

An Explication of the National Society of Genetic Counselors (NSGC) Code of Ethics

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This article reviews the work carried out by the NSGC ad hoc Committee on Ethical Codes and Principles between 1986 and 1991 and serves as a guide for interpreting the NSGC Code of Ethics. The NSGC Code of Ethics is written from the "ethic of care" perspective. It is based on the responsibilities that arise from the four primary relationships genetic counselors experience in their work: genetic counselors and themselves, their clients, their colleagues, and society. The values selected for each relationship and the resultant guidelines are explained. The Code of Ethics became effective January 1, 1992.

KEY WORDS: code of ethics; genetic counseling.

HISTORY OF THE CODE'S DEVELOPMENT

In 1985, just 6 years after its establishment, the NSGC addressed the need for a professional code of ethics. In response to this issue, the Board of Directors concluded that a better understanding of professional codes of ethics would be helpful. The following year, as President, Deborah

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Eunpu appointed an *ad hoc* Committee on Ethical Codes and Principles. The original members of this committee were Judith Benkendorf, Chairperson, Nancy Callanan (who served as chairperson from 10/88 to 10/89), Rose Grobstein, Seymour Kessler, and Susan Schmerler.

The committee began by reviewing 12 selected codes of ethics representing various health professions. Common themes among these codes as well as variations in their styles and format were noted. A report of this work was subsequently published in *Perspectives in Genetic Counseling* (Fall 1989, Vol. 11, No. 3, pp. 1, 4).

The committee defined a code of ethics as a statement of beliefs and guidelines for professional behavior which reflects the responsibilities, obligations, and goals of a professional group's membership. A natural outgrowth of the maturation of a profession is to establish and adopt a code of ethics. This development promotes the professional identity of the membership and the public recognition of this identity. By adopting a code of ethics, a professional organization demonstrates to society that it accepts responsibility for defining professional conduct, for sensitizing its members to important ethical issues, and for affirming professional accountability.

After completing the study of codes of ethics, the committee recommended to the Board of Directors that the NSGC develop a professional code of ethics. This recommendation was enthusiastically endorsed. In October 1989, the committee reconvened in Baltimore, Maryland for the next phase of the project. At this time, Kevin FitzGerald joined the committee in the role of ethics consultant. Early the following year, Seymour Kessler resigned from the committee due to other professional responsibilities.

The committee's creative work began when the goals for the final document were considered. The Code would be short enough to be referred to quickly, and formatted so that it would be easily comprehended and utilized. Next, those ethical principles and values which were central to the work of genetic counselors were delineated. It became apparent that genetic counselors view themselves in the context of relationships. These were identified as relationships with self, clients, colleagues, and society. With this focus on relationships, over the span of several months, an ethic of care was explored by each committee member as a potential starting point for drafting the Code.

On March 24-25, 1990, the committee convened in Atlantic City, New Jersey, in conjunction with the NSGC Region II and MARHGN Education Conference. During those 24 hours, each of the four relationships and the important values and guidelines were discussed. The committee endeavored to ensure that each guideline could be justified and applied to a broad spectrum of situations and settings. A rough outline was organized into

five sections and each committee member then selected a section to draft in greater detail during the next month.

A rough draft of the Code was written via two extensive conference calls. The rough draft was then reviewed by several bioethicists and subsequently submitted to the Board of Directors. The Board discussed the draft at length during their July 1990 meeting in Detroit, Michigan. In order to invite membership comments and reactions, considered crucial by the committee, brief committee reports were published in *Perspectives in Genetic Counseling* (Vol. 11, No. 4 through Vol. 13, No. 2). In August 1990, a copy of this draft of the Code of Ethics was mailed to NSGC members in preparation for an open forum to be held in conjunction with the 1990 Annual Education Conference in Cincinnati, Ohio. At this meeting, each section of the Code was separately presented by a committee member and discussed by the audience. Additional written feedback was accepted by the committee for several months following the conference. The Code then underwent a final revision which incorporated members' suggestions. The NSGC's legal counsel also reviewed the final draft.

The Code of Ethics has now been completed. It was presented to the Board of Directors at their mid-year meeting in July 1991, where it received unanimous approval. After membership approval, formal adoption of the Code occurred January 1, 1992. What follows in this article is a further explication of the Code and the choices made in its construction.

PREAMBLE

The Preamble presents a reader of the Code of Ethics with a context for interpreting the Code and its goals. It briefly states who genetic counselors are and what the NSGC is. The primary effects the Code will have on the NSGC and its members are also described.

INTRODUCTION

The Introduction states the goals and structure of this Code. Crucial to the Code is a statement of the values, principles, and beliefs upon which it rests. An "ethic of care" perspective was chosen as the best approach for grounding these values, principles, and beliefs. This approach resulted in basing the Code on the responsibilities that arise from the primary relationships genetic counselors experience in their work.

There are certain elements of the care approach which tend to set it apart from the historically predominant ethical perspectives in Western culture. The care ethic emphasizes the interdependence of individuals. Hence, decisions and actions are seen as primarily responsive, that is, responsive

to one's relationships. This perspective contrasts with the more common ethical emphasis of actions and decisions arising primarily from within the self-governing individual.

In an ethic of care, "self" is defined differently. Rather than emphasizing what sets one off from others in defining "self," the care ethic emphasizes how "self" is defined according to its connections to others. This ethic acknowledges subjective involvement in moral decision-making. A person should rely on his or her relationships in making a moral decision, because those relationships most define that person. This reliance is appropriate for both the genetic counselor and the client.

The care ethic finds its roots in the experiences and values expressed in the research and the literature concerning the moral perspective and development of women. Additionally, certain cultures, including many minority groups within our nation which emphasize family and community more than individuality, hold similar values. These roots, however, do not limit the applicability of this ethical stance any more than the roots of historically male-dominated Western culture limit applications of current predominant ethical theories. Prudence and care must be exercised in using any ethical perspective to guide and assess conduct.

Recognizing the need for such prudence and care, the authors of this Code acknowledge that it cannot provide for all contingencies. Therefore, using the accumulated experience of the members of the NSGC, specific situations were selected as requiring guidelines for resolving conflicts, especially among the possibly conflicting demands of a genetic counselor's various relationships. Other situations receive only general guidelines, so that genetic counselors may draw more extensively upon the resources of their own relationships to find the most appropriate responses.

SECTION I: GENETIC COUNSELORS THEMSELVES

Section I deals with the genetic counselor's relationship with self. In writing this section the values of competence, integrity, dignity, and self-respect were selected as basic professional attributes of genetic counselors. Professional competence requires the seeking out and acquiring of all relevant information in order to pursue any given professional task (item 1), as well as maintaining the highest possible standard of practice. In order to do this, items 2 and 3 suggest that genetic counselors strive to keep abreast of current trends and standards of practice, and continue their own education and training both formally and informally. They must also recognize the limits of their competence in any given situation (item 4).

Genetic counselors value themselves as individuals. Because of the demanding nature of their work, genetic counselors need to be dedicated

to maintaining their own physical and emotional health, especially as it affects professional performance (item 5). The professional activities of genetic counselors require a high level of sensitivity and awareness in numerous interpersonal relationships. Furthermore, they are often challenged on a personal level by the life-cycle issues their clients are facing. Genetic counselors who are self-aware and concerned about their own self-care will be the best possible resource to themselves, their colleagues, their clients, and society.

SECTION II: GENETIC COUNSELORS AND THEIR CLIENTS

The first decision made in developing Section II was in choosing a neutral term for the genetic counseling consumer, or help-seeker. The committee considered both "counselee" and "consultand," but thought "counselee" may not be correct for all our members, and "consultand" was too impersonal, removing the consumer from the interpersonal relationship of genetic counseling. A survey of codes of ethics revealed the two most frequently used terms were "client" and "patient." "Client" is used by social workers, family counselors, psychologists, and nurses in their codes. "Patient" is used by psychiatrists, physicians, physician assistants, and dental hygienists. Historically, the word "patient" has implied vulnerability and dependence. "Client" on the other hand, carries the image of an empowered consumer. The philosophical point of view of genetic counselors being closer to that of the first group, the committee chose to use "client."

The values relating to clients are based on caring and respect for individuality (uniqueness), welfare (best interests), and freedom (autonomy). These values influence the way genetic counselors deal with clients. Genetic counselors are encouraged to provide the best qualitative and quantitative care, protection, and services to clients. They should treat them faithfully and with empathy and consideration.

Items 1 and 2 of Section II emphasize the value of acceptance. A counselor should not allow external interests or biases to unduly influence the counseling session or lead to refusal of service. Clients come from a variety of cultural backgrounds and need to be understood within such diverse contexts. Originally, the committee thought "equally serve" would be clearer if written as "serve equally." It was realized, however, that clients' needs and circumstances differ and they all could not be served equally. The value of objectivity enjoins us from counseling friends.

The value of respect for clients' autonomy supports item 3. Counselors are expected to respect clients' rights to self-determination and human dignity. Clients must be allowed to make their own choices to the maximum extent that the situation allows. It is incumbent upon the genetic counselor

to enable clients to make their own decisions and act for themselves by providing or illuminating the facts and clarifying available alternatives and anticipated consequences.

The values of honesty and candor dictate that genetic counselors should acknowledge their own competence, education, experience, and limits, leading to item 4. Genetic counselors have their own ethical and moral systems, and these may at times come in conflict with those of a particular client. Genetic counselors need to be able to sever the relationship with a client if, by not doing so, the values underlying the Code would be violated. In addition, the counselor is obliged to refer the client to someone who can provide appropriate services.

The value of confidentiality (item 5) is virtually universal. In fact, often in state law the client owns the privilege of confidentiality. The committee considered the possibility that the sharing of an identified client's information may be justified on the basis of the counselor's judgment in a special situation, but rejected the idea because the various scenarios within which this could be possible are endless, making confidentiality meaningless. Discussing the specifics of a case with colleagues in order to educate them or gain insight for the benefit of a client, without identifying the client, is not to be considered a breach of confidentiality.

The term "exploitation" in item 6 encompasses mischarging or overcharging clients, providing unnecessary services, and using client funds, facilities, or ideas without permission. Genetic counselors should work completely and honestly for the best interest of the client, with appropriate, efficient, and prompt services. These values also enjoin counselors from experimenting with clients at their expense or deprivation, without informed consent. One should not profit personally from the information learned during a session. Under this item, delegation of responsibilities to substitutes (other than students or supervised employees) for providing services is considered unacceptable.

While the committee recognized that some codes specify guidelines for practitioners who are in private practice regarding charges, advertising, and recruitment, the NSGC Code is not intended to serve a disciplinary function, and therefore does not address these matters.

SECTION III: GENETIC COUNSELORS AND THEIR COLLEAGUES

Genetic counselors have professional relationships with other genetic counselors both within and outside of their own institutions. They also have relationships with other genetics and non-genetics health care professionals as well as students in genetic counseling and other fields in whose training or education they participate. Genetic counselors' relationships with all of

these colleagues are based on care, concern, mutual respect, support, cooperation, and a shared loyalty to the goals of the health professions. There are four items in the Code of Ethics that deal with these relationships.

Item 1 deals specifically with the genetic counselor's relationships with other genetic counselors and with genetic counseling students, making the use of "peer" appropriate. "Support" implies not only care and concern but also cooperation, encouragement, advocacy, validation, and assistance. Peer support can take many forms including two counselors discussing a complicated case, sharing one's expertise and knowledge by presentation at state, regional, or national meetings, and publication in the genetics literature.

With the formation of the National Society of Genetic Counselors in 1979, the first formal mechanisms for peer support were established. The NSGC newsletter, *Perspectives in Genetic Counseling*, and the Annual Education Conference provide avenues for communication on a national level with other genetic counselors and genetic counseling students. Through peer support, genetic counselors can personally influence the development of their profession by striving together to maintain and improve both the quality of genetic services and the professional development of genetic counselors.

Item 2 recognizes the responsibility of genetic counselors not only to adhere to the values and guidelines set forth in the Code, but to encourage ethical behavior in their colleagues. This guideline was not meant to suggest a spirit of "policing" within the NSGC, but rather to affirm the positive obligation of genetic counselors to assure that they and their colleagues perform their professional duties in an ethical manner. Genetic counselors must strive to prevent unethical behavior. The first step in prevention is awareness. Genetic counselors must be aware of and concerned about issues and situations that may pose ethical dilemmas for themselves and for their colleagues. Ongoing education and discussion is essential for maintaining a high level of awareness about ethical issues.

Genetic counselors are also encouraged to foster change in unethical behavior in their colleagues. This can be accomplished, perhaps, through a willingness to address openly any concerns about what is perceived to be unethical behavior. A genetic counselor may also seek consultation with the NSGC Ethics Subcommittee regarding situations that cannot be resolved on a personal level or within an individual counselor's local institution.

Item 3 addresses the genetic counselor's relationships with other health professionals and emphasizes the value of mutual respect upon which these relationships are based. Genetic counselors are encouraged to become knowledgeable about the professional expertise of their various colleagues. This guideline implies a responsibility to educate our colleagues

about the professional orientation of genetic counselors. This mutual respect should serve to enable professionals to develop strategies for cooperation which assure that their clients receive the highest quality of service.

The final item in this section recognizes the potential for conflicts among various members of a health care team. It emphasizes the value of cooperation and the dedication of all members of the team to providing the best possible service to clients. Genetic counselors are encouraged to resolve any differences among team members in a manner that does not compromise the quality of service provided to clients. It is implied that genetic counselors must resolve differences with colleagues without compromising their personal or professional ethical standards as delineated in other sections of the Code.

SECTION IV: GENETIC COUNSELORS AND SOCIETY

An ethic of care is most easily understood as it is applied to one's self, one's clients, and one's colleagues. How, then, is it to be understood as it is extended to include society?

The orientation of genetic counselors embraces a special body of knowledge that integrates genetic information and an understanding of human behavior. Genetic counselors also combine special skills that are used to impart scientific information to all clients, and a knowledge of behavior that is used to assist clients in making decisions in one of the most important areas of their lives: reproduction.

Society at large impinges on individuals' decisions in this area through laws, regulations, and institutional structures that influence these decisions. In attempting to ensure that clients are able to make decisions that are the best for them, genetic counselors have the responsibility to help provide a societal environment that is conducive to the freedom of choices. This is achieved (item 1) by being aware of the developments in society, current literature, research, and laws that may affect clients' health.

As they become aware of developments that limit choices in professional practice and that impinge on the choices of clients, genetic counselors should participate in activities that will bring about responsible social education and change (item 2). Genetic counselors should respond and participate in accordance with their individual values and the values of the profession.

Many policymakers and public officials do not have the knowledge and expertise of genetic counselors. Some decisions are made with inadequate awareness of the impact on individuals and society. Genetic counselors, therefore, should make themselves available as a source of reliable

information and opinions in order to try to minimize possible errors (item 3). It is certainly easier to avoid problems than to remedy them.

Knowledge in genetics is advancing rapidly. The public is not always aware of the impact that this knowledge may have on their lives. Item 4 recognizes that it is the responsibility of genetic counselors to try to keep the public aware so that they can make informed decisions, both for themselves and for society at large.

It is important to restate (item 5) the principle of non-discrimination. Non-discrimination may be practiced individually. Nonetheless, many forms of unjust discrimination exist in our society. This influences decision-making, and to say the least does not contribute to the betterment of society. As individuals, and as professionals, genetic counselors should maintain an acute awareness of discriminatory practices, with the goal of minimizing such practices in our society.

As citizens and as professionals, genetic counselors uphold and abide by the laws of our country. However, when laws are passed that are based on inadequate information, or in which little thought has been given to the impact on individuals, professions, or society as a whole, efforts should be directed toward changing these laws (item 6).

Genetic counselors will interpret and express these values in their unique ways. Their choices will be made in conformance with their own values and with the values of their profession. It is hoped that the decisions reached will be with the same thought and considerations given to clients. Society deserves the same considerations given to ourselves, our clients, and our colleagues.