in the genetic counsellee. For example, would more reflection and evaluation speed up the change process? Such questions are best answered by other research projects.

Another benefit in the application of Jarvis' (1987) contemplation learning model is that it promotes an understanding of the genetic counsellees. This was highlighted in all four transcripts once the genetic counsellee dialogue had been categorised according to the elements of the model. Transcript 1 serves as a particularly good example. After genetic counsellee dialogue had been categorised under the heading of 'The Person Entering Genetic Counselling', the conflict the genetic counsellees experienced about the cause of their baby's problems and the recurrence risk became apparent because comparisons between each of the statements made by the genetic counsellees could be made more easily. Of course, the usefulness of Jarvis' (1987) contemplation learning model does not obviate the need for genetic counsellors to attend to the unfolding story of genetic counsellees. As shown in Transcript 4, this also provides information about the experiences of genetic counsellees.

All transcripts illustrated that Jarvis' (1987) contemplation learning model is not followed sequentially. For example, information about how the genetic counsellees entered genetic counselling appeared to occur at any time during the genetic counselling session. In Transcript 1, much of this dialogue came towards the end of the genetic counselling session, apparently after the genetic counsellees developed rapport with the genetic counsellor. Since Jarvis' (1987) contemplation learning model is not followed sequentially, the genetic counsellor is required to continually revise hypotheses about the genetic counsellees throughout the genetic counselling session. The genetic counsellor may have developed an opinion about what the genetic counsellee knows or feels, only to realise that this opinion requires modification in the light of a more recent comment. The ability of genetic counsellors to do this is unclear and warrants investigation through future research. Perhaps, only after the genetic counselling session has ended, and Jarvis'

(1987) contemplation learning model has been applied, can the genetic counselling process be explored fully. Of course, if follow-up appointments become more accepted, it is possible that any new understanding of the genetic counsellees' resulting from a retrospective exploration and discussion of the case may be acted upon at a later session.

It had been anticipated that the categorisation of genetic counsellee dialogue according to Jarvis' (1987) contemplation learning model would be problematic (Chapter four, p.34). For some genetic counsellee dialogue it was difficult to determine to which category it should be allocated and the task of labelling genetic counsellee dialogue was a subjective decision. This is not a limitation of the application of Jarvis' (1987) contemplation learning model since the benefit in applying the model to genetic counselling is that it allows the path of genetic counsellees to be plotted. The labelling of genetic counsellee dialogue is simply a means to that end. Future research may use video recordings of genetic counselling sessions and thus nonverbal cues may be used to improve the categorisation of genetic counsellee dialogue. For example, a video recording of a genetic counselling session may show a discrepancy between a genetic counsellee's verbal and nonverbal behaviour. The genetic counsellee may say something like 'I know what decision to make' but exhibit a confused facial expression. The observation of a combination of verbal and nonverbal behaviour may alert the researcher to such discrepancies and result in a more questioning and accurate categorisation of genetic counsellee dialogue.

This thesis shows that the application of Jarvis' (1987) contemplation learning model to transcripts of genetic counselling sessions allows process issues to be explored. The application of the model also has the potential to observe relationships between process issues, such as genetic counselling style and methods, and change in genetic counsellees. Future research aimed at the elucidation of such relationships would assist genetic counsellors in knowing which style or method might best suit genetic counsellees and the change they are seeking.

Jarvis' (1987) contemplation learning model offers an appropriate structure for teaching genetic counselling students. Presently, many genetic counselling curricula follow a

medical approach, covering material according to body systems or disease states. Jarvis' (1987) contemplation learning model provides a means for organising course content in a more meaningful way. For example, instead of teaching the genetic counselling of diseases such as Huntington disease, anencephaly or Down syndrome separately, these subjects may be taught by examining the way in which families with problems such as these may be expected to enter genetic counselling - the areas of commonality and difference and how good interviewing skills may elicit these. Similarly, the types of changes to be expected in such families as they exit genetic counselling, and how to detect these, would be an important component of any genetic counselling course. The result would be courses in genetic counselling which are less disease orientated and more genetic counsellee focused.

Jarvis' (1987) contemplation learning model would give genetic counselling students a useful way of analysing their clinical experiences. It would encourage them to concentrate on process issues rather than the information given to genetic counsellees during genetic counselling sessions, and provide them with a framework for discussing cases with their fellow students and supervisors.