

# The field of genetic counselling psychology essay



**ASSIGN  
BUSTER**

Over the past fifty years, the field of genetic counselling has been constantly evolving, often changing the roles and adjusting the values of genetic counsellors within the field. This progress can be monitored by looking at the genetic counselling literature from various decades and comparing fundamental values of the profession at a certain time period. In this paper, an evaluation of genetic counselling services is based on four studies conducted in 1970s and 2000s. These studies were on genetic counselling provided for neural-tube malformations by Morris and Laurence (1976), Duchenne muscular dystrophy by Emery et al. (1972), the role of genetic counselling in multidisciplinary metabolic clinic by Hartley et al. (2010), as well as on the genetic counselling for patients with psychiatric disorders (Hill and Sahhar 2006).

The main focus of Morris and Laurence (1976) research was to assess the value of genetic counselling provided to couples who had a child with neural-tube malformations, an affected relative, or themselves had been suffering from these defects over the period of 8 years. The success of 160 genetic counselling sessions was measured by the clients' reaction to counselling, accurate recollection of risks, and the appropriateness of the actions taken as a result of the risk numbers provided. In this study, genetic counselling consisted of two consultations. During the initial consultation, information on the origin, possible causes of the neural-tube malformation, and risk figures was given. In addition, the counsellor addressed the couples' concerns and discussed the potential means of solving them using a nondirective approach (Morris and Laurence 1976). After the session, none of the couples had received the letter with the details of the consultation, it was only sent to

their general practitioner. A two-hour follow-up consultation was arranged at the couple's home, with a previous consent of the couple via a formal letter and the general practitioner. During this visit, a genetic counsellor had focused on the couples' reactions to counselling, accurate recollection of risk information, and their decision on further pregnancy (Morris and Laurence 1976).

The main purpose of Emery et al. (1972) study was to evaluate the effectiveness of genetic consultations given to women with confirmed diagnosis of Duchenne muscular dystrophy over the period of 4 years. The effectiveness of genetic counselling was measured in a similar way to the previously mentioned study, in addition to the influence of consultations on women's marital status. In contrast with the findings on neural-tube malformations (Morris and Laurence 1976), genetic counselling in this study consisted of two sessions and one follow-up visit. All three consultations differed in nature. Women referred to genetic counselling in this study were not aware of the exact risk numbers of them being a carrier for the X-linked Duchenne muscular dystrophy; therefore, the point of the first visit was to conduct a predictive test based on the serum levels of creatine kinase. As soon as the results were obtained, women came for the second consultation, where the information on the character of the disease, their carrier status and risk figures was given. Similar to the study done on neural-tube malformations, Emery et al. (1972) implemented a nondirective approach into the genetic counseling sessions, with a slight emphasis on the importance of the risk figures given to women who were in the 'high' risk group only. During a follow-up visit, a questionnaire was used to assess

women's reactions to counselling and their views on future pregnancies.

Neither counselled women nor their general practitioners received a detailed letter of the consultation.

pg. 2

Both of the studies showed that the majority of clients seemed to have a fairly good apprehension of the disease nature and recall of the risk numbers, with the outstanding memory of clients falling into groups of very high and low risk. However, Morris and Laurence (1976) found that 23% of their clients had a very poor recall due to various reasons. It was quite surprising to see that nearly one-fifth of the couples were disappointed with the nondirectiveness of genetic counselling mostly because they were looking for someone to make decisions for them. The question that immediately comes to mind is: What are the reasons for disliking the nondirective approach? Was it because the counsellor did not provide enough psychological support? If the counsellor was concentrating on being nondirective and let clients be completely responsible for their own decisions, then the counsellor might have missed the opportunity to emotionally connect with the clients and give them enough confidence to make the decisions of their own.

The evaluation of the effectiveness of genetic counselling in these two studies was mainly measured by the clients' ability to retain information on risks, their attitude towards advice given, and their future decision making (Emery et al 1972; Morris and Laurence 1976). However, both of these studies had no emphasis on feelings of other family members about the

disease, financial burden associated with the disease, and the social aspects of it. It was quite surprising to see that in the attempt to evaluate the effects of genetic counselling in Duchenne muscular dystrophy (Emery et al. 1972), there was no record of the actual feelings of the clients towards genetic counselling and the nondirective approach used. In my opinion, one cannot fully assess the attitude towards genetic counselling if it is measured through comprehension of the nature and risks of the disease, and not the emotional responses to the counselling process.

It can be seen from both of the studies, that nondirective approach was used as a method for conducting genetic counselling. Over the past three decades, nondirectiveness was an integral part of genetic counselling (Kessler 1997). As a result, the information given to families had an emphasis on the genetic aspect of the disease, the risks associated with it and the importance of those risks. Genetic counsellors restrained themselves from participating in active discussion, giving advice or making any decision for the client. The study on Duchenne muscular dystrophy (Emery et al. 1972) clearly shows that the decisions associated with future pregnancies regardless of the risks were left entirely to the woman. Looking through the literature on genetic counselling, there seems to be a lot of criticism of nondirective approach and dissatisfaction of many genetic counsellors that have recently entered the field with it (Kessler 1997; Weil 2003; Weil et al. 2006). A high rate of dissatisfaction with nondirective approach in the field could be well due to the fact that nondirectiveness was initially implemented in reproductive genetic counselling era, when genetic counsellors could only provide information on risks and prenatal testing, and left the decisions on

family planning up to the clients (Weil 2003). This is well illustrated by the studies on neural-tube malformations (Morris and Laurence 1976) and Duchenne muscular dystrophy (Emery et al. 1972).

The study done by Hartley et al. (2010) vividly shows how different the role of genetic counsellor is these days. It looks at a genetic counsellor as a part of one complex multidisciplinary environment providing a wide variety of health services to children with metabolic disorders. The distinct feature of the genetic counselling in such clinics is

pg. 3

that the counselling sessions are provided continuously over the life span of a patient. In contrast with the genetic counselling services in 1970s, the counsellors in this type of clinical environment have an opportunity to fully engage with the client, an advantage of addressing every concern the patient's family has, as well as providing a continuing emotional support (Hartley et al. 2010). The consultations themselves differ quite significantly from those taken place in reproductive genetic counselling era. During the first consultation, genetic counsellors do realize that the stress of recently diagnosed child with metabolic disorder often overrides the family's ability to take in the information on the disorder and risks associated with it. Keeping this in mind, genetic counsellors do not go into the genetic aspect of the disorder, but rather provide immediate psychosocial support and give an idea of what it means to live with a metabolic condition on the day-to-day basis (Hartley et al. 2010). Looking back at the studies done by Morris and Laurence (1976) and Emery et al. (1972), one could see a possible downside

of giving a whole lot of information in a single counselling session, which could be the underlying reason for client's poor recall of information when in distress. Therefore, the second consultation is usually held at least four months after the metabolic disorder is diagnosed. And it is during this session that the extensive information on the inheritance and nature of the condition, and the available community support groups (Hartley et al. 2010).

The study done by Hill and Sahhar (2006) also shows a newly developing role of a genetic counsellor in the field of psychiatric genetics. Due to the current limitations in the knowledge of psychiatric genetics, most of the genetic counsellor's work is devoted to providing helpful resources to the family, connecting them with support groups, emphasizing the importance of family support and helping to deal with the stigma associated with psychiatric disorders, however, the risks of recurrence are also explained. The counselling sessions also tend to be held over a long period of time, which gives clients more time to adapt to a genetic side of mental illness.

The two recent studies are similar in a way that there was a detailed summary letter written to the clients with the information covered during the counselling session (Hartley et al. 2010; Hill and Sahhar 2006). In studies done by Morris and Laurence (1976) and Emery et al. (1972), it is quite understandable that if someone wants to measure the ability of a client to remember the information given, then no summary letter should be sent. However, such letter tends to be crucial with helping clients to fully understand and retain the information on the disorder if they were not able to concentrate on it during the counselling session (Hill and Sahhar 2006).

These letters also serve as important starting point for sharing information within the family or with a general practitioner.

Both of the recently done studies on the genetic counselling emphasize a psychosocial approach to genetic counselling rather than nondirective approach. It is quite interesting, because few years before these papers came out, Weil (2003) did raise a question of whether nondirective approach should continue to be recognized as the main ethos for genetic counselling, or whether a new approach, emphasizing psychosocial direction, should be developed. As Weil (2003) suggested, some crucial values of nondirectiveness, such as “ providing balanced information, not imposing the genetic counselor’s values on the counselee, and supporting counselee autonomy” should be included in the central ethos of the genetic counselling practice in general, regardless of the approach used.