INVITED EDITORIAL
Empirical Evidence That Genetic Counseling Is Directive: Where Do We Go from Here?

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There is widespread support among medical geneticists and genetic counselors for nondirectiveness and value neutrality in genetic counseling (Wertz and Fletcher 1988; Penchirinha et al. 1992). Such support arises from a concern about early abuses in the eugenics movement and a recognition of the right to privacy and autonomy in reproductive decisions. Recently, discussions have focused on the desirability and practicability of nondirective and value-neutral counseling, with a number of authors questioning whether it is ever possible to achieve (Clark 1991; Kessler 1992; Burke and Kolker 1994). Despite the ethos of nondirectiveness that has prevailed in genetic counseling, there have been few empiric studies of directiveness, and no method of measuring it has been suggested or tested.

In this issue of the Journal, Susan Michie and her colleagues have presented a methodology for quantifying directiveness in a clinical genetics setting (Michie et al. 1997). On the basis of an analysis of transcripts of 131 genetic-counseling visits, they rated directiveness as a measure of advice (counselor states what is best for the client), evaluation (counselor expresses views about an aspect of the client’s situation), and reinforcement (counselor selectively affirms or rejects client’s behavior, thoughts, or emotions). Directiveness was also rated by each client who faced a decision during the consultation and by each counselor as a reflection of her general counseling style but, unfortunately, not after each client visit. The clients were seen for “routine genetic consultations” by 1 of 11 counselors, 5 with a “medical background” and 6 with a “nursing background” (p. 41). The authors report that all consultations were characterized by directiveness, including a mean of 5.8 advice statements per consultation. The more concerned the counselor rated that client, and the lower the client’s socioeconomic status, the more directive the communication. Of the clients facing a decision, the majority thought the counselor had an opinion about the best decision for them. However, only a minority felt steered toward a particular decision. There were no significant associations between counselor-reported, client-reported, or rated directiveness. Likewise, there were no associations between any measure of directiveness and client satisfaction or meeting of client expectations. These findings, together with the large observed variation in rated directiveness within counselors across consultations, led the authors to conclude that directiveness “is not a fixed style but can be varied by counselor, according to circumstances” (p. 45).

What can we learn from this study? First, as stated by the authors, the practice of genetic counseling “is not characterized . . . as uniformly nondirective” (p. 40). At last, here are observational data to substantiate the long-held impression that nondirective genetic counseling is impossible to achieve. Second, it is clear that, while measuring directiveness from the consultation itself is extremely valuable, it is a daunting task. The difficulty lies in determining when and how the counseling becomes directive. In the narrowest sense, directiveness has traditionally been reflected by those statements that direct, or the “advice” statements in the Michie study. These statements might follow the dreaded question “What do you think I should do?” It is rather astonishing that there was, on average, in excess of five such statements per session in Michie’s study, particularly because most genetic counselors generally agree that such advice statements are to be avoided when counseling clients. In her rating system, Michie has chosen also to classify as directive those statements that could more subtly steer clients. Some statements might selectively reinforce the client’s choices or attitudes, and others might be intended to provide optimism or encouragement to a client or to her decisions (i.e., “there’s a very good chance that you will have another healthy baby” [Michie et al. 1997, p. 42]). It could be argued that at least one of the categories of
directive statements scored in the Michie study, those classified at reinforcement, are reflective of a good counseling style rather than directiveness. A statement such as "I understand, that’s really very sensible" is one that is no doubt uttered often by well-trained counselors who highly value client autonomy and their own role as a facilitator of well-informed decisions. Kessler (1992) has suggested that directive counseling that supports the client’s decision direction is often helpful but requires “greater flexibility rather than dogmatism in genetic counseling practices” (p. 12). The counselors in the Michie study appear to be following Kessler’s recommendations regarding flexibility in genetic counseling.

Directiveness in the Michie study is based on the coding of counselor statements during the entire genetic-counseling session. Aspects of the counseling session other than how things are said can also influence clients. Directiveness can also be a function of what information is included in a consultation and how the facts are framed. Genetic counselors always have the power to influence clients by choosing to discuss one aspect of a situation while ignoring or downplaying another. Genetic-counseling norms dictate that, in recognition of their power to influence, counselors should present all the information pertinent to a situation so that clients’ choices are truly well informed. As illustrated in a study by Brunger and Lippman (1995), such practice is rarely upheld. Through interviews with genetic counselors and genetic-counseling students, Brunger and Lippman have shown how a genetic-counseling session is context dependent. For example, the information on Down syndrome that is included in a pre-amniocentesis counseling session differs greatly from that in a session concerning a neonate with Down syndrome. In addition, the counselors report tailoring each counseling session to meet the client’s requests and values. When providing counseling after a fetal diagnosis of Down syndrome, the counselors report that they attempt early in the counseling session to clarify a woman’s intentions about continuing or terminating her pregnancy and then provide whatever information might be needed to help justify that decision. For a woman leaning toward terminating her pregnancy, counselors appear to rationalize their unbalanced presentation of facts by believing that discussion of positive aspects of Down syndrome could be considered directive and critical of the woman’s decision.

Influence on clients’ decisions can arise simply from the availability of testing or even be inferred because a referral is made for genetic counseling. Clarke (1991) has argued that the mere offering of prenatal genetic testing implies an invitation to accept testing. He further points out that those offering testing rarely are involved with the care of individuals affected by the disorders for which testing is offered. Thus, the counselor is disadvantaged by not having firsthand information about the disorder to share with the counseling client while at the same time sending out the subtle message that the work of providing care to affected individuals is somehow less worthy or valuable than the work of offering prenatal testing for the disorder.

Most discussions of nondirectiveness have focused on prenatal testing and reproductive decision making, areas in which genetic counseling has been focused for at least 20 years. Genetic counseling will increasingly be provided in conjunction with the offering of presymptomatic or predisposition testing. Because early treatment might be effective for some disorders for which predisposition testing is available, providers arguably should recommend that clients be tested. How likely is it that the doctrine of nondirectiveness will or should be upheld in the era of predictive testing for common adult-onset disorders?

For several reasons, it is likely that most clients seeking genetic counseling in conjunction with predictive testing will be given directive counseling. Genetic counseling and testing will increasingly move into the primary care arena and be provided by nongeneticists. There is a perception on the part of nongeneticist physicians that patients want direction. Many physicians believe that opinion seeking on the part of patients is a sign of trust and that not to render an opinion is irresponsible (Geller and Holtzman 1995). The ethicist Arthur Caplan believes that primary-care physicians are unlikely to “warm to suggestions” (pp. 153–54) that conversations become nondirective when the subject turns to heredity. Moreover, he suggests that their patients are unlikely to accept nondirectiveness with regard to genetic discussions when that “ethos does not prevail in other aspects of their relationships with providers” (Caplan 1993, p. 154).

Although the role of the physician and provider in medical decision making in general is a changing one, there is essentially no evidence of support for a physician not rendering an opinion outside of the field of medical genetics. A number of studies have reported that, in response to excesses of medical paternalism, many adults, rather than simply following their doctor’s orders, want to play a role in decision making. A partnership model has evolved that incorporates high levels of both provider and patient participation in decision making (Roter 1987). This model acknowledges that the patients’ needs and desires be considered and that patients play a role in decision making, but it does not go so far as to advocate that physicians abdicate their role in providing recommendations (Thompson et al. 1993). Since genetic medicine appears to be unique in embracing nondirectiveness and avoiding opinion giving, it
would be logical to expect that there must be strong evidence that our clients want and benefit from nondirective counseling.

A review of the literature provides no evidence that a nondirective approach benefits our clients (Wolff and Jung 1995). To the contrary, there is an indication that genetic-counseling clients may welcome exactly the opposite. Shiloh and Saxe (1989) have shown that genetic-counseling clients reported a higher perceived risk associated with more neutral risk counseling, perhaps stemming from a client belief that the counselor must be concealing bad news. In another study, Furu and colleagues have reported that, among individuals with retinitis pigmentosa or choroideremia and their relatives, 80% would want to know the opinion of the genetic counselor with regard to whether they should have children or undergo abortion after a positive prenatal diagnosis result (Furu et al. 1993).

Shoshana Shiloh (1996), in reviewing decision making in the context of genetic risk, points out that many people may not always prefer to control what happens to them. Autonomy for such individuals may involve choosing how a decision gets made, rather than what the decision actually is. If the counselor takes on the role of facilitator of the clients' decision making, the counselor will need “expertise in decision-making theories and counseling techniques aimed at helping clients reach a decision wisely, rather than reach a wise decision” (Shiloh 1996, p. 87). In our own work exploring women's decision-making preferences with regard to genetic testing for susceptibility to breast cancer, we found that most women wanted to hear their providers' recommendation about testing (Holtzman et al. 1996). Women still wanted to make their own decisions, either by choosing to follow their provider's recommendation or by choosing to veto it. If a provider did not give a recommendation based on her expertise, women either believed that the provider is not fulfilling her duty or that she would not be getting her money's worth. We have suggested that concerns about autonomy should shift from focusing on the voluntariness of the decision itself to the voluntariness of the decision-making process. Such a shift would preserve autonomy and empower patients as they are able to play their preferred role in decision making.

One of the most significant contributions of the Michie study relates to the lack of association of rated directiveness with client satisfaction, whether the client's expectations were met, and self-reported client anxiety and concern. The study shows that, even when clients knew the counselor had an opinion as to what decision they should make, many clients did not feel steered by this opinion. The implication that provider directiveness may not really matter to clients forces us to consider whether focusing on nondirectiveness as the sine qua non of current genetic-counseling practice diverts attention from other important goals, process measures, or outcomes of genetic counseling. Such consideration is especially timely, given the need for outcomes-based measures (Mariner 1994). As Wertz et al. (1987) have shown, in the majority of counseling sessions, there is lack of agreement between the counselor and the client as to the agenda items that each wants to address. Without agreement between counselor and counselee as to what outcomes to expect, measurements will be meaningless. It is likely that the goals of genetic counseling vary according to individual client needs and should be established as each session begins. From the client's point of view, the goal might involve soliciting the counselor's expert opinion. Perhaps we need to accept that there are times when directiveness is permissible or possibly positive and elucidate better ways to make our services more responsive to our clients' needs.

References

Roter D (1987) An exploration of health education's responsi-