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Genetic Counseling in Practice

Nondirectiveness and Genetic Counseling

Gerhard Wolff[1,2] and Christine Jung[1]

Nondirectiveness is the generally required and professed standard for genetic counseling. However, studies are lacking in the field of human genetics and in other disciplines which address either the theory or practice of this type of therapeutic procedure in the context of genetic counseling. Moreover, there is no indication the further development this concept has undergone in client-centered therapy has been acknowledged in human genetics. This could be due to the historical development of genetic counseling, its inherent conflicts and often undefined goals, and the latent need of human geneticists to defend themselves against being accused of eugenic tendencies. Nondirectiveness and directiveness, however, can neither adequately describe what takes place in genetic counseling, nor can they — according to their original meaning — be used to define an ethical standard of genetic counseling. Starting with the writings by Carl Rogers (1942), an experiential approach is described, in which counseling is seen as a process of influence, which is wished by all the persons involved, during which activities are oriented toward the experience of the client, and which allows the counselor to communicate openly and directly with the client. The present study illustrates the use of the experiential approach in genetic counseling and shows that it can uphold the principle of ethics, which nondirectiveness demands and, at the same time, prevent the inevitable and unresolvable contradictions. This means that in their training genetic counselors must learn to recognize and constantly reflect on the influence they can and want to exert. In order to be able to use this influence in a responsible manner, genetic counselors must also learn to have a certain degree of flexibility so that they are able to check at any time how their client responds to this influence.

KEY WORDS: genetic counseling; nondirectiveness; directiveness; experiential counseling.

[1]Institute of Human Genetics, University of Freiburg, Germany
[2]Correspondence should be directed to Gerhard Wolff, Institut für Humangenetik und Anthropologie, Breisacherstrasse 33, D-79106 Freiburg, Germany.

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Rezepte schreiben ist leicht, aber im übrigen sich mit den Leuten verständigen ist schwer. (Franz Kafka: Ein Landarzt)

there is a definite tendency for all counselors to consider themselves as being non-coercive and non-directive. (Carl R. Rogers, 1942, p. 125)

INTRODUCTION

According to the survey carried out by Wertz and Fletcher (1989a), more than 75% of all medical geneticists in more than 75% of the countries surveyed consider themselves committed to the principle of nondirectiveness in genetic counseling (Wertz, 1989). For many years this principle has been used in every conceivable context to indicate an ethically responsible approach to the difficulties and consequences of genetic diagnosis. This frequent usage is in striking contrast to the lack of attempts made to provide concept or substance to the term of nondirectiveness in genetic counseling, with the exception of statements to the effect that counsellors should behave in a "neutral" manner and should leave decisions to their patients or clients. Both these statements are, in the final analysis, devoid of content, since it is evident that every patient/client, in the absence of direct physical force, makes up his/her own mind, and "neutral" would have to be defined or conceptualized as similar as "nondirective."[3]

Some meanings of this term or of a concept of nondirectiveness in connection with genetic counseling could be elucidated from the context in which it is used. Since 1983 more than 2500 works have been published in which the subject of genetic counseling is discussed, yet only four of them take a stand on nondirectiveness or nondirective counseling (Literature research Medline.83). These include two publications of the study on ethics and human genetics of Wertz and Fletcher (Wertz and Fletcher, 1989b, Wertz *et al.*, 1991), one about AIDS (Bayer, 1990), and one about counseling for the deaf (Arnos *et al.*, 1991). A search for literature on the subject in other data banks using the search strategy "ethics and (non-) directiveness in genetic counseling" produced a further seven papers which, however, make scant contribution to the conceptualization or content of the term nondirectiveness in genetic counseling: an editorial (*Lancet* II, 1982), suggesting the ineffectiveness of directive genetic counseling on the

[3]For example neutrality meaning the exclusion of any subjectivity is an untenable construct which is unrealistic. Franklin (1990) discusses for the psychotherapeutic/psychoanalytic domain 5 different dimensions or aspects of neutrality (behavioural, attitudinal, interpersonal, interactional and essential) all of which have their importance in the different contexts. These different aspects do not, however, represent an objective to be achieved under all circumstances, but are only options which the therapist can more or less approach (Mertens, 1993).

basis of published studies; a further publication of the results of the study by Wertz and Fletcher (1988); a general discussion of further developments in reproductive technologies and the importance of prenatal genetic counseling (Garber and Hixon, 1990); a Hungarian article about a "new" counseling method, "information guidance counseling" (Czeizel, 1990) which, in the light of earlier publications (Czeizel, 1981), can be understood as a variation on directive counseling; an empirical work on the subject of prenatal sex diagnosis and selective abortion (Burke, 1992); and two overviews of genetic counseling, more particularly in the context of decisions on reproduction (Seller, 1982; Brondom-Nielsen 1992). The papers of Yarborough *et al.* (1989) and Clarke (1991) concentrate more on various aspects of nondirectiveness in genetic counseling, and these will be discussed later on, as well as a publication by Kessler (1992), in which he more specifically considers nondirectiveness and directiveness as different strategies of influence in genetic counseling.

In the German-language literature no reference can be found to nondirectiveness as a concept for genetic counseling in the leading human genetics textbooks. The authors of these books are more concerned with the various dilemmas of genetic counseling when the objective of individual help is discussed in parallel with the benefits of prevention (see, for example, Fuhrmann and Vogel, 1982, p. 174). Raif and Baitsch (1986) take up various counseling concepts and draw a distinction between psychotherapeutic concepts and those mainly aimed at providing comprehensive help or transmitting information. In connection with the latter they discuss, inter alia, a "nondirective, client-centered providing of information" based on the models outlined by Headings (1975) and Hsia and Hirschhorn (1979). Headings (1975) suggested a process-oriented model for genetic counseling, in which the client is allocated a leading role and in which the counsellor is an active listener, attempting to understand the situation of the client and to clear up conflictual situations. Hsia and Hirschhorn (1979) define and understand genetic counseling as an "educational process," or a "learning process": an interactive process in which the main objective is to provide information while taking into account the needs and attitudes of the patient/client. Lippmann-Hand and Fraser (1979a, b, c) provide a detailed analysis of counseling sessions from which a concept of genetic counseling emerges based on providing information to be understood by the clients without a formal routine being followed. These authors reach the conclusion that the way in which the information is transmitted significantly influences the understanding and processing of the genetic risks. Reif and Baitsch (1986) themselves understand genetic counseling as "helping others make responsible decisions about themselves," achieved by means of a mutual exchange of information, based on the expectations, background

knowledge, and points of view of both sides, and incorporated into a long-term decision-making process. All these concepts are not significantly different one from another in so far as they emphasize the information aspect and, in so doing, revert to elements of client-centered psychotherapy. They do not, however, further develop nor explicitly refer to nondirectiveness as a concept.

One might well ask why, in applied human genetics, so little consideration has been given to such a central term as nondirectiveness, although it quite obviously is supposed to characterise a generally binding standard of quality of counseling in genetics and is frequently used with this meaning. We would like to answer this question by putting forward three hypotheses that would address this lack of considerations.

THE HISTORICAL HYPOTHESIS

This hypothesis states that the scant concern with the concept of nondirectiveness can be explained by the historical development of genetic counseling. It cannot be stated precisely when and where the concept of nondirectiveness was first introduced into genetic counseling.

A clue might be found in the fact that initially genetic counseling was mainly practiced by nonphysicians (biologists) to whom the paternalistic concept of the doctor–patient relationship, with its corresponding rules on indications and advice, was unfamiliar, and who, therefore, envisaged their job as being a more or less neutral transmission of information. Genetic knowledge was supposed to be a service provided for individual families in contradistinction to, and without the connotations of, the eugenics movement, which used such expressions as "genetic advice," among others (Reed, 1974). Reed introduced the expression "genetic counseling" in 1947, because he wanted to divorce it from the concept of eugenics, and he feared, genetic counseling would have been rejected, if it had been presented as a technique of eugenics (Reed, 1974). He considered genetic counseling to be a kind of "genetic social work," according to a statement he made in the forties. In so doing he stressed the psychosocial aspect of genetic counseling which was to acquire ever increasing value later on as genetic counseling developed into a separate branch of medicine. This kind of genetic counseling was therefore being practiced at a time before medical genetics existed as a speciality. Therefore, in terms of the traditional paternalistic doctor–patient relationship, the influence of medicine on the pattern of behavior in the counselor–patient/client relationship was relatively slight.

A further clue for the introduction of nondirectiveness in genetic counseling might be seen in the fact that — at least in the U.S. — social workers and psychologists trained in humanistic psychology started working in the field of human genetics. They also started applying the rule of nondirectiveness from humanistic psychology as founded by Carl Rogers to genetic counseling (Motulski, personal communication, 1992). In its original form, this counseling principle was established, scientifically evaluated, and practiced as a collection of rules for avoiding the hitherto directive counseling being offered. Professional unobtrusiveness, as practiced in this way, later fit very well with the strongly developing trend toward patient autonomy which was occurring independently.

All three factors mentioned — the demarcation from the eugenics movement, nonphysicians as genetic counselors, and the infiltration of a psychological counseling concept — have certainly contributed to the idea of respect for patient autonomy in genetic counseling. It is this respect for autonomy that has led to the apparent congruence between professional concepts and objectives and the interests of patients and clients. The assumption that all those involved in genetic counseling are pursuing the same objective makes it apparently superfluous to take up and conceptualize the theme of what actually occurs or should occur in genetic counseling. This is why (in the context of a counseling objective still to be defined) so little consideration and attention was and still is paid to the positive or negative influence of the paternalistic concept of the doctor–patient relationship in genetic counseling.

THE CONFLICT HYPOTHESIS

The conflict hypothesis states that nondirectiveness in genetic counseling is the formulation of a problem rather than its solution and that the almost non-existent concern with the concept is the expression of an underlying conflict. In medical genetics, unlike in traditional medicine, there is no evidence that in an individual case doctor and patient tacitly agree on a generally accepted identical objective such as healing or recovery.

> For example, the goal of an individual counseling session might be decision-making on prenatal diagnosis in a family with a child with Down syndrome because of an unbalanced chromosome translocation. In this situation, there might well be different opinions of the pregnant mother and her counselor on what would be a good, helpful, or even necessary decision.

In medical genetics, the terms "illness" and "prevention" are poorly, if at all, defined, and in genetic counseling it is often unclear who can actually be considered a "patient" and who, in the broadest sense of the

term, is therefore to be "treated." Of course, genetic counselors regularly have to give considerable thought to the "burden" of a disorder but they come to realize that this can only be done by taking into consideration various networks such as the partner, family, and/or society. Moreover, an evaluation of the disease cannot merely concern the identified individual on the basis of medical facts alone. Illness is not a general justification for the involvement of a human geneticist nor is the curing of an illness a declared aim. Even the expression, "prevention of illness," does not apply as a general definition of the genetic objective. The term genetic prevention as a means of impeding genetically transmitted illness is used almost exclusively in the context of family planning and prenatal diagnosis. In this context, genetic prevention means selection according to genetic criteria. The uncritical use of the term "prevention" conceals this tie to context, which requires moral rather than medical justification.

Genetic counselors therefore find themselves faced with the problem of defining the purpose of their intervention and the well-being of their patients and clients for whom they could justify a possibly directive influence, following the beneficience principle (helping and curing), as is widely practiced elsewhere in medicine.

> For instance, it might be argued whether it means beneficience to counsel the parents of the child with Down syndrome or other relatives to have carrier testing and prenatal diagnosis in order to "benefit" from knowing their genetic status and/or from the abortion of another possibly affected child.

The fact that genetic counselors invoke the principle of nondirectiveness can be viewed as an attempt to avoid the difficulty of defining a general goal or objective of genetic counseling. In the end they are avoiding confronting the conflicting objectives and ethical principles which exist in this field and thereby prevent these conflicts from being dealt with either in general or in individual cases. These inherent conflicts between objectives and principles include:

1. The conflict between so-called genetic prevention and individual autonomy in decision-making:

> In the case vignette given above this conflict lies in the fact that, with carrier testing and prenatal diagnosis, methods for primary prevention of a genetic handicap are available and therefore, in the conception of professional geneticists, are possibly considered to be medically indicated, whereas accepting individual autonomy in decision making means giving up the goal of genetic prevention.

2. The conflict between professional responsibility (damage prevention) and individual autonomy:

> The genetic counselor may have the goal to prevent suffering from the burden of a second child affected with Down syndrome in the family, while the family perhaps prefers not to know, or to deny the genetic risk. In this situation, accepting denial

and possible future suffering is in conflict with the professional demand to prevent harm.

3. The conflict between providing full information while at the same time protecting the patient/client:

This conflict possibly arises, for example, in the case of a pregnant mother, whose little boy, by CK-screening, has recently been diagnosed as having Duchenne muscular dystrophy (DMD). Giving the mother immediately full information of the fatal course of the disease and its heritability may possibly damage the mother's psychic health and the mother–child relationship, and, in this way, also the well-being of the child. On the other hand, giving information only step by step in order not to ask too much of the mother's coping capacity runs the risk of not fully informed decisions in regard to life and family planning.

4. The conflict between objectives pursued by individuals and by groups:

This conflict addresses the question, whether society is able and willing to accept solidarily and unconditionally individual objectives in regard to life and family planning. This might include accepting that the family at risk for having a/another affected child does not want carrier testing and prenatal diagnosis even in the case of a high risk for a serious genetic disease, and accepting necessary medical treatment of another possibly affected child in later years.

5. The conflict between the requirement that a decision be rational and the need for emotional working through:

Counseling the pregnant mother of a child with Down syndrome or of a boy with DMD demands of the counselor both, conveying genetic information in an understandable manner, and empathy, and of the mother comprehending information and emotional working through. On the rational level, the risk for Down syndrome or DMD seems to demand carrier testing to be done immediately and to enable prenatal diagnosis as early as possible, while emotional working through needs time and energy of both parties involved in counseling, the counselor and the parents.

6. The conflict between genetic prevention through active counseling and the right not to know:

This conflict arises in regard to the counseling of other family members (in the case of DMD female relatives of the mother), who do not want to come to genetic counseling or to know their carrier risk. The basic structure of this conflict is comparable to that outlined above (2).

7. The conflict between the prohibition against killing and abortion for genetic reasons; this conflict is self-explanatory.

8. The conflict between the medical and the social context:

This conflict may have two different structures. On the one hand, professionals often regard the child with Down Syndrome or DMD and counseling its family as a pure medical (genetic) problem, while the family is trying to accept a situation, in which they need only social and emotional support. On the other hand, the situation of the family and the affected child may be regarded by themselves and/or society as an avoidable problem, while medical professionals including genetic counselors are engaged in therapy, improvement of development, and integration of the

affected child and its family. Therefore, regardless of the structure of conflict, both sides involved are seeking solutions of problems on different levels.

In the survey of Wertz and Fletcher (1989a), medical geneticists in 19 countries mentioned with almost equal frequency such mutually exclusive objectives in genetic counseling as aid to individual decision-making (100%) and prevention of genetically determined diseases (97%). The improvement of the nation's state of health was considered a goal of genetic counseling by 74% and the reduction of the number of carriers of genetically determined diseases by a further 54% (Wertz, 1989, p. 34). The demand for, even assertion of, "nondirectiveness" in genetic counseling appears to be merely another way of formulating the basic problem, such as how different and sometimes conflicting values of doctor/counselor and patient/client can be respected as far as possible. Insisting on using this term without filling it with meaning and substance indicates a denial of likely conflict.

THE DEFENSE HYPOTHESIS

The defense hypothesis states that the lack of a clearly defined concept and failure to deal with nondirectiveness in genetic counseling result from an attitude in which the affirmation of nondirectiveness serves as a defense against attacks on the alleged harmful nature of applied human genetics. An attitude of this kind can allow no contradiction and therefore prevents critical consideration of nondirectiveness. This hypothesis can therefore also be entertained as an addition to, even a concrete expression of, the conflict hypothesis. The application of genetic knowledge to human beings has always had to contend with the reproach that it does more harm than good. On the one hand, invoking nondirectiveness can document an attempt to avoid doing alleged harm through directive counseling. This could be positively assessed as a critical self-reflection that expresses the recognition of the harmful potential of applied human genetics. The result would be a bulwark desired by the experts against their own dominance. At the same time, a line of defense against open or tacit criticism of directiveness or eugenic guidance is established. Anyone practicing nondirective counseling (whatever that means) cannot be harming his/her patients/clients or pursuing morally reprehensible goals. Used in this way, nondirectiveness degenerates into an empty slogan with no concept behind it. This usage prevents critical discussion of both the psychosocial and the societal implications of genetic knowledge as well as hampering discussion of such topics in individual counseling sessions. The most significant consequence of this defense strategy, however, is that discussion of professional

responsibility and its framework is thereby impeded, as well as any reflection in the profession about its own motives and objectives. Here the conflict and defense hypotheses concur.

Directiveness and Nondirectiveness

Kessler (1992) quite rightly points out that nondirectiveness as well as directiveness are badly defined both conceptually and operationally, and that in the realm of genetic counseling there is hardly any empirical information available about the relation between what directive or nondirective counselors say they do and what happens in practice. In his view, directiveness and nondirectiveness are merely different strategies of influence: in the first case an attempt is being made to influence behavior directly, whereas in the second it is the thought process that is being affected. Both strategies of influence are — if followed rigidly — fairly ineffective and inclined to give rise to problem situations of their own making. Kessler assesses the nondirective approach as, on the whole, more positive because it is less likely to cause conflict. Yet, he is of the opinion that in various phases of the counseling certain elements of both strategies are justified. He does not, however, provide convincing examples for using directive procedures in genetic counseling.

In view of the obvious difficulties in defining directiveness and nondirectiveness conceptually and operationally, we urge that: (1) these terms be dropped from use in genetic counseling; (2) the development of the nondirective concept within the field of humanistic psychotherapy be recognized; (3) the suitability of nondirectiveness to genetic counseling be investigated; (4) and a discussion take place on the conflicts inherent to genetic counseling in order to achieve an explicit "ethics of counseling." This was indeed the intention of Carl Rogers, the founder of nondirective counseling (Rogers, 1942). According to Rogers, the most important factor of the directive approach is the fact that the counselor defines the problem of the patient/client and its cause. The counselor makes proposals for further clarification and to overcome difficulties. The counselor, therefore, works on the basis of problems and results, aims at social agreement and claims the right of the capable to guide the noncapable. Rogers stressed that in this directive approach the counselor assumes great responsibility for the decisions of the client. The nondirective approach, on the other hand, is one in which the client defines the problem and selects life objectives with the counselor helping the client to find ways to achieve the stated goal(s) (Rogers, 1942, p. 124).

Rogers took nondirectiveness to be an expression of humility on the part of the counselor who does not claim to have the wisdom to solve other peoples' problems but is able to assist them. Rogers' defined objective was intellectual, cognitive and emotional maturity, achieved by consolidating the feelings of self-value and of being understood. As a result, he advised counselors to act with discretion concerning decisions and evaluations. It was and is a misunderstanding to reduce nondirectiveness to a technical rule such that the counselor is never to say or do anything which might reveal a personal experience, attitude or value and thereby act as a mirror or neutral conveyor of facts. Such a reduction in the understanding of nondirectiveness may lead to a situation whereby a patient/client is repeatedly confronted with the fact that the patient/client alone makes the decisions and the counselor acts as a participant with almost no degree of responsibility.

Rogers and others have further suggested that there are only a few crucial factors (counselor variables) which ensure that counseling is effective, such as respect, positive regard, genuineness, congruence, concreteness, and empathy (for review, see Truax *et al.*, 1965; Truax and Carkhuff, 1967). All of these are capacities inherent in each of us, whose effectiveness can be increased through education and training and which may be harmful if insufficiently developed. As one of the additional specific qualifications for a counselor Rogers mentioned "objectivity," which he described as controlled identification, constructive composure and emotional impartiality based on a receptive, interested attitude (Rogers, 1942, pp. 254-255).

Observing effective counseling factors can lead to conflicts when it comes to expressing negative feelings, criticism — or, as in the case of genetic counseling — when introducing new, possibly problematic aspects in a given counseling. Merely acting on the counselor variables like rules does not necessarily lead to "good" counseling. To enable the patient/client to gain insight into his/her own situation the counselor must, if necessary, confront him/her openly and directly with facts, assessments, and interpretations. This must be done so as to respect the personality of the client and acknowledge the unique value of the patient's/client's adaptation (Rogers, 1942, p. 143 ff). Insofar as he demands an integration of the level of relationships and the level of task-specific interventions, Rogers basically paved the way for the later development toward the client-centered (Rogers, 1951) and experience-oriented concepts.

Initially, to avoid directiveness, many guidelines were established to prevent the counselor from imposing his/her own value system, from influencing the client or from making him dependent. For example, rules forbade the counselor from stating his own opinion, answering questions, or expressing feelings directly (Gendlin, 1970). This system of rules can be understood as a reaction to the formerly widespread directive counseling.

The further development of experiential counseling (Gendlin and Zimring, 1955; Gendlin, 1974) means standing off from a "directiveness phobia," and realizing that we cannot not influence people, and that a counselor intends to influence (Litaer, 1992). In this paradigm the question of the principle of directiveness has little purpose. Instead, the questions deal with: (1) the ways and means of imposing influence, (2) the aim of such influence, (3) and the specific purpose of influence. The contribution which a counselor can make to the counseling process is no longer formulated in a negative way (i.e., the restriction on directiveness) but rather in a positive fashion within a framework of an unavoidable, even intentional and desirable influence. The work of counseling is understood as a process to be shaped in an active way, in which an attempt is made to stimulate the unfolding of the experience-process of the patient/client. The counselor considers himself/herself an expert in this process and can actively take the initiative by reinforcing those factors which enable the patient/client to express his/her own experience-based adaptation to a changed situation. Litaer (1992) distinguishes this kind of selective reinforcement, which he calls formal, from selective reinforcement of content whereby the counselor attempts to force the patient/client to adopt certain attitudes or behave in a certain way which appears to the counselor to be appropriate on the basis of the objectives he himself has chosen. This latter would be classified as a form of behavior which disregards the autonomy of the patient/client, further infringes ethical principles and is probably also ineffective in terms of achieving its objectives. Up to now, no one has done an empirical, prospective study of genetic counseling the results of which allow final conclusions about the cause-effect relationship of different counseling strategies. Nevertheless, many retrospective studies from the area of genetic counseling suggest that as regards discouraging people from having children, an expressed objective on the part of directive counselors in cases of high genetic risk, directive counseling is not more effective than counseling which considers itself to be nondirective (Editorial, 1982). While the assumption of nondirectiveness in counseling claims to be able to avoid bringing this kind of substantial influence to bear, the experience-oriented approach no longer attempts to deny this influence as a matter of principle but acknowledges its potential for achieving a more conscious contact with the manipulative potential of counseling.

An Experience-Oriented Approach and Genetic Counseling

With regard to genetic counseling and the task of the doctor or counselor involved, an experience-oriented approach means that the point of

departure for all activities is the experience of the patient/client. Anyone consulting a doctor cannot escape the information that information (expert knowledge) and possibilities of investigation (choices of action) are available. He or she must expect that information will be provided to them according to the indication rules applying in that context. This means that initially each individual's experience is ignored and overruled by the counselor's duty to provide certain information. Any rule committing the doctor or counselor to provide information or undertake certain measures must therefore be carefully considered and justified on the basis of a clearly defined objective.[4] The need for any further information and measures, and their extent must thereafter, however, be based on the experience of the client/patient who thus becomes an active subject in the counseling process. This viewpoint contains a new, specific distribution of roles to those involved in the counseling process, especially in comparison with a directive counseling strategy. In the case of directive counseling with a given decision being the counseling objective, the counselor can be considered the active subject and the patient/client as the object to be treated. In directive counseling, the information concerning genetic risk is the significant factor. In the case of counseling based on the patient's experience, the patient/clients above all, but indeed all those involved, are to be considered as active subjects entering into relationships with one another and mutually influencing each other. This leads to a situation whereby mainly patients/clients but sometimes also all participants come either to consolidate or to change their perception of or attitude towards a given individual situation (Wolff, 1992). The significant factors here, in addition to the information proper which is only rarely decisive, are above all previously held attitudes or decisions (Sorensen, 1981).

Since there exists no generally valid goal for genetic counseling and diagnosis, the experience-orientated approach requires that the objective be elucidated in each individual case. This clarification must be carried out by the counselor before the counseling, so as to avoid conflicts in the course of the counseling. Such conflicts may lead to situations in the counseling process, which might appear as if they could only be meaningfully resolved through a directive procedure, meaning manipulation of the patient/client.

[4]In this context we would like to criticize recommendations according to which the doctor of a 35-year-old woman is obliged to recommend her to have an amniocentesis with subsequent chromosome diagnosis, without the objective or implications of such a direct recommendation being stated and discussed. Is the objective supposed to be the identification of all fetuses with chromosome abnormalities? If so, then the question should be raised as to for what purpose apart from selective abortion. A "search and destroy" strategy of this kind would, however, be problematic from an ethical point of view insofar as it would be fundamentally calling into question the right to life of children with chromosome disturbances. The only defensible recommendation could therefore be to have (genetic) counseling.

For patients/clients who do not come to counseling with an clearly formulated objective, the possibility of clarifying this objective arises during the counseling. This should occur as soon as possible after the beginning of the sessions and should be actively encouraged by the counselor, for example by questions or inquiries about the past history of the patient/client. Should this lead to a discrepancy of objectives emerging between counselor and patient/client, these should be openly addressed in order to reach a joint counseling objective. This is not a trivial requirement since a tacit joint objective appears to be the exception rather than the rule in genetic counseling sessions. For instance, Wertz *et al.* (1988) showed that in only 26% of the genetic counseling cases they surveyed both the counselor and the client were aware of the major topics which the other party wished to discuss. Therefore, it does not seem easy to select a theme for genetic counseling—even one which is jointly considered important or occurs automatically. The results of Wertz *et al.* (1988) suggest that counselors and clients have different perceptions and attitudes in this regard.

In addition to the responsibility for the correctness of content, the counselor is also responsible for the structure and course of the counseling. This means that he/she must introduce the necessary elements of the counseling process such as obtaining the history, investigation/interpretation of results, information about possible illnesses, and working through this information, and deal with it in a competent manner. Even the structure of the counseling must be oriented toward the experience of the patient/client and, whenever possible, should be expressed in terms of an offer from the counselor which can be accepted or rejected by the patient/client. Rogers already indicated early on that, particularly in the case of short and one time contacts, a client-centered attitude is important: "If we utilize the time in trying to direct him, we gain satisfaction only because we do not see the confusion, the dependency, and the resentment which follow our unwarranted interference with his life" (Rogers, 1942, p. 248). To comply with this requirement in genetic counseling is not easy, since precisely the brevity and single nature of many counseling visits make it necessary for the counselor to prioritize various themes and problem areas for the patient/client and to structure the sequence of counseling and examination. In this regard, the counselor is required to show activity and "directiveness," meaning clarity and transparency. This situation still does not relieve the counselor from the task of discussing the significance of a piece of information, a stage or result of an examination with the patient/client before each further step is undertaken.

From this viewpoint, the emergence in genetic counseling of any unsolicited information during the history, such as the mention of a disease in the family which might cause the counselor to predict a higher risk for

the client or his/her offspring is certainly a difficult situation to handle. An unavoidable duty to provide information (in cases of possible increased risk where expert knowledge must be transmitted) exists in cases of treatable diseases or ones which could be counteracted through preventive measures (an example of this would be anamnestic information about cases of Polyposis coli running in a family). Whereas in other cases, the right not to know should be borne in mind as well as the consequences of providing undesired information (an example of this would be anamnestic information about a neurodegenerative illness such as Huntington disease). These two situations are differentiated one from another by the fact that in the first case there is a clear purpose to the intervention, based on the beneficience principle (helping and curing), whereas such a clear objective cannot be formulated in the second case.

In the experience-based approach, quite independently of the nature, treatability or preventability of a given disease, the significance for the patient/client of more or less incomplete knowledge must be grasped before any possible consequences of extending this knowledge is discussed. In such cases the information about a disease or possible increased genetic risk must be introduced at first as an offer to provide "information about information" and linked with a further offer to discuss its significance and relevance in decision-making with the patient/client. The passing on of specific information, for example about genetic risks, would itself depend on the outcome of this discussion. It is based on the experience and capacity for understanding of the patient/client and requires constant feedback. In certain counseling cases this might mean foregoing considerable amounts of information if it is considered irrelevant by the patient for his/her life and decision-making. It is, in any case, an illusion that one can provide "exhaustive" information. How much information the counselor should actually give is again something that only the experience of our clients can indicate. Information is only significant in the counseling process if it is relevant to the experience and decision to be taken. Many studies indicating incomplete reproduction of information transmitted in the course of genetic counseling suggest that apparently a large portion of genetic information considered by the genetic counselors to be of significance is irrelevant to the patient/client or is reformulated or interpreted in the light of their own personal experience (overview by Evers-Kiebooms and van den Berghe, 1979, Kessler, 1990, Frets *et al.*, 1990, see also the survey by Lippman-Hand and Fraser, 1979b,c). An approach based on experience and background, taking into consideration the relevance for individual decision-making should, with the appropriate documentation, make it unnecessary to fear the legal consequences of providing possibly incomplete information. This

approach can prevent patients/clients from being bombarded by information they are unable to integrate into their own personal life situation.

In addition to the necessary professional competence of the counselor, there is a further prerequisite for the experience-based approach which is that the structural (health policy) or social context within which all parties are acting, should also be known to the counselor and counselee. This requirement is only seldom met. Examples of this are the areas of prenatal and predictive diagnosis in which, for example, the meaning of the indications rules are not only unclear for the clients, but often also unclear for the doctors and the population at large, and in which all too often abortion might automatically and exclusively be considered the goal and only choice of action. Patients/clients need to know from the beginning what they are exposing themselves to in genetic counseling; in other words, what the goal of the profession of medical geneticists who are offering counseling and diagnosis actually is. In society as a whole there has as yet been no answer to the question of whether and under what circumstances genetic counseling has a social mandate. This question cannot be dealt with by referring to individual, nondirective counseling. The use of terms such as "prevention" or "therapy" (for example "therapeutic abortion"), attempting thereby to place this domain in the usual sphere of action of the medical profession, conceals the inherent liability of conflict. The unresolved conflict between, on the one hand, the objective of action being to prevent suffering and disease and on the other hand the intention being to help the individual is a painful experience for many counselors and their patients/clients during the counseling and one which they are unable to resolve in individual cases. It is often expressed as fear of the legal consequences after the possible birth of a sick or handicapped child, "caused" by incomplete information or by a recommendation which was not directive enough.

Clarke (1991) takes a stand on this conflict and its structural conditions in his essay on nondirective counseling and prenatal diagnosis when he observes that nondirectiveness in connection with prenatal diagnosis "... is inevitably a sham," since in his view the mere fact of prenatal diagnosis even without directive counseling behavior establishes a directive context. According to him, nondirectiveness only serves to transfer sole moral responsibility to the parents and helps the counselors wash their hands of any responsibility ("..it is their responsibility and we wash our hands of any responsibility"). In saying this, he is addressing the question of the responsibility of the counselor for decisions and consequences of actions. In this context, he is criticizing the term "prevention," which gives the impression that the birth of a handicapped child represents a medical failure, at least as long as it is not disproved. A further indication of "structural" direc-

tiveness for him is that, for example, an abortion, after a chance detection of a sex chromosome aberration, is usually considered a successful prenatal diagnosis and not an iatrogenic catastrophe. He calls for acceptance of responsibility for the consequences of intervention, which also, among other things, reflects the potential discrimination of genetic diagnosis for those who are alive and affected and in so doing takes into account the "full price" of prenatal diagnosis and abortion.

This demand of Clarke's is not addressed only to genetic counselors but to the medical profession and even society as a whole. It is a matter of answering the question of what objectives the medical profession or society is pursuing through prenatal diagnosis. Neither nondirectiveness, whatever the term might mean, nor an approach based on the individual's experience in counseling can contribute to answering this question. The latter approach at least harbours the potential of being applied to a group situation insofar as the attitudes and experiences of those concerned (groups) are taken into account and lead the way in structuring these medical fields as was and still is paradigmatically the case for the predictive diagnosis of Huntington disease.

Experience-Orientation and the Ethics of Counseling

In the case of orientation based on the experience and background of patients/clients, counselors are complying with a principle of autonomy which gives up the illusion of "absolute" autonomy and instead acknowledges the patient/client dependency on situation and information as well as recognizing his or her need for autonomy at that time. A question which remains open is how far orientation based on experience is helpful to guarantee the ethical principles of beneficience or of non-maleficience. As stated above, this approach enables the counselor to communicate actively and directly with his patient/client. This sort of communication ("directness") has nothing to do with a directiveness which attempts to intervene and guide the behavior of the patient or which does not respect his attitudes and values. It refers to the counselor variable "concreteness" and extends this to cover two dimensions of specific tasks: (1) one in which the counselor introduces and deals with active elements of the counseling process (for example history, information, diagnosis etc.); (2) one in which the counselor stimulates the decision-making process first by introducing all the options of the process and consequences of actions taken ("vertical level") and then by encouraging everything which can be expressed in the framework of readjustment to a changing situation in terms of experience ("horizontal level"). The latter is particularly important at the beginning

of the consultations since by this means integration of the emotional level can be achieved. It can, for example, mean encouraging the patient/client in an advanced state of the counseling process to forget all the information (figures) and just fantasize about the different options available.[5]

Should the counselor in this case be afraid of violating a basic principle or a counseling rule? Nondirectiveness claims to give "neutral" support, thereby safeguarding the principle of autonomy as far as possible. Apart from the unsatisfactory definition of such a term as neutrality, one must ask the question as to whether an attitude like this, if followed regularly, might seduce one into an "it-doesn't-concern-me" attitude and therefore make the counselor "irresponsible" in the true sense of the word. Yarborough *et al.* (1989) rightly discuss and criticize the term of nondirectiveness as insufficient for genetic counseling. They demand the observance of the principle of beneficience involving the commitment to averting possible harm since the counselor is not merely a neutral observer but is an "involved party." Strict non-involvement according to Yarborough *et al.* (1989) does not safeguard the principle of autonomy which, for the person actively involved, also includes shouldering responsibility for the consequences of action. They did not deduce from that, however, that a directive, paternalistic attitude must be adopted in which the counselor undertakes the final moral evaluation. The authors do though consider a prudent strategy of "reasoned persuasion" to be justified if the basis for decisions is "self-seeking" and no moral justification for an action is discernible. Such a strategy should consist of forcing patient/clients to take into account the interests of third parties and, if necessary, to reconsider a decision. The counselor should always bear in mind that his/her role includes the potential to bring unwarranted pressure to bear upon the life decisions of the patient/client. Yarborough *et al.* (1989) therefore demand that the ethical dimension of a decision be a matter for discussion though without the counselor undertaking the concluding moral evaluation. The authors do not, however, take into consideration the fact that "reasoned persuasion" is itself a method introduced on the basis of established values ("self-seeking" reasons for a decision) adopted by the counselor and reflecting his/her attitudes. This is why the authors find it difficult to draw a distinction between this method and the directive-paternalistic procedure which they do not like.

Conflictual situations in counseling regularly arise for counselors considering themselves nondirective when, as a result of attitudes or decisions

[5]Seymour Kessler reported in a Workshop: Genetic Counseling and Psychotherapy (National Society of Genetic Counselors 11th Annual Education Conference, San Francisco, 1992) on how he successfully used light hypnotic methods to make it easier for his patients/clients to reach a decision, of course not without talking through the results with them afterward.

of the patient/client, the experience and/or values of the counselor are infringed. Should a conflict of this nature touch on an unresolved personal problem area of the counselor, he/she must undertake to work this through for himself/herself and not to bring it into the consultation. Conversely, a patient/client whose autonomy should be safeguarded if not increased in the course of counseling has a right to openness, which must, however, clearly indicate that it does not represent professional wisdom but rather the attitude of an individual with his/her personal life and background. By the same token a patient/client is entitled to receive clear, direct answers to questions. In certain conditions this also applies to the famous/infamous question "What would you do in my place ?" The way of dealing with this question is considered by many to be a decisive criterion for the orientation of a counselor in the direction of directiveness or nondirectiveness. Here, too, the counselor, in giving a clear answer, is not violating any ethical principles or counseling rules as long as he/she is taking the experience of the patient/client as his/her point of departure and makes it clear in what capacity and circumstances he/she is answering the question. He may use his own referential system as long as he/she makes this fact clear and reverts soon enough to the "life trail" of the patient/client. (Lietaer, 1992). Since such a statement can easily be misunderstood we would like to provide an (negative) example, taken from Fraser (1977). In a discussion about directiveness in genetic counseling he reports from a session of a couple who had a child with trisomy 13:

> I explained about the low recurrence risk and the possibility of amniocentesis. The mother said, "I want it," and the father said, "I don't believe in abortion. Well, what are we going to do?" After we talked for a while the father said, as often happens, "Well, what do we do?", meaning "me." I said, "Well it's not my problem. I am not you. You'll have to come to some resolution with your conscience and work it out with your wife." After they talked a little more they asked, "What would you do if you had the trisomy child?" And I replied, "Well, one can never say what they actually would do in a situation. But I think I would be willing to take advantage of these means and be sure I don't have a recurrence."

Fraser concluded that in those cases when one could describe one's counseling behavior as directive, then directive counseling was justified: he himself would, however, rather describe it as "guidance."

Looking at the content of this discussion it might appear, at first glance, as if the counselor is justified in answering this question which he was asked three times; a question, furthermore, which many counselors who definitely view themselves as nondirective consider to be their personal "Waterloo" (Kessler, 1992). Others, more inclined toward activity and advice might feel the question to be liberating. Seen from the process or experience-oriented standpoint the answer to this question appears to be inappropriate and the advice uncalled-for. It is obvious that there is a con-

flict between the father and mother concerning the decision about amniocentesis and it does not appear far-fetched to infer that this conflict is interfering with the process of reaching a decision. The same question repeated three times is a good, if not definitive indicator of a blockage which may represent unresolved conflicts or unconscious problems. The apparently nondirective answer: "It's not my problem, you'll have to come to some resolution" seems not to resolve this blockage, but possibly exacerbates it by inducing a feeling of inadequacy, incompetence, and helplessness in the client. In the example given the subsequent session was, not surprisingly, of little use in regard to decision making. An experience-based approach on the other hand, would have led to the counselor pointing out the existence of the conflict in the situation of this couple, acknowledging the feelings connected to it and providing an opportunity for both parents to investigate their situation and problems in making a decision themselves, in order by this means to work out a solution. Yet the counselor may in fact be impeding the process by answering the question directly, without revealing his/her own values and referential system, and is thereby ignoring the real problem of abortion as brought up by the father, as well as the experience of the partner. He is therefore not only hampering the counseling process but possibly even exacerbating the conflict between the partners by taking the side of the mother. This way of answering the question cannot be described as the desired "directness" meaning "concreteness" which would have required the counselor at least to disclose his/her referential system. Finally, the counseling procedure, which did not take account of the experience of the couple, was also partly responsible for the question being put forth. This, too, is not taken into consideration in giving the direct answer.

Therefore, the requirement for "concreteness" or "directness" must, in no case, be confused with unreflected directiveness. The guideline and direction to follow, even in situations where specific questions are raised, is exclusively and in every case, the experience of the patient/client. For the particular question under consideration this means, at one end of the spectrum, that it — and this is usually the case — is to be understood merely as an expression of helplessness which should indeed be taken up in the counseling. At the other end of the spectrum it can be possible to give a direct, clear answer based on the partnership established between two people acting autonomously. This latter situation will, in the case of genetic counseling, however, be exceptional because of the brevity of the contact. As a rule both "directive" answers and "nondirective" evasions express the counselor's latent need to control the situation (Kessler, 1992). By giving a direct answer the intention is to provide a solution to a complex decision-making situation. The question must then be asked as to how and

why such a difficult situation has arisen. It could, for example, be the result of a discussion unconsciously leading toward an unclear situation which could only be resolved through a decision of the counselor. Or the patient/client with his/her question is merely reacting to latent pressure from a counselor who would like to be asked such questions in his/her capacity as an "expert in life questions." On the other hand, evading the question in a "nondirective" manner by indicating that it is not the counselor but the patient/client who has to make the final decision, in addition to the psychological effect of heightening the patient/client's feelings of helplessness and not knowing what to do, has precisely the consequence of opening up the way to nondirect, concealed manipulation of decision-making.

What is necessary is in fact a "psychotherapeutic basic attitude" which attempts to grasp the significance of situations, findings or information for the patient/client and to interpret them. This applies to those parts of both nondirective and directive (in the sense of a desirable directness) counseling which in themselves and exclusively applied can be frustrating both for counselor and for patient/client. Kessler (1992), therefore, quite rightly demands that the counselor be flexible, which means that he/she must have at their disposal a wide range of possibilities for reaction and intervention. This requirement expresses a dynamic understanding of counseling which also underlies the experience-oriented approach and makes it scarcely possible to formulate a rigid "concept" such as the experience-oriented laying down of rules or measures to be undertaken. What is required instead is a basic attitude which does not claim to be able to avoid the unavoidable influence of counseling/a counselor (as suggested for example in nondirectiveness), but rather acknowledges this influence and attempts to make use of it in a responsible way. This requires thought from the profession in general as well as individual views and value judgments both during initial and further training and before and after each counseling. It can be practiced and learned and the method can be easily adapted to the different concepts of conducting counseling sessions or to the ethics of counseling. So it is entirely possible and useful to apply some of the rigid rules of nondirectiveness in thinking about specific counseling cases or to run through the consequences of directive behavioral methods both in regard to the counseling situation and also in regard to the objectives and way in which the profession is practiced as a whole and to analyze the ethical principles being effective. An attempt should even be made to answer the question: "What would I decide?", though only for critical reflection purposes. It is fairly straightforward to analyze one's own established values by thinking over which of the ethical principles as a counselor or — if attempting to put oneself in the situation on a trial basis — as a patient/client, one wishes to safeguard or never violate under any circumstances. This

again does not exclude the utilization of other methods for thinking about ethics (for example teleological-utilitarian or narrative orientated) in order to acquire as complete a picture as possible. That the experience-oriented approach can be applied at both individual and group level is something which has already been addressed. All of this contributes to a conscious (and therefore in the best case conflict-free) consideration of one's own, unavoidable valuations.

That the counselor must be free of the need to contribute his/her own attitudes and value judgments is not a trivial demand because it depends on his capacity to have a flexible approach to his possibilities of influencing the patient/client and to be ready and able to check these capacities in the light of the background and experience of the patient/client. For genetic counseling, this flexibility must be well developed, since such different factors as history, examination results, provision of information, working through the situation or reaching a decision call for such very different qualities in a counselor. On the basis of knowledge about the psychological, social, and ethical aspects of possible problem situations and the reactions of patients/clients in genetic counseling, these capacities can be learned and practiced. They should be included as part of any initial and further training program in this field. If a counselor continually reflects over and checks the basis and practice of his interventions to guide and follow his patient/client, genetic counseling will not fall into the trap of nondirectiveness, but will meet its claim to be a process desired by all involved, and in which the influence of the counselor is as conscious as possible.

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