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Defining and Redefining the Scope and Goals of Genetic Counseling

ROBERT G. RESTA*

Many definitions of genetic counseling have been proposed since Sheldon Reed first defined the term in 1947. This study reviews selected definitions of genetic counseling including the most recent definition proposed by a committee of the National Society of Genetic Counselors. The analysis focuses on the professional background of who was formulating the definition; the reasons why the definition was created; medical, historical, and social factors; and the definer's implicit or explicit goals of genetic counseling. No definition of genetic counseling is ideal, and any definition can only reflect the values, ethics, goals, and medical practices of the person or group defining the practice of genetic counseling. © 2006 Wiley-Liss, Inc.

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INTRODUCTION

Sheldon Reed coined the term “genetic counseling” in 1947 [Reed, 1974]. Since then, genetic counseling and its goals have been defined in many ways. In this article, I will examine several key definitions of genetic counseling that have been proposed since 1947 and examine how they have been influenced by social, ethical, historical, medical, and professional factors.

The Original Definition—Genetic Counseling as Social Work

Sheldon Reed, a non-physician with a doctorate in genetics, coined the term “genetic counseling” in 1947 [Reed, 1974; Resta, 1997]. Reed was the long time director of the Dight Institute of Human Genetics in Minnesota, a hereditary disease clinic established in 1941 with funds from Charles Dight, a physician/philanthropist with an interest in eugenics [Reed, 1974].

Reed was uncomfortable with the terms “genetic consultation” and “genetic advice” that had previously been used. Thus, in a report to the Dight Institute Advisory Committee, Reed suggested replacing these older terms with

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“genetic counseling,” which Reed saw as “a kind of genetic social work.” For Reed “The primary function of genetic counseling is to provide people with an understanding of the genetic problems in their family.” [Reed, 1955, p 12; Reed, 1974]. This definition and goal

are largely non-medical as they do not address curing, preventing or treating disease, and Reed strongly felt that genetic counseling was not strictly the domain of physicians. Reed recognized that most general genetic counseling would be performed by community physicians who in turn relied on the help of geneticists at specialty heredity clinics [Reed, 1955]. For Reed, a genetic counselor was a health care professional with either a doctorate or a medical degree with a specialty in genetics, and who acted in the role of an advisor to the larger medical community as well as seeing patients with more complex genetic problems.

It is not surprising that Reed viewed genetic counseling as a form of social work, rather than as a primarily medical encounter. Laboratory testing for genetic disease was extremely limited in the 1940s and 1950s. It would be another decade before the number of human chromosomes was correctly identified and the chromosomal basis of Down syndrome established, dysmorphology and genetic syndromology were in embryonic stages, and the physiological basis of common inborn errors of metabolism such as PKU had yet to be worked out. The most common indication for patients to be seen at the Dight Clinic was to determine a child's racial appearance for purposes of

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adoption [Reed, 1955]. The records of the Dight Institute are recorded in 23 spiral notebooks that contain a chronological archive of inquiries made to the Dight Institute from 1948 to 1976. Five of the first eight inquiries recorded in the first two pages of the first volume in 1948 were concerned with a child's skin color vis-à-vis adoption. Following is a typical example from the Dight records: "Letter from Miss [], [] Bureau of Child Welfare, regarding adoption of [a boy], a 'near white' by a white mother. Usual question as to whether his children could show prominent Negroid characteristics" [Dight Institute Inquiries, August 30, 1948]. The use of the word "usual" implies that the Dight staff was familiar with such requests.

Other common questions and concerns of physicians and patients who contacted the Dight Clinic were whether potential mates were wise choices either due to family history or consanguinity, as well as questions about recurrence risks for various conditions, and whether those recurrence risks were high enough to warrant a (voluntary) sterilization [Dight Institute Inquiries, 1948–1949], as illustrated by this inquiry: "Phone call and letter from Mrs. [] regarding the possible marriage of [] and [], who are related slightly more closely than second cousins at least genetically. As they are 21 and 20 years old, respectively, recommended that they not marry." [Dight Institute Inquiries, Nov. 15, 1948]. Again, these inquiries are more of a social rather than medical nature. Treatment and diagnosis of genetic disease are not key elements of Reed's definition and goals, which is not surprising given the limited treatment

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and diagnostic testing options available in the 1950s.

Eugenics, Disease Prevention, Public Health

Despite attempts to divorce genetic counseling from eugenics after World War II, it was sometimes difficult to tell where eugenics ended and genetic counseling began [Resta, 1998]. For example, C. Nash Herndon, an early president of the American Society of Human Genetics, wrote in the 1950s: "The counselor must not only be concerned with the specific problem in inheritance raised by a given family but must also attempt to make some assay of the total genetic endowment of the persons in question. . . most people would agree that it would be advantageous for reproduction to cease in a family producing successive crops of idiots and imbeciles. . . Generally, . . . advice concerning heredity that is sound and advantageous for the individual family will also be found to be sound and advantageous for society as a whole" [Herndon, 1955, p. 89].

Not uncommonly, genetic counseling was couched in terms of public health, presumably to avoid the stigma of eugenics (see, e.g., the final chapter of [McKusick, 1964]). Robert F. Murray Jr, a pediatric geneticist at Howard University, citing data from a study by Cedric Carter on the effects of genetic counseling, wrote "These data are evidence that genetic counseling tends to have the desired effect; that is, to influence high risk families not to have further children. . . It is probably a long way off, but. . . the day may come when the effect of genetic counseling may well be felt in a significant way in the general population." [Murray, 1968, p. 149].

Directive genetic counseling with public health goals has been regarded as antithetical to genetic counseling that emphasizes the medical and psychological impact on the individual, where non-directiveness is a key value [Fine, 1993; National Society of Genetic Counselors, 2005]. However, eugenic-sounding public health concerns of the 1960s clearly co-existed with a concern for the psychological impact of genetic counseling, contradicting the notion that

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example, Murray, supporting a public health view of genetic counseling, stated: "It is possible to give the risk figures in more than one way so that parents can be influenced in their decisions to have more children" [Murray, 1968, p. 147] in order to minimize the impact of genetic disease on public health. Yet on the next page of the same article Murray also displayed a genuine concern for the emotional impact of genetic counseling: "The physician who counsels must keep in mind the total psychological constellation of the family. . ." [Murray, 1968, p. 148]. Directiveness was not, in the minds of some geneticists, at odds with a concern about the psychological impact of genetic disease. Interestingly, disease prevention is implicit in some of the current goals of genetic counseling such as cancer prevention, albeit not through reproductive control [Koch and Nordahl Svendsen, 2005].

Psychologically Focused Definitions and the Establishment of a Genetic Counseling Professional

Emphasis on the psychological and emotional aspects of genetic disease and counseling is usually regarded as a more modern component of genetic counseling. However, the importance of psychosocial aspects of genetic counseling

Emphasis on the psychological and emotional aspects of genetic disease and counseling is usually regarded as a more modern component of genetic counseling. However, the importance of psychosocial aspects of genetic counseling has been recognized since the early years of genetic counseling.

has been recognized since the early years of genetic counseling. Reed was not alone when he raised concerns that genetic disease could evoke feelings of guilt and shame [Reed, 1955]. For example, in 1959 the medical geneticist J. A. Fraser Roberts acknowledged this when he wrote: "Giving genetic advice involves much more than the assessment of risks and the quotings [sic] of chance. Much can often be done to dispel feelings of guilt. . . Patients can be helped to rationalize their problems, to live with the hard lot that may be theirs or realistically face a measure of risk" [Fraser Roberts, 1959, p. 248].

In the early 1960s, Robert Tips, a pediatric geneticist, was one of the earliest geneticists to attempt to integrate counseling theory into genetic counseling: "Genetic counseling consists of clinical procedures whereby the patient with genetic disease is evaluated in terms

of his relationships and management in the scope of his family environment. The opportunity for such family units to participate in a therapeutic program, which creates an atmosphere conducive to the exploration of over-all family problems, distinguishes this from the traditional, stereotyped, mathematical probability approach." [Tips et al., 1962, p. 239]. Tips explicitly described psychological issues that arose during genetic counseling: "The manner of family history inquiry and sociologic and psychologic interviews requires structuring so that parents have the opportunity to divulge emotional stresses permeating the family milieu through a catharsis which circumvents such defense mechanisms as projection, rationalization, self-condemnation, repressions, and feelings of misdirected guilt and hostility. These processes arise out of misconception about reproduction and the genetic nature of disease and require expression in order to attain an atmosphere conducive to resolution" [Tips et al., 1964, p. 113]. Tips view of genetic counseling extended beyond the counseling skills possessed by most physicians, and he saw the need for specialized training to assess the psychological impact of genetic counseling.

Tips was not alone in calling for a psychological component to genetic counseling. For example, Robert Bringle, an educational psychologist, and Raymond Antley, a medical geneticist, felt that the personal and family milieus, rather than society, were the focus of genetic counseling: "Genetic counseling is. . . defined as enabling the counselee to comprehend the medical facts of genetic disorders, hereditary risks, and alternatives, as well as to make a healthy adjustment to a family member's disorder and risk of recurrence. The process of learning is broken down into a hierarchical relationship between acquisition, understanding, and personalization of facts and applied to the genetic counseling situation." [Bringle and Antley, 1980, p. 304].

However, in most cases, authors who noted the importance of psychological issues in genetic counseling

provided few specifics about how psychological counseling could be incorporated into genetic counseling [Fraser, 1974]. Indeed, to this day, few, if any, fellowships in medical genetic offer extensive training in counseling techniques and philosophies.

Genetic counseling as a primarily psychological interaction was spurred by the introduction of the professional genetic counselor, that is, a non-physician with graduate level training in both genetics and counseling. The first such program in the United States was established at Sarah Lawrence College in 1969 where the counseling model relied heavily on the humanistic client-centered philosophy of the psychologist Carl Rogers (who was not directly involved with genetic counseling). While most genetic counseling programs vary in the amount of psychological training they provide, all emphasize the key role of psychological influences on the genetic counseling process. The focus on psychological issues is what genetic counselors regard as the key issue that separates them, professionally and clinically, from other health professionals who provide genetic counseling. The psychosocial underpinnings of genetic counseling practice are laid out in the works of two therapists, Seymour Kessler and Jon Weil [Resta, 2000; Weil, 2000].

In a definition proposed by two master's level genetic counselors, genetic counseling was viewed as a primarily psychological, rather than medical, encounter: "Genetic counseling is a dynamic *psychoeducational* (emphasis in the original) 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 [Biesecker and Peters, 2001]. Very few physicians would feel comfortable delivering a service defined in this way.

Limiting the Practice of Genetic Counseling

At the same time that the genetic counseling profession was trying to establish itself in the early 1970s, some physician geneticists sought to limit the practice of genetic counseling to physicians. The definitions of genetic counseling in these situations tended to focus more on medical and statistical, rather than psychological, matters [Sly, 1971].

A leading figure in the debate about which health professionals should conduct genetic counseling, the well-respected medical geneticist Charles Epstein, wrote a controversial article that specifically tried to limit the practice of genetic counseling to physicians. Epstein felt that although there was room for master's level counselors, in his view the primary providers of genetic counseling should be physicians, and this is reflected in his definition: "Genetic counseling is the process of providing information about the risk of occurrence and recurrence of genetic disease and, when appropriate, of taking steps to modify those risks" [Epstein, 1973, p. 40]. Epstein viewed genetic counseling as primarily a medical process of establishing a diagnosis or risk, and then offering options to modify the risks. Psychological issues were ancillary to the counseling process, and could be handled by various non-physician specialists, but he felt that a physician geneticist should perform the genetic counseling.

Epstein considered social workers, doctorate level geneticists, and genetic associates (as genetic counselors were sometimes referred to then) to be valuable team members, "Nevertheless, their ultimate value in counseling and ability to function depends on the presence of the responsibility-taking medical geneticist-physician-counselor, and for this reason I do not regard these individuals as 'genetic counselors.' To me, the term 'genetic counselor' connotes one who is capable of giving genetic counseling, with all that it entails. It is my contention, and I am prepared to be proven wrong, that except in the rarest of instances, non-medically trained individuals are not so

prepared" [Epstein, 1973, p. 43]. In fact, over time, Epstein became a strong supporter of the genetic counseling program at Berkeley and of genetic counselors in general.

Responding to Changes in Technology and Society

Significant advances occurred in medical genetics during the 1960s and early 1970s, such as the introduction of amniocentesis and improved cell culturing, newborn screening for genetic diseases, banded karyotypes that allowed better identification of chromosomal disorders, and biochemical assays to identify inborn errors of metabolism. Social trends included greater emphasis on reproductive autonomy, the legalization of abortion and birth control, an increased role for patients in managing their medical care, and less importance on determining racial admixture for adoption [Fraser, 1974].

In the early 1970s, the National Genetics Foundation, Inc., along with funding from the National Institute of General Medical Sciences, sponsored a workshop in response to the greater demand for genetic counseling and medical genetics services. The participants included 22 geneticists, including members of the Committee on Genetic Counseling of the American Society of Human Genetics (ASHG), the leading American professional genetics organization at that time. The committee was given the responsibility to "evaluate and make recommendations about the status of genetic counseling, its goals, natures, achievements, and needs" [Fraser, 1974, p 637].

The committee first agreed upon a definition of genetic counseling: "Genetic counseling is a communication process which deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. The process involves an attempt by one or more appropriately trained persons to help the individual or family to: (1) comprehend the medical facts including 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 the risk of recurrence of that disorder" [American Society of Human Genetics Ad Hoc Committee on Genetic Counseling, 1975].

Like Sheldon Reed suggested 25 years earlier, the workshop members felt that the family doctor was the most appropriate health care professional to do the counseling, since the family physician was more familiar with the family's medical and social background. However, the workshop group further recognized that genetics was becoming so sophisticated that most community physicians had neither the expertise nor time that was required for genetic evaluation and counseling. Hence they suggested that there was a need for a medical geneticist who worked in cooperation with other medical specialists [Fraser, 1974]. The workshop group felt that within the genetics clinic, the physician geneticist was the primary provider of genetic counseling, and other health professionals served an auxiliary role "in interviewing, searching files and literature sources, collating information, and following up families" [Fraser, 1974, p. 652]. This view of who should provide genetic counseling is consistent with the above-noted view of Charles Epstein, who was also a member of this workshop group.

The committee also acknowledged that psychological aspects of genetic counseling could be more important than medical issues: "Exploring these feelings [of guilt, shame, etc.] may be far more important than providing a statistical estimate of the risk...but in practice this aspect of counseling tends to be neglected" [Fraser, 1974]. For master's level genetic counselors, the definition justified the profession's emphasis on the psychological component

of genetic counseling, a component that had previously been inadequately addressed.

The definition proposed by the committee was debated at AHSG annual meeting in 1973 and the ASHG membership was later polled about the definition, which was eventually published in the American Journal of Human Genetics, ASHG official publication. To this day, it is still widely referred to as “The ASHG Definition.”

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The ASHG definition was the most all-encompassing, formal definition of genetic counseling for its time, and helped establish the acceptance of medical genetics and genetic counseling by the larger health care community. The definition served to guide several generations of physician and non-physician genetic counselors, presumably because it captured in whole or in part the essence of what they strived for in providing medical genetic services regardless of their training.

The Newest Definition

In 2003, the National Society of Genetic Counselors (NSGC) formed a committee, co-chaired by the author, that

was charged with surveying definitions of genetic counseling and, if the definitions were found wanting, to

In 2003, the National Society of Genetic Counselors (NSGC) formed a committee, co-chaired by the author, that was charged with surveying definitions of genetic counseling and, if the definitions were found wanting, to create a new one.

create a new one. Several factors led the NSGC to investigate the need for a new definition of genetic counseling. First, the ASHG definition was wordy, complex, and did not fully reflect changes in medical care and genetics that have transpired over the last 30 years. A second factor was a desire on the part of master’s level genetic counselors to increase their visibility among health professionals and the public by establishing themselves as experts in this arena. Third, advances in genomic medicine has led to genetic counselors expanding their roles to newer settings such as counseling for common diseases like cancer, helping formulate health care policy for governments and health care organizations, and working in laboratories. A definition that identified elements common to all settings was viewed as a way of keeping the field from breaking into sub-specialties that shared almost no common unifying principles.

The process of creating this definition has been outlined elsewhere [Genetic Counseling Definition Task Force, 2006]. In brief, the committee spent several months formulating a definition that was felt to reflect the current practice and scope of genetic counseling. The definition was then reviewed on multiple occasions by an Advisory Committee, the NSGC Board

of Directors, the NSGC membership, various respected authorities on genetic counseling, and professional and lay organizations with an interest in genetic counseling. At each stage, comments were critically reviewed, and changes were incorporated.

The committee felt that advances in predictive testing, treatment, and prevention of genetic diseases such as hereditary breast and ovarian cancer

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necessitated a definition that reflected more than just reproductive issues, one of the traditional realms of genetic counseling (even pediatric genetic counseling often involved discussion of recurrence risks for families). This caused some of the committee members to re-think the role of non-directiveness, which, as noted above, is a fundamental ethical concept of genetic counseling. The committee of course does not support coercion of patients to make decisions about testing or reproduction. However, non-directiveness appeared to be at odds with the prevention of cancer, one of the goals of genetic counseling for hereditary cancer syndromes [Weil, 2000; Koch and Nordahl Svendsen, 2005], and was viewed as an ineffective

counseling technique. Thus some members of the committee took the controversial view that non-directiveness is not a global value of all aspects of genetic counseling and was not specifically included or excluded in the definition [Weil, 2003].

The definition authored by the committee, and approved by the NSGC Board of Directors in 2005, is as follows:

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence,
- Education about inheritance, testing, management, prevention, resources, and research,
- Counseling to promote informed choices and adaptation to the risk or condition.

The definition can be simplified by using only the first sentence. The entire definition can be used in more formal situations such as textbooks or training programs, or as a basis for research on genetic counseling such as assessing to what degree the components of risk assessment, education, and counseling are incorporated into genetic counseling, as well as serving as the basis of outcome measures of the success of genetic counseling and the usefulness of the definition itself.

International Definitions

The definitions described above were primarily from the United States and Canada, and primarily reflect ethical, social and medical traditions in those countries. Of course, genetic counseling is practiced in other countries. Definitions of genetic counseling in the UK and Australia are largely similar to the American and Canadian definitions. However, this is not necessarily the case in the non-English speak-

ing world, where genetic counseling may reflect non-Western values and traditions in medical practice, as well as the availability of medical services in general.

In 1995, the International Bioethics Committee of UNESCO published a report on the bioethical implications of genetic counseling. The report contains six definitions of genetic counseling from countries in four continents (Africa, Europe, North America, South America) [Revel, 1995]. These definitions were provided by an expert from each country and do not necessarily reflect consensus opinions within those countries. However, because they illustrate the wide range of definitions and scope of genetic counseling around the world, it is helpful to cite the non-US definitions directly [Revel, 1995, p. 11] (I have omitted the US definition since I have previously cited many US definitions):

United Kingdom: "Counselling entails precision of diagnosis, the estimation of risks, and a supportive role to ensure that those who are given information are able to benefit from it and from the interventions that are available."

Italy: "The objective, methods and indications of genetic consultation are (1) Objective: to provide information to patients (and/or blood relations of a patient) at risk of contracting a disease that may be hereditary on: consequence of pathology in question, probability of contracting and transmitting it, possibility of keeping it in check and treating it; (2) Methods: construction and analysis of pedigree, calculation of the risk of recurrence (mendelian or empirical), estimation of the consanguinity coefficient, more specific analysis. (3) When is counselling indicated: known or presumed illness in patient or family, congenital malformation, mental retardation, consanguinity, recurrent miscarriages, infertility."

Chile: "A medical process of communication between a physician and a consultant (counselee) where scientific knowledge, data and facts are exchanged in order to provide a framework to understand the genetic problem of the patient and the family."

Argentina: "Better called 'genetic advising'—a useful tool in preventive medicine."

Zaire: "Information on eventual pathology, not therapeutic but predictive."

In the near future, more countries will presumably incorporate more Western style medical care as they start to resolve basic health issues of reducing childhood morbidity, mortality, and hunger. Since genetic tests will likely play an increasing role in medical care, the practice of genetic counseling will continue to expand around the world and adapt to local medical, historical, ethical, and sociocultural influences.

DISCUSSION

Over the last 60 years, genetic counseling has been defined as a form of social work, a tool of eugenics, a type of public health intervention, a means of individual or familial disease prevention, and a specialized process of counseling and education. It is impossible to create a platonic definition of genetic counseling that fits all cultures, historical periods, or medical settings. Definitions, of necessity, are shaped by the medical, social, professional, technological, and ethical milieus in which they were developed, along with the biases and goals of the person or group defining the practice. Studies of the process or effectiveness of genetic counseling needs to take these

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factors into consideration. What counts as success in Argentina may not count as success in the United Kingdom. What counted as success in the United States in 1967 may be considered inappropriate counseling in 2006. The content and course of a genetic counseling session conducted by a medical oncologist might be very different than the same session conducted by a genetic counselor.

Although it is tempting to impose a trajectory of increasing “modernness” over time, definitions of genetic counseling do not follow a clear, uninterrupted historical progression. Some elements of genetic counseling thought to be progressive, such as non-directiveness or focusing on psychosocial issues, were raised 40 years ago. Conversely, goals of genetic counseling thought to reflect the ethos of an earlier time, such as disease prevention, are implicit in recent models of genetic counseling. However, in contrast to earlier models, recent models do not support reproductive control as a means of disease prevention [Weil, 2000; Koch and Nordahl Svendsen, 2005].

Definitions of genetic counseling are, in a sense, idealized and reflect the components that the authors *think* should take place during genetic counseling. However, what genetic counseling *ought* to be may be quite different than what genetic counseling *is*. There is surprisingly little research on what transpires during genetic counseling sessions [Lehtinen, 2005]. This is a field ripe for research that has much to tell us about what genetic counseling actually is and could allow the development of a definition that reflects actual, rather than idealized, practice. But a definition can only reflect the practice of genetic counseling at any given moment in time.

Definitions should not limit the scope and practice of genetic counseling but instead should help ensure that clients receive appropriate medical care and counseling by outlining what type of care genetic counseling clients should receive.

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