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## Mini Review

# Goals of genetic counseling

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The goals of genetic counseling have differed over the past three decades. Two schools of thought are prominent in reviewing past literature. One upholds the goal of preventing birth defects and genetic disorders while the other promotes a goal of improved psychological well-being in client adaptation to a genetic condition or risk. Both types of goals emphasize that clients should make their own reproductive decisions; however, the former relies on clients making decisions that will reduce the impact of genetic disorders. The differences in the types of goals may be due to the training and orientation of genetics health care providers, socio-cultural views, or priorities of health care settings. Regardless, there are ample reasons to dismiss the prevention of birth defects as a goal. This mini-review recommends use of genetic counseling sub-specialties as a framework for considering different client needs and thus different counseling goals and specific aims in the reproductive, pediatric/adult, and common disease settings. Given the extent of new genetic information, technologies, and the need to evaluate genetic counseling practice, genetics health care providers should work toward arriving at consensus on the goals of genetic counseling, and in doing so, the needs of clients should be considered.

### BB Biesecker

National Human Genome Research  
Institute, NIH, Bethesda, MD, USA

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Corresponding author: B. Bowles Biesecker, MS, Associate Investigator, NHGRI/NIH, 10 Center Drive MSC 1852, Bldg 10, Room 10C101, Bethesda, MD 20897-1852, USA. Tel.: +1 301 4963979; fax: +1 301 4967157; e-mail: barbarab@nhgri.nih.gov

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Over the past three decades, goals of genetic counseling have differed. One major goal clearly stated by some providers was to prevent birth defects and genetic disorders (1). Others have claimed the importance of helping genetic counseling clients cope with and adapt to genetic information (2). Specifically, Shiloh and colleagues summarized genetic counseling objectives as client 'learning, understanding, choosing and coping' (3). This mini-review outlines the written history of the goals of genetic counseling, explores their tensions and argues for a psychoeducational practice model based on goals to promote client understanding and well-being. More specifically, genetic counseling sub-specialties are presented as a framework for considering how a psychological goal translates into specific practice aims that can be researched.

### The prevention of birth defects and genetic disorders

In 1977, Lubs asserted the importance of identifying and counseling clients prior to the birth of an affected child in order to maximize client options (4). He emphasized the importance of early referral of affected children to maximize opportunities for

treatment and prevention. Similarly, Hsia stated that the essence of genetic counseling was informative: that its aim was to convey relevant genetic facts and reproductive options with the goal of enabling families to plan reproductive decisions and to adjust realistically to, or cope better with their genetic problems (5). These preventive goals were first asserted before the availability of prenatal diagnosis and so prevention was largely related to client decisions about subsequently having affected children. Genetics health care providers aimed to equip clients with appropriate information, believing that if they understood a scientific explanation, they would use it to make rational or logical reproductive choices (i.e., ones that made sense to providers). They were based on a good deal of faith that the decisions providers thought best would largely match the desires and values of their clients.

Into the 1980s, there continued support for the goal to prevent birth defects. Moser cited the prevention of the birth of genetically ill children as the primary goal of genetic counseling, reinforcing the notion that this goal, whether implicit or explicit, remained in the minds of genetics providers (6). Reif and Baitsch in 1985 described an overall shift

in the goals of genetic counseling from eugenics toward preventive medicine (7). They noted general support for an information model, one that emphasized client-informed decision-making. It was their claim that there were minimal differences in the stated goals, but differences in how counselors strived to reach them. How this shift was reflected in genetic counseling practice, however, had not been studied. Even later, in 1986, Kelly stated the purpose of genetic counseling as the maximal use of medical technology to reduce the incidence of genetic disorders, and hence, the financial impact on society (8).

The prevention of birth defects into the 1980s implied not only a goal of avoiding biological pregnancies that risked being affected, but due to the availability of prenatal diagnosis, also implied facilitating client decisions to terminate pregnancies when the fetus is affected. The prevention of birth defects goals continued to persist in the literature, even though counselors' experiences with different client choices after prenatal diagnosis highlighted the very personal nature of such decisions (9). Further, individual clients and genetic support groups representing families affected by various genetic conditions vocalized that they were not necessarily interested in preventing the condition in their family (10–12). Prevention of birth defects and genetic conditions is generally troublesome for ethical reasons, but it has also been acknowledged by geneticists as unattainable due to both the presence of new mutations in the population and the largely unknown (and typically sporadic) and therefore unalterable causes of most birth defects (13). Coupled with more recent advancements in the US disability rights movement and emerging perspectives from various representatives of the disabled community, there are ample arguments against a contemporary genetic disease prevention goal for genetic counseling. The intent of genetic counseling to advocate for the abortion of affected fetuses as an objective of genetic counseling is unjustified, yet has remained an implicit (and sometimes explicit) goal (14).

### Goals of client psychological well-being

Although it is tempting to this author to presume that the goals associated with client psychological well-being (the second school of thought) paralleled the emergence of the profession of master's level genetic counselors, these goals actually existed as early as the prevention goals (15). In 1956, Kallman emphasized the importance of psychological understanding in genetic counseling when he pointed out that a counselor cannot assume that a

client will be realistic about his/her genetic circumstances (16). He expressed concerns that pitting intellect against emotion in the presentation of genetic information might result in psychological injury. He emphasized the importance of genetic counseling in addressing the client's fears, hopes, defenses, and rationalizations in order to help the client view the situation as it is, rather than as the client might hope that it is. In 1972, Hecht and Holmes reiterated the importance of the mental health component in genetic counseling (17). Falek also identified genetic counseling goals: to provide the family, in a personalized manner, information about recurrence risks with a long-term goal of facilitating rational decision-making (15). These goals were accompanied by an acknowledgement of the emotional impact of these issues and the need for genetics health providers to 'deal with them'. Falek promoted a coping framework for understanding the reactions of genetic counseling clients. Kessler, in 1979, discussed the fine line between past eugenic goals and those of prevention of birth defects in genetic counseling. He highlighted the discrepancies in whether the goals to prevent had a societal intent or were individualized. He chose to describe the tasks rather than the goals of genetic counseling as communicating genetic information, helping clients reach pertinent decisions, and helping them cope with the information and the consequences of the genetic disorder (18).

Emery claimed that by 1984 there had been an evolution from what Kessler described as content-oriented to person-oriented genetic counseling (19). He based his claim on the acknowledgement in the literature that genetic information often has profound psychological effects, which may have long-term consequences that can extend to relatives. He asserted that a qualified genetic counselor had to be aware of the client's fears, hopes, defenses, and rationalizations in order to help him/her deal with his/her problems in a realistic manner. Many of the providers promoting psychological goals were trained in psychiatry or psychology and were well aware that clients do not necessarily make logical or rational choices (although they may be logical to the client). They recognized that scientific explanations are only one way to understand risk, allowing for personal interpretation and meaning (2, 20). Genetic science does not necessarily alleviate guilt or anxiety in the client. In some cases, the information itself may actually raise anxiety or reinforce feelings of guilt or responsibility. A psychological goal of genetic counseling aims to help clients cope with such feelings and adapt to their circumstances.

## Two parallel tracks of goals

The preceding evidence from stated goals reveals that two parallel tracks had developed and infrequently intersected in the literature. They were bridged somewhat by the most often cited definition of genetic counseling written by a subcommittee of the American Society of Human Genetics (ASHG):

Genetic counseling is a communication process that deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to: (1) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available management, (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, (3) understand the alternatives for dealing with the risk of recurrence, (4) choose a course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (21)

The overt prevention focus was omitted and attention to client adjustment included. This definition focused on a goal of effective communication between a genetics health care provider and a client. But as Kessler remarked in 1979, communication is the means to practicing genetic counseling rather than the goal. The ASHG definition reflected negotiation and compromise among the differing perspectives of the genetic health care providers who authored it, and although it omitted reference to prevention, one could argue that it is implicit in its intent (22). As noted by Sorenson and Culbert, it added complex and non-quantifiable elements to the goals of genetic counseling (23). It also neglected to acknowledge the importance of the counselor–client relationship.

By 1979, Antley had highlighted the emerging conflict in counselor goals among proponents of different counseling orientations, those who promoted genetic disease prevention and those with psychosocial goals in mind (24). In order to resolve the growing disparity, he outlined the limitations of the goals of client education or psychological well-being and instead promoted the goal of facilitated decision-making, citing the importance that both education and psychosocial counseling play

as secondary aims to the primary goal of client decision-making. While this discussion worked toward providing a consensus on the goals of genetic counseling, it was not applicable for those cases when genetic counseling offers no choices or options to clients. Also in 1979, in the Foreword to Kessler's textbook on genetic counseling, Epstein reviewed early genetic counseling definitions, each of which included a goal to prevent or reduce the incidence of birth defects (25). The descriptions of genetic counseling had expanded to include the communication of genetic information and helping the client to make a decision and were more often silent on the issue of reducing birth defects. Dr Epstein commented on the notable switch in emphasis to counseling; however, he went on to remark that prevention of birth defects remained a goal of genetic counseling in many instances.

## Non-directiveness as a principle not a goal

Non-directiveness is a guiding principle for genetic counseling that promotes the autonomy or self-determination and personal control of the client (26–28). The literature on non-directiveness at times has confused it as a goal of genetic counseling (12). It has also been considered as an intervention but rather, as Kessler noted, is best regarded as 'a way of thinking about the relationship between client and counselor' (29). The inconsistency in descriptions of non-directiveness in the literature has made it challenging to assess its implications for achieving the goals of genetic counseling. This may have been made more difficult by the two different schools of thought on the goals. Undoubtedly, non-directiveness is most relevant to reproductive genetic counseling and the personal nature of reproductive decisions. It may have little relevance to the goals of altering behaviors to promote health in the context of predisposition to disease or to adapt to a genetic condition or risk. Even as a guiding principle and not a goal, non-directiveness is thus of circumscribed importance to genetic counseling.

## Research into the goals of genetic counseling

Although there is not an abundance of research on genetic counselors' pragmatic goals, what little there is provides valuable insight into their origins. Sorenson and Culbert in 1977 suggested that the orientation of the genetic counselor (his/her balance between psychosocial discussion and information provision) was determined by the goals the counselor has in mind (23). They reported out-

comes of a study ascertaining what topics counselors discuss within genetic counseling sessions. They concluded that counselors most often want to discuss the familial impact of affected children, alternative forms of parenthood, and notification of at-risk family members who may be carriers of an altered gene. The most common orientation, therefore, was one that identified education as primarily important, and this majority of counselors endorsed goals consistent with a preventive medicine goal. Their results suggested that the topics that the smaller proportion of psychologically oriented counselors preferred were the expectations, values, and personal beliefs of the clients. These counselors wanted to let clients define the end point of counseling themselves. For clients to do so, the genetic counselor could not adopt a view of genetic counseling as preventive medicine.

In 1988, Wertz and Fletcher reported survey results on the attitudes of an international sample of 677 genetics health care providers (30). There was nearly 100% consensus on three of seven goals presented to the respondents. These included: helping individuals/couples understand their options and the present state of medical information so that they can make informed decisions, helping individuals/couples adjust to and cope with their genetic problems, and removing or lessening patient guilt or anxiety. The majority of respondents did not endorse goals to improve the health of the population or reduce the incidence of carriers, contrary to the results of Sorenson and Culbert. Similar to the results of Sorenson and Culbert but in contrast to the results of Wertz and Fletcher, in 1995, James and colleagues found that among a sample of US genetic health care providers, the goals of preventing disease or abnormality and improving the general health of the population were still strongly supported (31). The majority of the 204 respondents supported an educational model of genetic counseling that encouraged clients to make their own decisions, but also apparently trusted that clients would make preventive decisions.

The goals of genetic counseling should ideally complement those of counseling clients, who are often unsure what genetic counseling has to offer or what they may gain (32). Only a few studies to assess the goals of genetic counseling have included the views of clients. Recently, studies have been conducted ascertaining client expectations, desires, and needs. Veach and colleagues reported that clients named information gained and assistance with decision-making as the most beneficial aspects of genetic counseling (33).

Central to the discussion of genetic counseling goals are its outcomes, representing a way to operationalize the goals in order to assess whether or not they have been realized. Clarke and colleagues in 1996 outlined the deficiencies of evaluating genetic counseling outcomes in terms of client knowledge, reproductive plans, or reproductive behaviors (34). In contrast, they suggested that genetic counseling should be evaluated by asking clients questions about the process, such as short- and long-term satisfaction and changes in expectations. Michie and colleagues found that client and counselor expectations influenced their relationship as well as practice outcomes (35). Based on a small qualitative study of genetic counselors and their clients, my colleagues and I found that counselors viewed meeting client expectations as the primary goal of genetic counseling. Paradoxically, clients often did not know what to expect. We recommended new measures for evaluating genetic counseling that included more readily ascertained short-term outcomes: a client's sense of being heard, encouraged, valued, supported, and attended to. Long-term outcomes included improved communication about genetic issues in the family, anticipation of feelings or experiences stemming from future events, and clarifying values underlying decisions or attitudes. Additional research is needed to assess such outcomes and their relationship to the goals of genetic counseling.

#### **A need for consensus on the goals**

Identifying a unifying goal for all of genetic counseling may not be realistic or useful given the different reasons why clients seek services. But there should be consensus among providers within the same country, at least, in order to standardize practice, deliver clear messages to clients, and to serve as guides in the education of genetic counselors and in the evaluation of services. When assessing the need for consensus on the goals of genetic counseling, the socio-cultural context should be considered. Due to differences in health care priorities and resources, countries may have values and health care systems that support different genetic counseling goals. Whether or not there should or can be worldwide consensus on the goals of genetic counseling should be discussed internationally.

The disparity in genetic counseling goals suggests that the practice of genetic counseling varies, rendering it difficult to teach or evaluate (36). While a chronological review of the goals lends some understanding to the evolution of genetic counseling goals, it does not fully explain the dis-

cordance. Some of the discrepancy may be explained by differences in the training or orientation of genetic health care providers, the wide variety of reasons clients seek genetic counseling and their disparate needs, as well as the socio-cultural context of genetic counseling. Yet for three decades, little progress has been achieved in arriving at goals to which the majority of genetic health care providers can agree. With the tremendous explosion in genetic information and technologies that has occurred in the past decade, there is increased interest in solidifying the goals of genetic counseling so that empirical data may be sought to evaluate its effectiveness and the essential elements of the process (37–39). This has practical importance in determining who is adequately trained to conduct genetic counseling and in determining how providers effectively meet client needs. Further, whether or not the goals are consistent with those of related medical genetics services such as carrier screening programs or newborn screening is a useful distinction for practice guidelines as well as research.

### **A psychoeducational paradigm for genetic counseling**

Contemporary genetic counseling should strive to achieve the psychoeducational goals of genetic counseling that emphasize assisting clients in their adaptation to genetic risk or a genetic condition. A proposed contemporary definition supports such goals:

Genetic counseling is a dynamic psychoeducational process centered on genetic information. Within a therapeutic relationship established between providers and clients, clients are helped to personalize technical and probabilistic genetic information, to promote self-determination and to enhance their ability to adapt over time. The goal is to facilitate clients' ability to use genetic information in a personally meaningful way that minimizes psychological distress and increases personal control. (38)

The primary goals of genetic counseling within this definition resemble those of other psychoeducational counseling interactions: promoting understanding, achieving informed consent, facilitating decision-making, reducing psychological distress, restoring feelings of personal control, and advancing adaptation to stress-inducing events. Genetic health care providers should be trained to develop expertise not only in clinical and human molecular genetics and reproductive options, but also in compassionate therapeutic counseling that addresses

feelings of loss of personal control, bereavement, reduced self-esteem, social isolation, and stigmatization. Support for these goals comes from research in behavioral medicine that has improved understanding of the cognitive and affective aspects of adaptation (40). Further, there is greater understanding of the complexities of human behavior related to health, including some of the reasons why patients do not consistently adhere to medical recommendations, the complex ways patients perceive genetic conditions, the ways patients internalize and interpret uncertainty and risk, as well as the ways patients make decisions about pursuing health-enhancing lifestyle behaviors (41–44).

While an emphasis on genetic counseling goals of client psychological well-being is most likely to be useful to clients, it is inherently inconsistent with a goal to reduce the incidence of genetic conditions in society. A goal that trusts clients to make good decisions for themselves that are consistent with their own values and needs does not (and should not) assume that the decisions will be consistent with that of providers. Furthermore, clients will not necessarily make thoughtfully considered decisions, be rational, or make choices that reduce the burden of genetic disease on society. Yet, most clients are reasonable and will make decisions (such as avoiding the birth of severely affected children) that are best for them and most likely as well for society. In contrast, a goal promoting prevention ignores the needs and values of clients over a societal good and thus confuses the counseling process. For example, a couple who has two children affected with cystic fibrosis and chooses to undergo a subsequent pregnancy without testing, thereby accepting the 25% chance that a subsequent child will be affected, may represent a family that is emotionally, physically, and economically prepared to care for another affected child. They understand what the condition means for their children and what it may mean for another. Yet to a health care provider or medical administrator, the decision to undergo a subsequent pregnancy may be viewed as illogical or irrational, one that reasonable people would avoid altogether. Genetic counseling based on goals of psychological well-being may accept this decision as a good one for the couple and may view the process that leads them to this decision as valuable.

In order to promote the desirable goals of psychological well-being, the literature needs to address further what clients may gain from genetic counseling. They may develop a deeper understanding of the genetic condition or risk in the family, a feeling that someone cares about them, a

feeling that they are valued and not shunned during a time of emotional need, the knowledge that others have survived what they face and insight that they are likely to survive successfully as well, and the reassurance that there are practical resources available, such as medical and educational services. Kessler emphasizes the importance of genuinely helping clients to feel better about themselves, be efficacious in their decision-making, and understand better their actions and behaviors in order to gain perspective and cope more effectively (45).

The overarching psychoeducational goals can be made more specific if they are discussed by subspecialty. Three genetic counseling subspecialties are reproductive, pediatric/adult, and common disease. In each of these areas, the specific aims (for the client and thus the health care provider) differ.

### Reproductive genetic counseling

Reproductive genetic counseling offers options to clients related to testing (prenatal or carrier) and child-bearing. The majority of clients are not adapting to a genetic condition or birth defect in their family but rather naively facing choices about how to avoid having an affected child. The focus of the counseling is often on client decision-making, including accepting the consequences of the choice(s). The counseling process itself includes the client's cognitive interpretation of the information (understanding) and her/his affective responses (feelings). *The goal of reproductive genetic counseling is to promote the client's self-determination in exercising choices.* It is achieved through discussion of client values and beliefs incorporating how the client/couple personalizes the genetic information in a way that is both useful and meaningful (46). This goal of facilitated decision-making can thus be achieved within a client-centered psychoeducational approach and yet has distinct aims:

1. To deliver personalized genetic information to the client in a useful way.
2. To explore the meaning of the information with the client in light of personal values and beliefs.
3. To promote the client's preferences for reproductive options with consideration of alternatives, consequences and barriers.
4. To prepare the client for accepting the outcome of the choice(s).

The rationale for this goal and its aims is based on the uncertainty associated with the chances for most birth defects to occur and the lack of preven-

tive options currently available. The option of terminating an affected fetus is not properly viewed as prevention, but in nearly all cases a difficult choice about a pregnancy. When preventive options are available, such as the use of folic acid to reduce the chances for having a child affected with a neural tube defect, or smoking cessation to reduce the chances for pregnancy loss or growth retardation, then reproductive genetic counseling shares its goals with that of general medicine and nursing (47). The goal in such cases is to promote healthy births. As strides are made in the area of primary prevention, this goal will apply more generally to reproductive genetic counseling without implying that clients ought to terminate affected fetuses in order to meet the goal. However, since there are likely to remain conditions that will not be preventable, extreme care will need to be taken to not to eliminate goals aimed at promoting client psychological well-being.

### Pediatric/adult genetic counseling

In the majority of cases/situations that present to a pediatric or adult genetics clinic, few immediate decisions face the client. Typically, a family member is already affected with a condition and the clients are seeking to understand the diagnosis, prognosis, and recurrence risks. Genetic counseling thus focuses on understanding, accepting, and adapting to a genetic diagnosis or risk (uncertainty), and their impact on the individual and family. Taylor identified three central components to adjusting to health-threatening information or events: 1) a search for understanding (including search for a cause); 2) a search for mastery; and 3) the restoration of self-esteem (40). Clients often adapt successfully without the help of health care providers, but seek assistance if it is offered. Pediatric/adult genetic counseling offers clients help with understanding the scientific cause of the genetic condition and gaining feelings of mastery by discussing resources and presenting future options. In these ways genetic counseling can facilitate the process of client adaptation. Future reproductive decisions may also hinge on the information and its meaning for families so long-term decision-making is important in this setting, although less urgently so than in the prenatal setting. *The goal of pediatric/adult genetic counseling is to facilitate client understanding and acceptance, both aspects of adaptation.* It includes the following specific aims:

1. To discuss client understanding of cause as it relates to a scientific explanation and the client's interpretation.

2. To explore the role of client illusions (personal beliefs) and their role in adaptation.
3. To promote feelings of personal control and mastery over a genetic condition.

### Genetic counseling for common disease

The relatively new entry of genetic counseling into oncology, neurology, cardiology, and psychiatry (as examples) presents an additional goal. In these settings, genetic counseling addresses risk for more common diseases (cancer, Alzheimer's, Parkinson's, schizophrenia, coronary artery disease, etc.) and increasingly includes offers of predictive genetic testing. *The goal of genetic counseling for common disease resembles that of other health education programs: understanding personalized disease risk and enhancement of health-promoting behaviors.* This goal harkens back to a public health aim of disease prevention. Promoting decision-making about the use of genetic testing and discussions of reproductive options and risks to children may also play a role in genetic counseling for common disease; however, the primary goal is health promotion. Specific behavioral recommendations may be made and encouraged. Models for effective genetic counseling for common disease may benefit from lessons learned in behavioral medicine prior to the identification of specific genetic predisposition. The goal of genetic counseling for common disease includes the specific aims:

1. To promote health-enhancing behaviors.
2. To enhance accurate and useful risk perception.
3. To facilitate adaptation to genetic risk.
4. To prevent disease.

### Summary

In this time of emerging genetic technologies and new genetic tests, the goals of genetic counseling still require clarification. A new emphasis is being placed on prevention and health education in genetic counseling. However, this does not justify returning to the original proposed goal of reducing the incidence of genetic conditions. The new climate of genetic technologies and the concomitant public surge of interest in genetics and its application to health suggest that now is an opportune time for thoughtful consideration of genetic counseling goals.

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