SCIENTIFIC CONTRIBUTION



The principle of nondirectiveness in genetic counseling. Different meanings and various postulates of normative nature

Accepted: 2 April 2022 / Published online: 16 April 2022 © The Author(s), under exclusive licence to Springer Nature B.V. 2022

Abstract

The article aims at organizing multifaceted discourse on the concept of nondirectiveness in the practice of genetic counseling. The analysis of areas where nondirectiveness was invoked and discussed reveals the problematic confusion of different meanings of the term that often leads to false conclusions about the relations between the professional standards and the practice of genetic counseling. The article offers clear and comprehensive description of different approaches to nondirectiveness and various ideas associated with the term. Normative consequences of various meanings attributed to nondirectiveness are explored. The article concludes by presenting important but unsolved problems regarding both theory (the meaning of nondirectiveness and its operational definition) and practice of genetic counseling (the scope and content of the norm of nondirective counseling).

Keywords Nondirectiveness · Genetic counseling · Medical genetics · Professional standards

Introduction

The principle of nondirectiveness is generally believed to have become the major rule of genetic counseling during the second half of the twentieth century. Several researchers of this period have indicated the multitude and complexity of the reasons underlying this phenomenon, which include: public outrage associated with the use of medical procedures to conduct morally doubtful actions of social nature (e.g. tragic experiences from the World War 2 and the Nazi crimes that were committed in the name of racial purity, as well as forced sterilizations made in Europe and the United States); significant changes made in medical practice in relation to the movement for patients' rights; expansion of women's rights, including those associated with reproduction; origination of first specialists in the field of genetics from the scientific circles that used to provide facts but not formulate recommendations; and finally, the circumstance under which, at the end of the 1960s, a separate specialty in the form of genetic counseling appeared, almost entirely

According to the findings of Wertz and Fletcher, nondirectiveness was widely accepted in the international community of clinical geneticists in the mid-1980s (Wertz and Fletcher 1988) and still highly valued in the early 2000s. (Wertz and Fletcher 2004). However, although numerous geneticists declare attachment to this principle, a single, generally applicable definition for "nondirectiveness" has not been established until now. The lack of definition has generated a plethora of controversies and disagreements and forced some professional associations to entirely abandon the term (Resta et al. 2006; Jamal et al. 2020). The elimination of the term or its replacement by others, also vaguely defined, were meant to rather bring the discussions to a close than to find a satisfactory solution to the problems raised. Some of them, crucial to the clinical practice of genetic counseling, has remained. The article presents a comprehensive analysis of the areas where nondirectiveness was invoked and discussed. It summarizes the main debates on the principle of nondirectiveness and its role in genetic counseling. The article concludes with the list of normative problems and questions that have not been satisfactorily developed by bioethicists and deserve further comprehensive



dominated by women, who were considerably less inclined to tell the patients what they should do compared to their male counterparts (Resta 1997; Wertz and Fletcher 2004; Kessler 1997b; Sorenson 1993).

Weronika Chańska weronika.chanska@uj.edu.pl

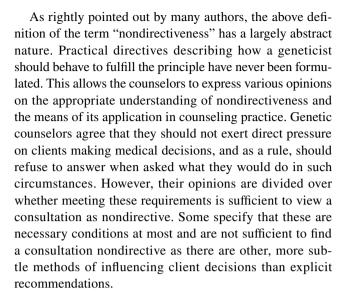
Department of Philosophy and Bioethics, Jagiellonian University Medical College, Michałowskiego 12, 31-126 Kraków, Poland

analysis. The article presents therefore a comprehensible overview of various meanings of the term "nondirectiveness" and the normative consequences of choosing some of them, providing a stimulating starting point for further analysis to be taken up by more theoretically oriented bioethicists as well as practitioners and professional organizations establishing norms of conduct of genetic counselors.

I use the typology proposed by Barbara Biesecker as a useful tool for organizing my extensive analysis of areas where nondirectiveness was invoked and discussed (Biesecker 2000). I focus my attention on four groups of meanings of the term "nondirectiveness". The first one is closely related to the question of nondirectiveness as a main goal of genetic counseling. The second one concentrates on nondirectiveness as a guiding policy on genetic testing. The third one takes nondirectiveness as a useful descriptive term to characterize the style of communication of genetic counselors. The forth meaning of the term refers to nondirectiveness as a theoretical basis of counseling practice aimed at following the individual needs of the client. I argue that the second and the third meaning attributed to the nondirectiveness are misguided and do not allow to draw any interesting normative conclusions regarding the practice of genetic counseling. While the first and the forth generate particular normative concerns which demonstrates that the disagreements over the meaning of nondirectiveness in genetic counseling are disagreements about values not about the word.

Nondirectiveness as the main principle of genetic counseling

The first meaning of "nondirectiveness" signifies the prescription aimed at a genetic counselor which states that genetic consultation should be conducted in such a way that it does not assume the actions to be taken by the counselee. This prescription originates in commonly held belief that decisions associated with genetic testing are private matters, based on personal beliefs. The objective of assuming the nondirectiveness principle is to minimize the influence of the genetic counselor on the counselees' actions and support them to make independent decisions concerning genetic testing. Thus, the principle safeguards the decision-making autonomy of clients. According to the National Society of Genetic Counselors Code of Ethics, nondirectiveness can be realized by the counselors by "providing clients with and explaining them with significant facts, explaining the possible means of further proceeding and the possible outcomes of the decisions they make" (National Society of Genetic Counselors 2018). So defined principle of nondirectiveness for a long time has been seen as a main goal and a central value of genetic counseling.



Since the mid-1990s, several works criticizing the validity of assuming nondirectiveness as the leading principle of genetic counseling have been published. These critiques can be divided into three main groups:

- those pointing to the impossibility of providing genetic consultation in a completely nondirective manner;
- those questioning the too narrow scope of duties of a genetic counselor, resulting from assuming the nondirectiveness principle; and
- those questioning the validity of asking a genetic counselor to assume a morally neutral attitude toward the choices made by the counselees.

Impossibility of making genetic consultation completely nondirective

In the first group of works, the authors primarily concentrate on indicating that a genetic counselor presenting only medical facts and refraining from providing their opinions on how the client should proceed cannot be considered as completely nondirective. This is because there are more subtle ways of exerting influence. Therefore, the authors suggest that introducing the nondirectiveness principle ordering a consultant to refrain from expressing personal convictions and providing clients with suggestions is at the most a prerequisite, but not sufficient factor to support clients in making autonomous decisions.

This group of critiques also include numerous empirical studies which revealed that despite the declarative attachment of the geneticist community to the idea of neutrality, actual consultations deviate from it markedly (Bosk 1993; Leroy 1993; Sorenson et al. 1981; Rothman 1986). In addition, some views directly state that demanding complete neutrality from genetic counselors is unrealistic. At best, the counselors can acquire carefulness and learn to identify



their own moral convictions so that they have the least possible impact on the course of consultation. However, their effect cannot be completely eliminated (Marks 1993; Rentmeester 2001).

Dispute over the scope of duties of a genetic counselor

The dispute concerning how the nondirectiveness principle should be realized in practice also involves the followers of a more traditional approach to genetic counseling, which is described by the literature as the "decision-making model," and those who follow the approach combining the skills and techniques acquired from psychotherapy in counseling practice—called the "counseling model" (Kessler 1997a). In essence, it is not a dispute over the nondirectiveness principle itself, but over the scope of duties of the genetic counselors and the role they should play in consultation with a client. At the same time, it can be considered as the confrontation of two different approaches to the principle of autonomy and the methods of its practical realization.

In the decision-making model, the genetic counselor is viewed as an educator (Hsia 1979). Due to their background and professional experience, consultants are capable of establishing strictly medical information (such as the genetic mechanism behind a given disorder or the likelihood of its reappearance in the offspring) and present it clearly to the client. However, they do not have access to the world of values and beliefs of the counselee. For this reason, genetic counselors lack the knowledge that would authorize them to provide any recommendations to their clients.

Followers of the decision-making model believe that medical facts provided by a counselor are of objective nature. They delineate the scope of what should be provided to each client. From this standpoint, this information can be seen as "neutral"—the amount of facts and how they are provided do not depend either on the counselor or on the character of the client. The authority of a counselor comes from the truth that resides in facts—an objective truth that is independent of the character and the needs of the client as well as the personal views of the counselor.

However, the desires, aspirations, needs, and values of the clients have completely different characters. They are strictly subjective—they belong to the client and only the client has direct access to them. A counselor does not have the knowledge of a counselee's inner world. For this reason, it is difficult for counselors to place themselves in the clients' position and tell what would be the best for them. Therefore, the followers of the decision-making model believe that the best thing a counselor can do to the client is to refrain from providing any advice or recommendations.

The second postulate of this model's followers is to order the counselor to refrain from assessing the decision or

actions of the client. Even when the client's choices appear irrational, the counselor does not deal with enough data that can authorize expressing a negative opinion or attempting to change the client's choice. In such a situation, the best thing the counselor can do is to refrain from personal assessment and respect the decision made by the client.

In the decision-making model, autonomy is understood as the capacity of a client to make rational decisions based on objective facts in such a manner that the decisions made are closest to the needs and values of the decision-making party. This understanding of autonomy determines a counselor's scope of duties. The task of the counselor is to create the conditions needed for the client to undertake autonomous action. Counselors shall provide the appropriate facts that will become the premises in the client's decision-making process. At the same time, they should restrict their personal convictions and assessments so as not to "contaminate" the facts aimed to be transferred. The right for autonomous action is here understood as a negative right. It protects a client from being exposed to the undesirable influence of third parties in the process of decision-making.

On the other side of the dispute there are people who follow the counseling model. They who would like to understand the nondirectiveness principle in a wider sense; not just as a principle that delineates what a counselor should not do but also as a principle imposing a series of much further-reaching positive duties on him. The literature refers to this approach as the "broad definition of nondirectiveness." (Weil 2003). It aims at promoting client's autonomy, which is understood as an active decision-making process that is free of cognitive errors and distortions resulting from strong emotions. (Sorenson 1993; White 1997; Eunpu 1997; Djurdjinovic 1998; Weil 2000; McCarthy Veach et al. 2003).

The followers of this definition of nondirectiveness believe that autonomy should be understood as a positive right to obtain all assistance from the counselor which will help the counselee in making the best possible decision. The task of the counselor is to make every necessary step for ensuring that the client's decision-making process has a correct and responsible course. The representatives of this view do not provide a direct definition of such a decision-making process. Far more often, they would focus on indicating the shortfalls and imperfections of the model proposed by their opponents. They underline that the traditional decisionmaking model was developed by professionals and it does not always meet the needs of real clients. What is normally communicated to a client is a result of certain assumptions about what an average, rational person would like to know. The view of the counselees about the information that would help the clients in the decision-making process may differ from that of professionals, e.g. expressing understanding and providing support in a difficult situation are far more



important to the counselees than obtaining dry medical facts. (Shiloh et al. 1990).

According to its critics, the traditional decision-making model does not emphasize voluntariness which is one of the basic criteria that determines whether the decision was made by the client in an autonomous and conscious manner. Rather, this model focuses solely on eliminating the external factors that may disturb a client during the decision-making process (in particular, pressure or judgment by a counselor) and completely ignores the internal factors (such as characters, states, emotions of a client) which also significantly affect the way the clients transform the given information and make decisions.

Stress is the most common internal factor that affects a client's capability to take autonomous action in the context of genetic counseling. It has various sources, one of which is the fact that the information provided during genetic consultation is typically highly complex, often abstract in nature, and expressed in measures of likelihood, which is difficult to interpret by an average client. Clients often have to make their choices quickly (e.g. in the event of prenatal diagnostics), and the consequences of the choices are far-reaching not only for the clients themselves but for their relatives as well (Schild 1984). Moreover, the stress experienced by the clients leads to many cognitive disturbances, which negatively affect their decision-making process.

Furthermore, certain individual traits of clients significantly impede their decision-making ability. These include emotional instability, impulsiveness, attaching excessive importance to specific information and rejecting others, excessive fearfulness, irrational convictions and belief in superstitions, constant hesitation, and lack of decisiveness about which alternatives should be chosen or a general tendency to avoid making life's important decisions. According to the followers of the new approach, counselors ought to use all available methods to assist the clients and direct their thinking process toward the correct (i.e. rational) route.

Another plea on the decision-making model is that it does not pay sufficient attention to the client's consideration. In this approach, the role of a counselor ends when a client is provided with the appropriate medical facts. The further "processing" of these facts is the sole responsibility of the client. According to the followers of the counseling model, such restriction on the role of counselors does not contribute to the good of clients.

The allegation refers to the possible impact on the client's decision created by common errors that occur when people are processing and interpreting information. Genetic counseling deals with a series of factors that handicap the proper consideration process. One of these is the need to operate the measures of probability (e.g. in the form of individual risk of transferring a disease to the offspring). Clients often face great difficulties in this type of reasoning. Many individuals

divide the results in a dichotomous manner—into "good and "bad", while each of them is less or more probable. The second factor is the frequent need to make decisions in uncertain situations, for example, regarding the phenotypic traits of an offspring suffering from a genetic disorder. Even in the case of severe genetic diseases, such as the classic Down syndrome, it is difficult to unambiguously forecast the degree of mental disability or the presence of other developmental malformations. Under such circumstances, clients refer to a series of heuristics, or simplified inference methods, which often prove unreliable, leading to cognitive errors (Kahneman et al. 1982).

The way in which clients process the information also depends on how it is presented to them (e.g. whether the measure of risk has been communicated in numerical, descriptive, or comparative manner) (Shiloh and Sagi 1989). Their final decision is further influenced by an entire set of family circumstances, which include the following: presence of a disabled child in the family; how they assess the burden (physical, social, emotional, financial) of raising a child who has greater than average needs; whether they would like to have more children or are content with the current size of their family; assessment of their parenting abilities; and envisaged reaction of the family and acquaintances (Ekwo et al. 1987; Frets and Niermeijer 1990; Frets et al. 1990; Lippman-Hand and Fraser 1979; Rapp 1988; Wertz et al. 1984, 1986). Empirical research shows that clients' decisions are rarely made taken into account only the level of risk and a simple account of profits and losses related to the possible choice. Their values and life experience more often considerably determine their choices.

Considering the complexity of the decision-making process associated with genetic testing, as well as the strictly personal nature of such decisions, the followers of the counseling model postulate that the scope of a counselor's duties should be broadened. According to them, a counselor should make every possible effort to help the clients in making decisions in a rational way—free of cognitive errors and distortions resulting from strong emotions. In this spirit, Marry White proposes the dialogue model of counseling, whereby a counselor and a client jointly engage in the decision-making process (White 1997). It assumes the form of an exchange of ideas, where every party imparts unique knowledge and experience. Counselors should provide a set of medical, psychosocial, and normative information to the clients. In addition, they should offer different views of the problem and help the clients to recognize their own values and the importance of every possible decision. They should also dispel the irrational fears of the clients, and if necessary, underline the importance of the information that has been ignored or overlooked. To ensure the proper course of the decisionmaking process, the counselors can question or challenge the views of the clients if their choices seem irrational or



ethically doubtful. On the other hand, the clients should feel free to mention their values, convictions, life objectives, and the circumstances they are currently in and which influence their decision during genetic consultation. According to the followers of the counseling model the approach to counseling as dialogue remains nondirective in the meaning that the counselors do not settle the content of the final decision, but only care about the correct course of clients' reasoning.

The above analysis shows that different normative disputes are held over the critique of the nondirectiveness principle. Some of them concern the scope of a counselor's duties, while others deal with the limits of a client's freedom. All of these are significant disputes. However, they should be explicitly vocalized. Bringing all these diverse threads under the slogan of criticism of the nondirectiveness principle obscures important problems and makes their solution more distant.

Dispute over the moral neutrality of genetic counselors

The third group of critiques aim at assuming nondirectiveness as the main principle of genetic counseling. They challenge the validity of asking counselors to assume a morally neutral attitude toward the choices of their clients. Therefore, it is a question of whether the nondirectiveness principle orders counselors to adopt a morally neutral attitude about the client's choices.

Caplan is one of the best known representatives of this critique. In his article published in 1993, he presented an overview of a wide range of ways by which the term "non-directive" can be used in relation to the practice of genetic counseling (Caplan 1993). Caplan concluded that the majority of authors using this word identify it with the postulate that counselors should retain a morally neutral attitude toward the client's choices (Yarborough et al. 1989; West 1988; Harris 1991). He is convinced that this identification is erroneous, in fact doubly erroneous, because it does not correctly reflect the content and aim of nondirectiveness and recommends a counselor to assume an attitude that is immoral in many cases.

According to Caplan, nondirectiveness is only roughly related to moral neutrality. It is actually a communication principle originating from psychological and psychotherapeutic practice (Caplan 1993). Nondirectiveness points to a series of techniques that should be used by a consultant to help the clients reach their own convictions and values. In other words, it is a recommendation for professionals which orders them to encourage clients to actively participate in the consultation and make an "insight" into it. Counselors shall remain passive in the sense that their primary task is to realize the needs of a concrete client and not their own. Their main work is to carefully listen and react to the needs

and questions of the clients, and not impose challenges or strive for confrontation.

Caplan indicates that the prescription for genetic counselors to maintain nondirectiveness does not serve anything but establishing efficient communication between them and their client. Thus, this principle is instrumental and not a moral recommendation. A good (i.e. efficient) communication has nothing to do with morality. What is more, Caplan is convinced that asking a genetic counselor to retain a morally neutral attitude by assuming that every decision made by a client is morally acceptable would be something completely wrong. Nondirectiveness identified with adopting moral neutrality and acceptance of each client choice makes counselors powerless when confronted with explicitly immoral choices of certain clients (such as the selection of specified sex of the child, planned birth of a disabled child, or the birth of a child so that he/she becomes an organ donor for siblings).

In line with other critics who understand that the nondirectiveness principle orders counselors to retain moral neutrality, Caplan underlines that consultants may not behave as if they were unaware of the fact that genetic practice carries a number of choices bearing a significant moral burden. The postulate for retaining moral neutrality cannot be used as a kind of camouflaged avoidance of taking a position in the dispute over the following: the moral acceptability of pregnancy termination; the quality and value of the life of severely disabled newborns; the principle of client's autonomy and the limits of parental freedom; and the influence of individual decisions on the health care costs incurred by the society (Burke and Kolker 1994). Out of necessity, genetic practice is entangled in difficult moral choices. Counselors should not make these for clients. However, they may not pretend as not involved in the clients' choices.

The counselor's attachment to total nondirectiveness, which is understood as retaining moral neutrality and refraining from assessing or influencing the client's decisions, also seems inappropriate if one considers that modern genetics does not operate only within reproductive decisions, but its achievements also have importance in the prevention or early detection of somatic diseases. The announcement of the human genome sequence in 2000 and the successive publication of the full sequence of each individual chromosome, together with its physical structure and map of specific genes, caused a flood of new knowledge concerning the genetic contributions to human diseases. For example, hereditary syndromes predisposing individuals to common malignancies such as breast, ovarian, colon, prostate, melanoma, and endometrial cancer have been described. In addition, a number of syndromes predisposing to rare cancers have been recognized. Cancer genetic risk assessment—a process of identifying and counseling individuals at risk for familial or hereditary cancer—has been established as a



medical consultative service. The information of increased risk of familial cancer can be useful in developing a plan of management for cancer screening, prevention, and risk reduction. Under these circumstances, providing the client with advice on the correct action is perfectly appropriate. Indeed it becomes a professional obligation of a counselor, which is equal to the obligation of specialists in other fields of medicine, to provide patients with specific cancer screening and risk reduction recommendations (Clarke 1997; Trepanier et al. 2004).

Nondirectiveness as a guiding policy on genetic testing

In the second area of debate delineated by Biesecker, the term "nondirectiveness" is used to signify the principle regulating social access to genetic testing. It orders that a counselor can perform any genetic test on a person or couple who express such a wish, as long as the individuals were given exhaustive information on the properties of the test as well as its possible outcomes and their clinical importance. The counselor's obligation is to order the performance of the test required by the client, irrespective of his view on the test benefits. Such an understanding of nondirectiveness has also been widely discussed and criticized by some parties. Without going into the detail of those disputes concerning typically different principles than the nondirectiveness, it can be indicated that the debate covers, i.a., the controversies regarding the use of genetic testing for determining the fetus sex. Assuming this strong understanding of nondirectiveness commands a counselor to perform the test for this purpose as well; even if the counselor has the grounds to believe that the knowledge obtained from the test will be the basis for a client's decision on pregnancy termination. Another subject of the debate is the diagnostics of the so-called late-onset diseases and whether the so-called presymptomatic tests should be carried out in minors (those who cannot make an independent decision and for whom the parents make the decision). In a nutshell, all those debates focus on the limits of a client's decision freedom (autonomy) and thus the resulting obligations of the professional performing genetic testing. In other words, all problems raise the question whether a client's decisional autonomy is of absolute nature.

The problems addressed here should and actually have been thoroughly analyzed by professional associations. It is commonly agreed that prenatal tests should not be performed for non-medical reasons. Testing for establishing sex or paternity, and subsequent selective abortion if the fetus is of the 'wrong' sex or from the 'wrong' biological father are deemed unprofessional. There is also a wide professional consensus that genetic testing for late-onset conditions in minors should be avoided unless there is a clinical intervention appropriate in childhood or testing would be in the child's best interests. Genetic providers are licensed to provide testing that is in accordance with the current medical practice and professional ethical guidelines. The same rules apply to providers in other areas of medicine. Associating nondirectiveness with the duty to follow the rules of professional conduct does not distinguish genetic counseling from other health care providers and makes the concept of nondirectiveness redundant and superfluous.

Nondirectiveness as a style of communication

The third area of debate specified by Biesecker concerns its use for signifying the style of communication that should occur between a geneticist and a client during a genetic consultation. Such an approach to nondirectiveness is typically found for those authors who conduct empirical testing on genetic counseling (Michie et al. 1997; Meiser et al. 2008). Many of these researchers utilize the tools created earlier for describing the course of psychotherapeutic sessions and try to apply them to genetic advice. The constatations contained in the conclusions of these authors' studies dealing with the directive or nondirective course of session result from the analysis of the grammatical structure of the sentences uttered by the counselor. However, they do not take into account the real content communicated during the advice or the intentions of the person conducting the session, nor consider whether the given course of the session affected the decision of the client. This observation is significant because a relatively high number of publications state that genetic counselors provide advice in a manner inconsistent with the professional standard (indicating that they exert an unauthorized influence on the clients' decisions). At the same time, the evidence cited by the authors of these publications is often based on the empirical research where the directiveness of a genetic counselor is measured by counting the words deemed to be prescriptive. This method lumps together all forms of advice, directions, suggestions, and recommendations into a single, undifferentiated jumble that



¹ See for example the report by the Task Force of the European Society of Human Reproduction and Embryology that cites professional statements on that issue (Dondorp et al. 2013).

² See for example the statement by the American Society of Human Genetics (Botkin et al. 2015) or by the European Society of Human Genetics (Borry et al. 2009).

is further categorized as directive utterances. This form of word processing does not allow to draw any normative conclusions about the existence or absence of the actual influence of the consultant on client's decisions.

Nondirectiveness as a theoretical basis of counseling practice

The fourth meaning of nondirectiveness is derived from the works of an American psychologist, Carl Rogers, and is strictly linked to the counseling model of genetic practice described above. According to this meaning, nondirectiveness is used to signify how a consultant provides the advice. Advice provided in a nondirective manner indicates that the counselor does not use a uniform, stiff advice scheme, but adjusts its course and contents to the needs and values of the client. This type of consultation can be referred to as client-oriented counseling.

The American authors quite commonly believe that the views of Carl Rogers and his client-centered psychotherapy model greatly influenced the development of genetic counseling models (Kessler 1997b; McCarthy Veach et al. 2003; Djurdjinovic and Peters 2017; McCarthy Veach et al. 2003). Furthermore, these ideas paved the way for the psychotherapeutic model of genetic counseling, which is understood as an objection to the medical model, fixed and not taking into account the needs of the individual client (Kessler 1979). Psychotherapeutic model-based genetic consultation is not only used to communicate medical information to the patient but also aims to provide the patient with assistance and support in the search of assigning importance to his experience (disease or the possibility of its reoccurrence). In addition, its target is to strengthen the competences and wellbeing of the client—by indicating the available resources, underlining the capacity to deal with difficult situations, and reducing the guilt and shame experienced by the person. The course of a genetic consultation is largely dictated by patient needs. Therefore, rather than applying one universal model, an individual approach is proposed for each client. It is also assumed that genetic consultation has long-term outcomes—it not only concerns the present decision of the client but also considers how the patient will deal with its consequences in the future.

Despite the numerous similarities between the stipulates of the Psychotherapeutic Model of genetic counseling and Rogers' ideas, his views differ from the mentioned model in various important aspects. The vision of the counselee is different from Rogers' concept. The counselor also has other tasks.

Firstly, when postulating the nondirectiveness of a psychological counselor, Rogers means that the client should define the purpose of the meetings and accord structure to

them, while the counselor should follow the needs of the client. There is no one, imposed and believed-to-be-model method for conducting psychological consultation. Similarly, it is not possible for a therapist to diagnose the client's needs and apply an appropriate scheme of action. This is because the therapist deals with a human in all his complexity, and not just with a problem to which there is an objective solution.

Secondly, Rogers states that every person has a deeply rooted capacity for autonomous action. This means the capacity for choosing their own life goals, tools for their realization, and taking responsibility for personal choices and decisions. The main obstacle on the way to this autonomy is the fear of discovering who one really is. It prevents a person from reaching his own feelings, desires, and needs. In this way, it blocks the possibility of realizing his real goals. Only by making a dialogue with this "inner myself" a fully autonomous action can be performed. The work of the therapist consists in helping the clients with finding themselves (Rogers 1967).

Thirdly, Rogers assumes that the clients know what is good for them. The task of the therapists is to only create the conditions that will enable the counselees to reach this knowledge. Thus, the "truth about oneself" is strictly personal. What is good for one person does not have to be good for the other. Therefore, there is no other individual apart from the clients who could define their needs and identify the way through which they can be satisfied. The prescription for therapists to refrain from interference and from imposing their own viewpoint is not a courtesy concession in those circumstances, but it is the only appropriate behavior.

Fourthly, Rogers believes that people who lost the connection with their "inner self" can regain it via contact with another person. A therapist can create suitable conditions for the client to search and express oneself. The success of a therapy does not depend on the technical skills held by the therapist—such as professional knowledge or the familiarity and dexterity in using the given techniques. What really matters is the specific attitude of the therapist—creating a feeling that he is someone who understands the client. According to Rogers, such an attitude consists in unconditional positive regard, empathic understanding, and congruence (Rogers 1980). Interest and attention from the part of the therapists makes the clients listen to their own emotions—taming them, becoming aware of them, ceasing to be ashamed of them, and hiding them from themselves.

In the Rogers' therapy model a therapist's assistance for a client consists in assisting the person in the search of the conditions for his self-discovery, decision making, and utilizing his own strength. Such conditions may occur through a specified interpersonal relationship. The task of the therapist is to create and maintain such a relationship.



There is no place for judgment on the basis of this relationship. What is more, a therapist does not advise anything to the client. His relationship with the client is completely nondirective. If there is any judgment within such a meeting, it is of nonmoral nature. At best, it can be determined whether the decision made by the clients was more or less in agreement with themselves. However, it cannot be stated whether the decision was good or bad (in the moral meaning).

There are some significant differences between the assumptions of Rogers' therapeutic approach and genetic counseling models. These differences, profound from the philosophical standpoint, often go unnoticed by the authors who deal with the theory of genetic counseling.

Various meanings of nondirectiveness and different normative prescriptions

The above analysis shows that the word "nondirectiveness" assumes different senses depending on the chosen counseling model. As a consequence, different practical directives are derived from the adoption of the nondirectiveness principle in each model, and altogether, the aim of the counselor and the vision of the counselee are understood differently.

The decision-making model prohibits a counselor from assessing the clients' actions and telling the clients what should be done. Here, the genetic counselor assumes the role of an educator. He shall focus on communicating facts and should at all cost refrain from expressing his opinion or give any advice on how the clients should act in the given situation. According to this model, a good decision is the one made by someone who was provided with all significant information.

In turn, the counseling model acts in the service of rationality. It asserts that a counselor's task is to extract the emotions experienced by the client, so as to release the client from these emotions or minimize their impact on the person's decisions. Taming the emotions is necessary for the client to adequately assimilate the information transmitted to him and reach a fitting state to take a mature action. In addition, the counselor should make sure that the client does not make the common cognitive errors and appropriately considers the available choices. As a matter of fact, this model proclaims the conditions of rational action. The consultant knows what kind of decision is the correct (rational) one and should direct the client toward such a decision. However, certainty does not concern the content of the decision, but its nature—it is determined by providing the conditions for reaching that decision. Based on this model, a good decision is a rational one.

And finally, according to the Rogers' model—a specific type of maieutic—a counselor and a client should try to create conditions that would enable the latter to reach his own emotions. Emotions reflect the true "self" of the client. When a client is able to reach them, he will know what to do. On this model's basis, which is different from the above two models, it cannot be said that there is one right course of action. In its simple definition, which is manifested in genetic counseling models, nondirectiveness primarily means the prohibition of a consultant from exerting influence on the manner in which decisions are made by the client. However, it is still assumed that the professional knows what is good for the client, but he decides not to tell this directly to the person. Rogers' approach is far more radical in this aspect. According to this, the professional does not really know what is good for the client. Every person must discover this for oneself, and others cannot do this for him/ her.

Contemporary skepticism about the nondirectiveness principle and its usefulness for genetic practice.

The nondirectiveness principle, which has been proclaimed as the main rule of genetic counseling and is widely accepted by genetic counselors, has never been translated into practical directives. This has given rise to various speculations, beliefs, ideas, and disputes about its content. Many of these have been verbal disputes, occurring through discussions between different parties who had contrasting understandings of the key term or who attempted to apply it to a slightly different field of professional duties. Some of these disputes have concerned the scope of a counselor's professional obligations, while others have dealt with the limits of a client's freedom. These have intertwined with discussions about genetic consultants' responsibility to their clients and the whole of society, the role of counselors as gatekeepers in accessing genetic services, and whether it is possible to separate scientific advances from their practical applications that have normative implications. Bringing all these diverse threads under the slogan of criticism of the nondirectiveness principle have obscured important problems and led many authors to believe that this principle should be discarded (White 1997; Weil et al. 2006). Some professional organizations have eliminated this term from the definition of genetic counseling practice (Resta et al. 2006). Nowadays, some authors argue that nondirectiveness should not play any important role in defining the moral obligations of the genetic counseling profession (Jamal et al. 2020).



In my view, the contemporary discussion of the genetic counseling profession and its foundational values is seriously flawed:

- 1. It is American-centric: Most articles on genetic counseling are published in American journals and are written by American authors. They have a tendency to assume that the professional culture of American genetic counselors is ubiquitous and this way of understanding the basic professional concepts is widespread and identical. What these authors often fail to realize is that their understanding of the nondirectiveness principle is rather narrow and is limited to the consultant's obligation not to interfere in a patient's decision-making. My analysis shows that this is an erroneous conviction. The principle of nondirectiveness is much more comprehensive and can indicate different normative conclusions.
- It is dispersed and focused on solving ad hoc problems in selected areas of clinical practice (e.g. Ryan et al. 2015; Forbes et al. 2017). These ad hoc solutions are then used by some authors as the building blocks of an all-encompassing model of genetic counseling: a "new ethical framework" (Jamal et al. 2020). However, adopting this strategy has the following negative consequences: (1) It blurs the distinctions between the goals and the ethos of genetic counseling and the values that shape the practice of other medical professionals. This creates uncertainty as to the future of the genetic counseling profession and the distinct value of the genetic counselor over and above education about genetics that may be provided by other health professionals (Austin et al. 2014). (2) There is a tendency to eschew the term "nondirectiveness" in favor of broad yet ill-defined terms such as autonomy, beneficence, nonmaleficence and justice. This strategy only ostensibly solves the normative problems. Proposing more values to govern the practice of genetic counseling creates more problems since these values often come into conflict with each other in clinical practice.
- discussions, the issues raised, and the solutions proposed. In consequence, a very simplistic understanding of the principle of nondirectiveness is presented and the proposed new solutions are unsatisfactory. The proposed "new ethical frameworks" lack coherence, are ill-defined, and offer only specific, practical normative solutions in the practice of genetic counseling. Various models of genetic counseling are constantly being developed and proposed. Most of them simply offer old content under new names but do not solve the old problems. This is due to a paucity of critical and philosophical reflection on the key concepts and values of genetic practice. The proposed solutions are haphazard and do not get to the heart of the matter; in particular, they do

not measure up to the fundamental value conflicts that arise in genetic counseling practice.

The benefits of remembering past ethical debates

Elimination of the term "nondirectiveness" from ethical debate cannot be seen as a satisfactory solution to many problems that are still present in the practice of genetic counseling; it signifies the end of the debate and gives the false impression that all disagreements have been settled. This is not the case, and the practice of genetic counseling would benefit immensely from remembering these important disputes. The debates have raised important questions and brought to light complex problems regarding both the theory and the practice of genetic counseling:

- 1. How should the decisional autonomy of clients of genetic services be properly circumscribed? Should it be understood as a positive right that obligates a genetic counselor to provide all services that the client perceives as beneficial? Or—as is the case in other areas of medical practice—should the autonomy of the client be understood as a negative right (the right to refuse genetic services or to demand only those that are deemed appropriate by professionals)?
- 2. What is the scope of the professional obligations and standards of conduct of genetic counselors? Should genetic counselors formulate suggestions and recommendations for clients, and in what circumstances?
- 3. Is it ever appropriate for a genetic counselor to exert moral judgment on a client's decisions and refuse cooperation if he finds them immoral?
- 4. Does genetic counseling aim to help clients make rational decisions concerning testing or give meaning to the client's personal experience? As a consequence, should genetic counseling be provided in a uniform manner (based on the concept of a rational client), or should it be individualized, tailored to the specific needs of each client?

Some of these questions are as pertinent today as ever. It is my contention that more critical and philosophical reflection on the key concepts and values of genetic practice is needed before "new ethical frameworks" for genetic counseling are proposed. By providing a comprehensible overview of the various meanings of the term "nondirectiveness" and the normative consequences of choosing some of them, I want to provide a road map of the ethical problems that have not yet been addressed.



392 W. Chańska

Author contributions WC is the only author for this publication. She takes all responsibility for its content.

Funding The research has been funded by Narodowe Centrum Nauki, Poland; the grant number: 2014/15/B/HS1/01651.

Data availability Not applicable.

Code availability Not applicable.

Declarations

Conflicts of interest No competing interests.

References

- Austin, Jehannine, Alicia Semaka, and George Hadjipavlou. 2014. Conceptualizing genetic counseling as psychotherapy in the era of genomic medicine. *Journal of Genetic Counseling* 23 (6): 903–909. https://doi.org/10.1007/s10897-014-9728-1.
- Biesecker, Barbara. 2000. Reproduction, ethics, the ethics of reproductive genetic counseling: nondirectiveness. In *Encyclopedia of ethical, legal, and policy issues in biotechnology*, ed. T.J. Murray and M.J. Mehlman, 977–83. New York: Wiley.
- Borry, Pascal, Gerry Evers-Kiebooms, Marina C. Cornel, Angus Clarke, and Kris Dierickx. 2009. Genetic testing in asymptomatic minors: Recommendations of the European Society of Human Genetics Recommendations of the European Society of Human Genetics. *European Journal of Human Genetics* 17 (6): 720–721. https://doi.org/10.1038/ejhg.2009.26.
- Bosk, Charles. 1993. The workplace ideology of genetic counselors. In *Prescribing our future: Ethical challenges in genetic counseling*, ed. D.M. Bartels, B.S. LeRoy, and A.L. Caplan, 25–37. New York: Aldine de Gruyter.
- Botkin, Jeffrey R., John Belmont, W., Berg, Jonathan S., Berkman, Benjamin E., Bombard, Yvonne, Holm, Ingrid. A., Levy, Howard P., Ormond, Kelly, Saal, Howard, M., Spinner, Nancy, B., Wilfond, Benjamin, S., and McInerney, Joseph, D. 2015. Points to consider: Ethical, legal, and psychosocial implications of genetic testing in children and adolescents. *The American Journal of Human Genetics* 97 (1): 6–21. https://doi.org/10.1016/j.ajhg. 2015.05.022.
- Burke, Meredith, and Aliza Kolker. 1994. Variation in content in prenatal genetic counseling interviews. *Journal of Genetic Counseling* 3: 23–38. https://doi.org/10.1007/BF01414604.
- Caplan, Alan. 1993. Neutrality is not morality: The ethics of genetic counseling. In *Prescribing our future: Ethical challenges in* genetic counseling, ed. D.M. Bartels, B.S. LeRoy, and A.L. Caplan, 149–165. New York: Aldine de Gruyter.
- Clarke, Angus. 1997. The process of genetic counseling: Beyond nondirectiveness. In *Genetics, society and clinical practice*, ed. P.S. Harper and A.J. Clarke, 179–200. Oxford: BIOS Scientific.
- Djurdjinovic, Luba. 1998. Psychosocial counseling. In A guide to genetic counseling, ed. D.L. Baker, J.L. Schuette, and W.R. Uhlmann, 127–166. New York: Wiley.
- Djurdjinovic, L., and J. Peters. 2017. Special Issue Introduction: Dealing with psychological and social complexity in genetic counseling. *Journal of Genetic Counseling* 26 (2): 195–198. https://doi.org/10.1007/s10897-017-0080-0.
- Dondorp, W., G. De Wert, G. Pennings, F. Shenfield, P. Devroey, B. Tarlatzis, P. Barri, and K. Diedrich. 2013. ESHRE task force on

- ethics and law 20: Sex selection for non-medical reasons. *Human Reproduction* 28 (6): 1448–1454. https://doi.org/10.1093/humrep/det109.
- Ekwo, Edem, Jae-On. Kim, Gosselink Carol, Jonh Opitz, and James Reynolds. 1987. Parental perceptions of the burden of genetic disease. *American Journal of Medical Genetics* 28: 955–63. https://doi.org/10.1002/ajmg.1320280422.
- Eunpu, Deborah. 1997. Systemically-based psychotherapeutic techniques in genetic counseling. *Journal of Genetic Counseling* 6: 1–20. https://doi.org/10.1023/A:1025630917735.
- Frets, Petra, Hugo Duivenvoorden, Frans Verhage, Martinus Niermeijer, Sophie van de Berge, and Galjaard Hans. 1990. Factors influencing the reproductive decision after genetic counseling. *American Journal of Medical Genetics* 1990 (35): 496–502. https://doi.org/10.1002/ajmg.1320350411.
- Frets, Petra, and Martinus Niermeijer. 1990. Reproductive planning after genetic counseling: A perspective from the last decade. *Clinical Genetics* 38: 295–306. https://doi.org/10.1111/j.1399-0004.1990.tb03584.x.
- Forbes Shepherd, R., T.K. Browne, and L. Warwick. 2017. A relational approach to genetic counseling for hereditary breast and ovarian cancer. *Journal of Genet Counseling* 26 (2): 283–299. https://doi.org/10.1007/S10897-016-0022-2.
- Harris, Rodney. 1991. The new genetics: A challenge to traditional medicine. *Journal of the Royal College of Physicians London* 25: 134–140.
- Hsia, Edward. 1979. The genetic counselor as information giver. In Genetic counseling: Facts, values, and norms, ed. A.M. Capron, 169–186. New York: Alan R. Liss.
- Jamal, Leila, Will Schupmann, and Benjamin E. Berkman. 2020. An ethical framework for genetic counseling in the genomic era. *Journal of Genetic Counseling* 29 (5): 718–727. https://doi.org/10. 1002/jgc4.1207.
- Kahneman, Daniel, Paul Slovic, and Amos Tversky. 1982. Judgment under uncertainty: heuristics and biases. Cambridge: Cambridge University Press.
- Kessler, Seymour, ed. 1979. *Genetic counseling: Psychological dimensions*. New York: Academic Press, Available from: https://www.gceducation.org/wp-content/uploads/2019/06/ACGC-Core-Competencies-Brochure_15_Web_REV-6-2019.pdf.
- Kessler, Seymour. 1997a. Psychological aspects of genetic counselling. IX. Teaching and counseling. *Journal of Genetic Counseling* 6 (3): 287–95. https://doi.org/10.1023/A:1025676205440.
- Kessler, Seymour. 1997b. Psychological aspects of genetic counselling. XI. Nondirectiveness revisited. American Journal of Medical Genetics 72: 164–71.
- Leroy, Bonnie. 1993. When theory meets practice: Challenges to the field of genetic counseling. In *Prescribing our future: Ethical challenges in genetic counseling*, ed. D.M. Bartels, B.S. LeRoy, and A.L. Caplan, 39–54. New York: Aldine de Gruyter.
- Lippman-Hand, Abby, and Clarke Fraser. 1979. Genetic counseling
 The post-counseling period: II. Making reproductive choices.
 American Journal of Medical Genetics 4: 73–87. https://doi.org/10.1002/ajmg.1320040109.
- Marks, Joan. 1993. The training of genetic counselors: origins of a psychosocial model. In *Prescribing our future. Ethical challenges in genetic counseling*, ed. D.M. Bartels, B.S. LeRoy, and A.L. Caplan. 15–24. New York: Aldine de Gruyter.
- McCarthy Veach, Patricia, Bonnie S. LeRoy, and Dianne M. Bartels. 2003. Facilitating the genetic counseling process: A manual for practice. New York: Springer.
- Meiser, Bettina, Jennifer Irle, Elizabeth Lobb, and Kristine Barlow-Stewart. 2008. Assessment of the content and process of genetic counseling: A critical review of empirical studies. *Journal of Genetic Counseling* 17 (5): 434–451.



- Michie, Susan, Faye Bron, Martin Bobrow, and Theresa M. Marteau. 1997. Nondirectiveness in genetic counseling: An empirical study. *Amercian Journal of Human Genetics* 60 (1): 40–47. https://doi.org/10.1007/s10897-008-9173-0.
- National Society of Genetic Counselors. 2018. National society of genetic counselors code of ethics. *Journal of Genetic Counseling* 27 (1): 6–8. https://doi.org/10.1007/s10897-017-0166-8.
- Ormond, Kelly, Mercy Ygona Laurino, Kristine Barlow-Stewart, Tina-Marie. Wessels, Shelley Macaulay, Jehannine Austin, and Anna Middleton. 2018. Genetic counseling globally: Where are we now? *American Journal of Medical Genetics Part C* 178 (1): 98–107. https://doi.org/10.1002/ajmg.c.31607.
- Rapp, Rayna. 1988. Chromosomes and communication: The discourse of genetic counseling. *Medical Anthropology Quarterly* 2 (2): 143–157. https://doi.org/10.1525/maq.1988.2.2.02a00040.
- Rentmeester, Christy. 2001. Value neutrality in genetic counseling: An unattained ideal. *Medicine, Health Care and Philosophy* 4 (1): 47–51. https://doi.org/10.1023/a:1009972728031.
- Resta, Robert. 1997. Eugenics and nondirectiveness in genetic counseling. *Journal of Genetic Counseling*. 6 (2): 255–258. https://doi.org/10.1023/a:1025624505382.
- Resta, Robert, Barbara Bowles Biesecker, Robin L. Bennett, Sandra Blum, Susan Estabrooks Hahn, Michelle N. Strecker, and Janet L. Williams. 2006. A new definition of genetic counseling: National Society of Genetic Counselors' task force report. *Journal of Genetic Counseling* 15 (2): 77–83. https://doi.org/10.1007/s10897-005-9014-3.
- Rogers, Carl. 1967. On becoming a person: A therapist's view of psychotherapy. London: Constable.
- Rogers, Carl. 1980. A way of being. Boston: Houghton-Mifflin.
- Rothman, Barbara Katz. 1986. *The tentative pregnancy*. New York: Viking Penguin.
- Ryan, J., A. Virani, and J.C. Austin. 2015. Ethical issues associated with genetic counseling in the context of adolescent psychiatry. *Applied & Translational Genomics* 5: 23–29. https://doi.org/10. 1016/j.atg.2015.06.001.
- Schild, S. 1984. Markers for stress and criteria for ongoing counseling. *Birth Defects Original Article Series* 20: 107–113.
- Shiloh, Shoshana, Orit Avdor, and Richard M. Goodman. 1990. Satisfaction with genetic counseling: Dimensions and measurement. *American Journal of Medical Genetics* 37: 522–29. https://doi.org/10.1002/ajmg.1320370419.
- Shiloh, Shoshana, and Michal Sagi. 1989. Effect of framing on the perception of genetic recurrence risks. American Journal of Medical Genetics 33: 130–35. https://doi.org/10.1002/ajmg.1320330121.
- Sorenson, James R. 1993. Genetic counseling: Values that have mattered. In *Prescribing our future Ethical challenges in genetic counseling*, ed. D.M. Bartels, B.S. LeRoy, and A.L. Caplan, 3–14. New York: Aldine de Gruyter.

- Sorenson, James R., Carole M. Kavanagh, and Marc Mucatel. 1981. Client learning of risk and diagnosis in genetic counseling. *Birth Defects Original Article Series* 17 (1): 215–228.
- Trepanier, Angela, Mary Ahrens, Wendy McKinnon, June Peters, Jill Stopfer, Sherry Campbell Grumet, Susan Manley, et al. 2004. Genetic cancer risk assessment and counseling: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling* 13: 83–114. https://doi.org/10.1023/B:JOGC.0000018821.48330.77.
- Weil, Jon. 2000. Psychosocial genetic counseling. New York: Oxford University Press.
- Weil, Jon. 2003. Psychosocial genetic counseling in the post-nondirective era: A point of view. *Journal of Genetic Counseling* 12 (3): 199–211. https://doi.org/10.1023/a:1023234802124.
- Weil, Jon, Kelly Ormond, June Peters, Kathryn Peters, Barbara Bowles Biesecker, and Bonnie LeRoy. 2006. The relationship of nondirectiveness to genetic counseling: Report of a workshop at the 2003 NSGC Annual Education Conference. *Journal of Genetic* Counseling 15 (2): 85–93.
- Wertz, Dorothy, and Fletcher James. 2004. *Genetics and ethics in global perspective*. Berlin: Springer.
- Wertz, Dorothy, and Fletcher James. 1988. Attitudes of genetic counselors: A multinational survey. *American Journal of Human Genetics* 42: 592–600.
- Wertz, Dorothy, James Sorenson, Timothy Heeren, and Opitz John. 1984. Genetic counseling and reproductive uncertainty. *American Journal of Medical Genetics* 18: 79–88. https://doi.org/10.1002/aimg.1320180112.
- Wertz, Dorothy, James Sorenson, and Timothy Heeren. 1986. Clients' interpretation of risks provided in genetic counseling. *American Journal of Human Genetics* 39: 253–264.
- West, Richard. 1988. Ethical aspects of genetic disease and genetic counselling. *Journal of Medical Ethics* 14 (4): 194–97. https://doi.org/10.1136/jme.14.4.194.
- White, Mary. 1997. "Respect for autonomy" in genetic counseling: An analysis and a proposal. *Journal of Genetic Counseling* 6: 297–313. https://doi.org/10.1023/a:1025628322278.
- Yarborough, Mark, Joan Scott, and Linda Dixon. 1989. The role of beneficence in clinical genetics: Non-directive counseling reconsidered. *Theor Med* 10 (2): 139–49. https://doi.org/10.1007/ BF00539879.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

