
Professional Issues

A Practical Account of Autonomy: Why Genetic Counseling is Especially Well Suited to the Facilitation of Informed Autonomous Decision Making

Jan Hodgson^{1,3} and Merle Spriggs^{2,3}

In genetic counseling, facilitation of autonomous decision-making is seen as a primary aim and respect for autonomy is used to justify a nondirective counseling approach whereby clients are free to make their own choices after being given all necessary information. However in the genetic counseling literature, autonomy as a concept appears to be interpreted variably and often narrowly. We offer a practical account of autonomy that is coherent, consistent and philosophically defensible for the genetic counseling setting. At the same time we demonstrate how nondirective counseling may serve to frustrate rather than facilitate client autonomy. We suggest that promoting purposeful dialogue rather than counseling that is nondirective is more conducive to client autonomy.

KEY WORDS: autonomy; genetic counseling; decision making; nondirective counseling.

INTRODUCTION

In order to facilitate autonomous decision making it is important to be clear about what we mean when we talk about autonomy. We need to know the set of problems and questions faced and we need to

identify what we expect from the idea of autonomy. As well as being relevant to the setting, our account of autonomy must be coherent, consistent and philosophically defensible.

Using a hypothetical scenario we will illustrate an account of autonomy, explain its particular relevance for the genetic counseling context and discuss the implications for nondirective counseling.

Scenario

Anna (18 weeks pregnant) and her partner Bill attend for genetic counseling in their first pregnancy, following a diagnosis of Down syndrome. The amniocentesis had been recommended by their obstetrician due to Anna's age (38) but neither had considered until now what they would do if the result showed a fetus with Down syndrome.

How can we articulate a theory of autonomy for use in this situation?

¹Genetic Education, Murdoch Children's Research Institute, Royal Children's Hospital, Flemington Rd, Parkville, Victoria, 3052, Australia. And Department of Paediatrics and Center for the Study of Health and Society, University of Melbourne, Victoria, Australia.

²Ethics Unit, Murdoch Children's Research Institute, Royal Children's Hospital, Flemington Road, Parkville, Victoria, 3052, Australia. And, Centre for the Study of Health and Society, University of Melbourne, Victoria, Australia. And, Centre for Human Bioethics, Monash University, Victoria, Australia.

³Correspondence should be directed to Merle Spriggs, (Bioethicist, PhD); e-mail: merle.spriggs@mcri.edu.au or Jan Hodgson (PhD student, B.Sc [Hons.], Graduate Diploma Genetic Counseling); e-mail: jan.hodgson@mcri.edu.au.

WHAT DO WE EXPECT FROM THE CONCEPT OF AUTONOMY IN PRENATAL GENETIC COUNSELING?

Genetic information may differ from other types of medical information in that:

1. in addition to its relevance for an individual it may have implications for other family members
2. in prenatal diagnosis the information is not usually being obtained in order to provide any medical treatment, rather it is most often performed so that parents are given an opportunity to make choices about a pregnancy

In order to identify what we expect from the concept of autonomy in genetic counseling we need to understand (a) the goals of genetic counseling and (b) how genetic counseling is practiced.

Goals of Genetic Counseling

While the goals of genetic counseling are often not clearly articulated they would appear to include:

- facilitation of informed autonomous choices
- education - which includes information on options available, risks and limitations of those options
- provision of emotional support

Increasing 'well-being' (physical, psychological and spiritual) is also cited as important (Biesecker, 2001) but it is not clear from the literature just how the practice of genetic counseling may increase well-being generally and it is possible that this may refer to other stated objectives such as the relief of guilt and shame (Chapple *et al.*, 1995).

From a public health perspective a possible goal of genetic counseling could be to improve public health and reduce what is sometimes referred to as 'the burden' of disease as, for example, through newborn screening programmes. Attempting to change reproductive outcomes may reduce the incidence and severity of genetic disease and thus reduce the consumption of resources. This kind of positive eugenics may create tension between autonomous choices and public health programmes (Biesecker and Marteau, 1999).

One critic of the process of genetic testing and screening in pregnancy has controversially suggested that the real purpose of genetic counseling is population 'quality control' (Rothman, 1986, p. 2), a claim that has also been levelled specifically at prenatal diagnosis (Lippman, 1991). These claims recognise the inherent power differential that may be present in some health care encounters.

It has also been suggested that the role of the genetic counselor is to provide short-term psychotherapy (Biesecker, 1998) although it is unclear whether any current training programmes for genetic counselors reflect this depth of counseling skills or whether the time allowed for such encounters is adequate for this. Even those who would disagree with this purpose do however, emphasise the importance of some acknowledgment of clients' emotional state and indeed the term 'genetic counseling' would appear to imply a consideration of 'psychological well-being' (Veach *et al.*, 1999).

Genetic Counseling Practice

Several studies have attempted to explore the process of genetic counseling (for example Kessler, 1981, Lippman-Hand and Fraser, 1979, van Zuen 1997, Rapp, 1999), but more research is needed to facilitate assessment of current practice (Biesecker and Peters, 2001). However there does appear to be a consensus among genetic counselors that counseling should be both client centred and nondirective.

Nondirective Counseling (ND)

Nondirectiveness describes a counseling style developed for use in psychotherapy practice whereby counselors do not give advice, pass judgements or convey opinions (Rogers, 1951). Its transfer to the genetic counseling setting may have failed to acknowledge the differences between a psychotherapy session (where it could be argued that there are free choices to be made) and many genetic counseling settings where there is frequently complex information to be conveyed, often in a short time, in order for clients to make a choice that may affect themselves and others. The relevance of ND for genetic counseling has been articulated as 'procedures aimed at promoting the autonomy and self-directedness of the client' and is an active process designed to guide clients to 'their own decision' (Kessler, 1997). The particular relevance of

ND in prenatal settings appears to be based on a desire to uphold the personal nature of reproductive decision-making and a reluctance to pass judgement on the worthiness of a life (Murray, 1996).

The view of ND as the ‘central ethos’ (Weil, 2003) of genetic counseling has been challenged and debated by many (see for example Bartels *et al.*, 1997; McConkie-Rosell and Sullivan, 1999; Beisecker, 1998). It is possible that historically genetic counselors have judged ND to serve as a way of respecting client autonomy. However this refers to autonomy in its most minimal sense—as provision of information and noninterference with client choices.

There is little evidence to show that ND is either what clients want (Somer *et al.*, 1988, Michie *et al.*, 1997), that it is useful in meeting clients’ needs (Shiloh, 1996), that it is achievable in practice or that it is a means to respecting autonomy (Yarborough *et al.*, 1989; Lippman, 1991; Clarke, 1991; Kessler, 1992; Bernhardt, 1997; Elwyn *et al.*, 2000).

Directiveness has been described in a variety of ways from “advice, evaluation, reinforcement” (Michie *et al.*, 1997) to “a form of persuasive communication involving various combinations of deception, coercion and threat” (Kessler, 1997). Studies that have tried to measure directiveness in practice have suffered from this lack of consensus about the concept. It is not just the counseling style that may appear directive, other components such as body language and word choices may in themselves be directive. Increasingly there is recognition that the term ‘nondirective counseling’ may not describe what is actually seen in practice (McConkie-Rosell and Sullivan, 1999; Weil, 2003) although a dearth of process studies makes this claim hard to substantiate.

Problems with Nondirectiveness

In the absence of evidence to the contrary, strict adherence to a nondirective counseling style may lead to the following problems:

- It may deprive clients of the benefit of the counselor’s experience in such situations and increase the likelihood that clients make choices which are “partially informed or poorly reasoned” (White, 1997).
- It may allow genetic counselors to distance themselves from decisions made by clients, both emotionally and legally, which may lead to clients perceiving themselves as being abandoned

- An inability to question or challenge clients’ beliefs may fail to respect a person’s autonomy by assuming that (a) clients have been given and have understood the correct amount of relevant information, (b) they have adequate skills to determine how this information fits with their own life values and wishes, and (c) they have the necessary decision-making skills.
- It may be inappropriate in certain contexts such as when the counselor needs to make a ‘clinical recommendation’ concerning treatment or investigations, as in surveillance for cancer, or when the counselor wishes to make an “ethical recommendation” (Elwyn, *et al.*, 2000).
- Despite implying a ‘moral neutrality’ it may also allow denial of the fact that there is, in many situations, a moral judgement to be made by clients (Caplan, 1993). Recognition of this may be a crucial component of the decisionmaking process. If moral/ethical guidance was considered a justifiable goal of genetic counseling then it may be appropriate and even required for genetic counselors to be directive when clients make ethically bad choices. The big question then is how and who should determine what are ethically bad choices.
- If counselors are totally client led it would be impossible to incorporate any ethical or moral exploration unless the client invited it. This may not be respecting client autonomy in a broader sense.

Contemporary definitions of ND suggest that rather than it being used to describe a counseling style or technique, its utility may be as a value that genetic counselors can use to guide their practice and assist them in facilitating autonomous choices. Moral justification for the use of ND is that it may respect client autonomy. However that is based on a narrow definition of autonomy whereby giving information and allowing clients to make their own decisions is sufficient. It appears that ND may be outdated as a practice and has dubious utility. It may be timely for genetic counselors to come to some consensus about appropriate directiveness in areas such as encouraging medical surveillance, sharing genetic information within families or restricting what may be inappropriate testing (e.g., predictive testing in children or sex selection).

As we will see, this current passive stance concerning autonomy (born from a desire to appear nondirective) coupled with an overly narrow view of autonomy may inhibit counselors from respecting or promoting their client's autonomy.

WHAT IS AUTONOMY?

The central idea in the concept of autonomy is "self-government" or "self-rule" (Beauchamp and Childress, 2001). Autonomy is a concept used in different settings "relative to a set of problems and questions" (Dworkin, 1993). We speak of autonomous nations, autonomous persons and autonomous choices. In various settings the meaning of 'autonomy' is related but different. In other words, it is coherent for autonomy to have a somewhat different meaning and a different role in different settings.

CLARIFYING CONCEPTS OF AUTONOMY

Sometimes different ideas of what constitutes autonomy are run together in ways that are *not* consistent and that can cause confusion. Disentangling these different ideas is essential. In order to have a meaningful discussion about genetic counseling and client's decisions, it is important that apart from having a useful and adequately well-developed idea of what constitutes autonomy we are also clear about the kind of concept we are using and that we use it in a consistent way. Some views of autonomy are not applicable or useful in a clinical or genetic counseling setting. A practical descriptive account of autonomy will be defended and it will be argued that various views of autonomy which amount to (i) freedom, (ii) a constraint on action or (iii) a moral judgment, are not useful in this setting.

Views of Autonomy that are not Applicable or Useful in Genetic Counseling: Autonomy as Freedom

In a clinical context autonomy is sometimes used as a synonym for freedom or liberty. On this restricted view, the availability of prenatal testing and the availability of termination of pregnancy would be sufficient to bestow autonomy. Nevertheless, the availability of choices is not what makes a woman autonomous or able to make autonomous decisions. A woman's lib-

erty can certainly be affected if access to testing and termination is denied—but the availability of these procedures by themselves does not confer autonomy. Autonomy is a richer concept than liberty or freedom. It is about acting or choosing in a way that reflects a person's preferences. The autonomy of a woman's choice can be affected if she has been manipulated or coerced, or if in relation to the available evidence, she lacks understanding of what the choice entails.

Respect for Autonomy as a Procedure or Constraint on Action

Another approach to autonomy that is inadequate in a clinical setting is treating autonomy as a procedure or a constraint on action. Autonomy or 'respect for autonomy' is sometimes appealed to as a constraint on action or to promote noninterference with people's choices. Often, when autonomy is referred to in this way, the focus is on the regulation of someone else's behavior rather than with what constitutes autonomy. An example of this can be seen in the area of biomedical research where abuses have occurred. The requirement for voluntary informed consent that came from the Nuremberg Trials and the Nuremberg Code was a device to make sure that atrocities such as the Nazi war experiments never happen again. Obviously the Nazis would never have been able to obtain voluntary informed consent from the subjects of their experiments. In the context of research, although autonomy may be appealed to as the underlying value of informed consent and there is more to informed consent than agreement or consent (Faden and Beauchamp, 1986; Beauchamp and Childress, 2001)—the *function* of informed consent may be a limit or check on the authority of others (Engelhardt, 1978). Biomedical researchers may pay lip service to the doctrine of informed consent and its underlying value of autonomy, but used in this way these concepts are problematic. They do not demand any level of understanding by clients and have nothing to say about the standard of deliberation required for an autonomous choice.

Similar appeals to 'autonomy' may be occurring in the genetic counseling setting. Just as, informed consent may become a procedure to be followed to avoid legal liability rather than signifying the underlying value of autonomy, nondirective counseling can become a procedure or a counseling technique to ensure that genetics is not associated with a eugenic role

(Michie *et al.*, 1997). If respect for autonomy is used to justify nondirective counseling and we do not have a clear idea of what we mean by autonomy, the guiding value of nondirective counseling could simply be the fear of being associated with a eugenic role.

Autonomy as an Evaluative Concept

Another account of autonomy that is not useful in a clinical setting or in genetic counseling is autonomy used as an evaluative concept. Autonomy is sometimes used evaluatively in the sense that decisions we think ought to be protected are labeled ‘autonomous.’ From this view, there is a tendency to think that it follows by definition that something ought to be respected once it is labeled autonomous. Simply naming a person, action or choice as ‘autonomous’ implies that it qualifies as deserving respect and it follows that these persons and choices should not be interfered with and interference, if it does occur, is a violation of autonomy. Conversely, those who use an evaluative notion of autonomy may argue that a choice can be paternalistically overridden by denying that it is autonomous.

When autonomy is an evaluative concept it implies an ethical conclusion. The speaker is making a judgment. Solutions arrived at by relying on an evaluative concept tell us more about the person trying to resolve an issue than they do about autonomous actions or choices. An example of an evaluative concept of autonomy from the general clinical context is illustrated in what is often cited as a classic example of an autonomous choice—the refusal of a blood transfusion by a Jehovah’s Witness. The refusal is taken to be autonomous because even though it is not a choice most would make, it reflects the sincerely held values of the Jehovah’s Witness.

Nevertheless, it is debatable whether the decision is autonomous. Some have argued that the Jehovah’s Witness’s choice is not autonomous because the choice and the values which inform it are based on *beliefs* that are not rational—in part because the Jehovah’s Witness’s beliefs about abstaining from blood “are not responsive to evidence” (Savulescu and Momeyer, 1997).

The point here is that when people begin with the idea of a choice that they would be loath to override such as a Jehovah’s Witness’s refusal of blood and they label the choice ‘autonomous,’ they are using the term evaluatively. In deciding whether or not to respect the Jehovah’s Witness’s choice, the evaluative concept of

autonomy actually does no work—so this kind of concept is not helpful. What is needed in a clinical context and in genetic counseling is a practical account of autonomy that gives a description of what constitutes an autonomous choice—not preconceived judgments.

The Most Applicable Useful Account of Autonomy for Genetic Counseling: A Practical Descriptive Account of Autonomy

The criteria of a practical descriptive account of autonomy gives us a specific idea of autonomy but it does not tell us how to act. It is important to understand that the concept of what it is to be autonomous and the question of whether or why we ought to respect autonomy are separate issues (Spriggs, 2005).

When we are concerned with the choices people make the most applicable and useful account of autonomy is that which provides a description or criteria on which to judge people’s decisions as autonomous or lacking in autonomy. Statements in which the term ‘autonomy’ are used in this way are factual statements: they can be true or false and no ethical conclusions are implied by the fact that a decision is deemed autonomous or not autonomous. The only thing we can establish is that a person or choice has certain characteristics e.g., saying that someone is autonomous means something like—this person engages in critical reflection, has understanding and acts in accordance with his or her values. When ‘autonomy’ is a description, it gives us a detailed picture of what an autonomous person or an autonomous decision is like. Autonomy is empirically discernable—capacities and competencies, preferences and desires, and rationality have a central role. In health care settings the provision of relevant information is a necessary requirement.

This practical descriptive account of autonomy is based on Gerald Dworkin’s theory:

Autonomy is conceived of as a second-order capacity of persons to reflect critically upon their first-order preferences, desires, wishes, and so forth and the capacity to accept or attempt to change these in light of higher-order preferences and values. (Dworkin, 1988, p. 20)

By exercising such a capacity, persons define their nature, give meaning and coherence to their lives and take responsibility for their choices. Ultimately, the kind of person they become is a result of these choices—and that could mean that they are an autonomous, mostly autonomous, sometimes autonomous or never autonomous person. (Spriggs, 2005, p. 241)

Based on this kind of well-developed theory, autonomy is compatible with values such as obligation and commitment. There is a common misconception that to be autonomous a person must be self-sufficient and independent, relying on his or her own resources, seeking to fulfil private goals. But autonomy is *not* synonymous with an unencumbered self. Autonomy is available to caring benevolent people with family commitments and loyalties to others—not just to selfish people who do not allow the needs of others to interfere with their plans. The crucial thing is that that the person is leading the kind of life he or she thinks is worth leading. Based on this conception of autonomy “the autonomous person can be a tyrant or a slave, a saint or sinner, . . . a leader or follower” (Dworkin, 1988, p. 29), a rugged individualist, member of a family or intimate group.

It does not follow that genetic counselors must respect all autonomous choices/decisions and override those that are nonautonomous. Genetic counselors can argue (if they can provide good reasons) that although a particular decision is not autonomous it is better to respect it than not do so. They may decide to go along with a decision they consider nonautonomous because no harm will come of it. There are also decisions that can be considered autonomous but it is better *not* to respect. For instance, genetic counselors could refuse assistance for couples who decide they want to use sex selection or want help in creating a child with a disability—even though they may consider the client’s choice autonomous. The point being made is that the assessment of autonomy should be based on psychological criteria—it does not automatically mean this choice should be protected. This account of autonomy is applicable and useful for the genetic counseling setting. It gives us criteria to identify an autonomous choice or decision. It also prevents us from feeling pressured to say that a decision is autonomous because we think it is better not to override it or to say that a decision is nonautonomous because we think there is reason not to honour it or to override it.

AUTONOMY AND THE GENETIC COUNSELING CONTEXT

In the general clinical context, a theory of autonomy provides criteria for doctors and other relevant persons to decide when patients’ decisions should be respected and when intervention is justified. In addition

to this, genetic counselors need criteria to help them determine when counseling has been successful and to decide when counseling can conclude. i.e., when a client’s decision is substantially autonomous at which time (unless the person is incompetent and is constrained in a significant way e.g., manipulated or coerced), the decision can be considered autonomous. Full autonomy requiring full information and knowledge of outcomes is an unrealistic ideal that is often not possible and is not necessary. People can autonomously choose a partner, buy a house and make financial decisions, without knowing how these decisions will turn out (Beauchamp and Childress, 2001). In the same way, a decision based on prenatal testing or prenatal diagnosis, even when it involves uncertainty, can be autonomous. These decisions are autonomous in terms of the evidence available and the options that are available.

Autonomy does not require knowledge of outcomes. Genetic counseling however, provides the opportunity to consider possible outcomes. Later regret is possible but largely futile unless client’s decisions are based on an incomplete assessment of information or they have not properly reflected on the values they are using to guide their choice. Genetic counselors have a vital role in ensuring that reflection and deliberation take place.

OUTLINE OF WHAT IS INVOLVED IN AN AUTONOMOUS CHOICE FOR ANNA AND BILL—DEMONSTRATING THE PHILOSOPHICAL DEFENSIBILITY AND PRACTICAL NATURE OF AUTONOMY

In genetic counseling, autonomy is decision specific. We only need to assess the autonomy of the decision made by Anna and Bill rather than decide whether they are autonomous persons or whether their whole life is autonomous. We might say a *person* is autonomous as a kind of shorthand when we think the person in question has made an autonomous decision and we may refer to the autonomy *of the person* when we are wondering about whether they have the capacity to make an autonomous decision but the focus of the clinical encounter for genetic counselors’ is a particular decision or choice.

Given the diagnosis of Down syndrome, counseling support for Anna and Bill will create an environment within which they can acquire the necessary information and use their skills to make an informed

choice about what to do next. Anna and Bill need to know and consider the implications of the available options. These options are:

1. continue the pregnancy and raise the child
2. continue the pregnancy and have the child adopted
3. terminate the pregnancy

Rich and relevant information about each option needs to be presented in an appropriate manner taking into account Anna and Bill's values, educational level, and previous knowledge.

Adequate time and relevant resources need to be made available to Anna and Bill. Information about each option should be available to counselors working with clients in this situation and failure to provide such information has been described as "unprofessional and unethical" (Asch, 1994). It is the responsibility of genetic counselors to ensure that their ideas, for example, about people living with Down Syndrome are based on evidence.

Information About Down Syndrome Should Include (in Addition to Education About how Down Syndrome Occurs)

- The uncertainty of phenotype and the possible spectrum of intellectual and physical disability and the supports available.
- Physical aspects of Down syndrome including possible associated medical conditions and the supports and or treatments that are available for these.
- An exploration of what this particular child has the potential to mean in the context of this particular family. A realistic representation of what life is like for some families where there are children and adults with Down syndrome may allow Anna and Bill to judge how this fits with their ideas about their own family. This may be facilitated by reading local accounts of living with Down syndrome; for example in Australia we may use the excellent book 'Ups and Downs' which contains easily read narratives of the varying experiences of 14 Australian families (Costigan, 2000).
- An opportunity to meet with families and access support groups if desired.

Regarding Termination of Pregnancy, Anna and Bill Need to be Informed About

- All possible methods of termination of pregnancy including what is currently known about the potential physical and psychological aspects of termination of pregnancy at this gestation as well as any possible impact on future reproduction.
- Availability of follow up support and counseling and the existence of groups such as SAFDA (Support after Fetal diagnosis of Abnormality).
- Recurrence risks for Down syndrome

Regarding Continuing with the Pregnancy, Anna and Bill Need to Know

- The practicalities of this including any special requirements for antenatal care and the birth.
- The availability of local support services and support groups.

With each option an important role for the genetic counselor is to offer some discussion exploring communication skills that may be useful in dealing with possible reactions from others.

It is important to note that autonomous decisions do not have to be 'good' or palatable choices. It is still possible to make autonomous choices when the range of options is restricted or the options are not to our liking. Autonomous decisions can be made in reduced circumstances, when we have received a devastating diagnosis and even when we are physically unfree. With a practical descriptive account of autonomy that gives a description of what constitutes an autonomous choice (based on psychological criteria), we are able to understand that even a prisoner can make autonomous choices (Spriggs, 1998).

Choices do not have to be prudent e.g., if someone says "I'll chance what happens later," this can be an autonomous choice (Spriggs, 2005, P. 222). A couple could decide: "We'll chance what happens later." Anna and her partner could respond in this way to suggestions that they may regret having a termination. They could also respond in this way when questioned about deciding not to have the termination, if that is what they decide.

SUMMARY: AN AUTONOMOUS CHOICE INVOLVES

- *Critical reflection.* Autonomy is assessed according to the way a person reasons. We don't assess Anna and Bill's decision according to whether we think they should or should not have a termination of pregnancy. Unless their decision is clearly lacking in rationality and understanding we look at the way they reason and arrive at their decision. Dialogue has an important role in allowing clients to explore their decision-making processes.

Autonomous decisions are backed by reasons. This involves critical or higher order reflection; thinking critically about desires. Some people worry that the shock and stress Anna and Bill may experience on being given this diagnosis may be a barrier to autonomous decision making. Nevertheless, rather than interfering with autonomous decision making, it can be argued that when people are prompted to reflect upon, reassess, and even restructure their values, they are exercising autonomy. The decision they make might reflect a sudden dramatic change in values but that does not mean it is not autonomous. Genetic counselors are extremely well placed to facilitate clients' "engagement" with the situation and offer support to clients while they do the "work of worry" (McAllister, 2003). It is our belief that encouraging this type of active reflection and deliberation, rather than focussing on information, reassurance and reduction of stress *per se*, may better assist clients in reaching an autonomous decision. In addition this process may increase individuals (or couples) satisfaction with the decision made and thus is less likely to cause any possible later regret.

- *A fundamental idea about how we want to live.* When questioned, Anna and Bill should be able to critically reflect on whether their decision fits with the kind of life they want to lead. They are able to defend their choices in terms of their own values. Dialogue has an important role in this—not only so others can help assess the decision but can also help Anna and her partner clarify for themselves the suitability of their decision and clarify and consolidate their values.
- *Awareness of influences on deliberation.* A person cannot choose autonomously if they are

cognitively impaired, brainwashed, coerced, deluded or disturbed, if they lack understanding or if they are choosing out of fear or depression severe enough to prevent critical reflection. Dialogue has a role here in helping Anna and Bill to become aware of influences on their thinking and can also clarify any misconceptions and misunderstandings they may have.

- *Rationality.* Rationality is an important component of an autonomous choice to the extent that it rules out decisions with obviously absurd or unintelligible ends and decisions based on false or irrational beliefs. Again, dialogue has a role in exploring clients' thoughts about their reasons for choosing a particular option.

DIALOGUE HAS AN IMPORTANT ROLE IN AUTONOMOUS DECISION-MAKING

Dialogue, as a two-way interactive process, is a practical aid for promoting and enhancing autonomy. The imposition of dialogue helps people make decisions backed by reasons. As well as providing information, talking with others helps people to critically reflect. It helps ordinary people who may not have reflected on their preferences at a higher level do so.

In addition, as we have demonstrated, shifting the focus from nondirectiveness to dialogue is more conducive to autonomy. As such, the genetic counseling setting is particularly well suited to the facilitation of informed autonomous decisions. Nevertheless, we need to be very clear about what we mean when we refer to autonomy. If we rely on an overly narrow view of autonomy we may be simply promoting the outdated idea of nondirectiveness disguised in a different form. Also, if we are vague about what autonomy means or rely on various shifting concepts, our discussions will lack meaning and value.

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REFERENCES

- Asch, A. (1994). The human genome and disability rights. *Disabil Rag Resour*, 13, 12–15.
- Bartels, D. M., LeRoy, B. S., McCarthy, P., & Caplan, A. L. (1997). Nondirectiveness in genetic counseling: A survey of practitioners. *Am J Med Genet*, 72(2), 172–179.
- Beauchamp, T., & Childress, J. (2001). *Principles of Biomedical Ethics* (5th ed.). New York: Oxford University Press.
- Bernhardt, B. A. (1997). Empirical evidence that genetic counseling is directive: Where do we go from here? *Am J Hum Genet*, 60(1), 17–20.
- Biesecker, B. B. (1998). Future directions in genetic counseling: Practical and ethical considerations. *Kennedy Inst Ethics J*, 8(2), 145–160.
- Biesecker, B. B., & Marteau, T. M. (1999). The future of genetic counseling: An international perspective. *Nat Genet*, 22(2), 133–137.
- Biesecker, B. B., & Peters, K. F. (2001). Process studies in genetic counseling: Peering into the black box. *Am J Med Genet*, 106(3), 191–198.
- Biesecker, B. B. (2001). Goals of genetic counseling. *Clin Genet*, 60(5), 323–330.
- Caplan, A. L. (1993). Neutrality is not morality: The ethics of genetic counseling. In D. M. Bartels, B. S. Le Roy, & A. L. Caplan (Eds.), *Prescribing Our Future: Ethical Challenges in Genetic Counseling* (pp. 149–165). New York: Aldine de Gruyter.
- Chapple, A., May, C., & Champion, P. (1995). Parental guilt: The part played by the clinical geneticist. *J Genet Couns*, 4(3), 179–191.
- Clarke, A. (1991). Is nondirective genetic counseling possible? *Lancet*, 338(8773), 998–1001.
- Costigan, J., & Fidler, E. (2000). *Ups and Downs-Lives of Love, Challenge and Commitment*. Blackburn, Victoria: PenFolk Publishing.
- Dworkin, G. (1988). *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press.
- Dworkin, G. (1993). Autonomy. In R. Goodin & P. Pettit (Eds.), *A Companion to Contemporary Political Philosophy* (pp. 359–365). Oxford: Blackwell.
- Elwyn, G., Gray, J., & Clarke, A. (2000). Shared decision making and nondirectiveness in genetic counseling. *J Med Genet*, 37(2), 135–138.
- Engelhardt, H. T., Jr. (1978). Basic Ethical Principles in the Conduct of Biomedical and behavioral Research Involving Human Subjects. *National Commission for the Protection of Human Subjects of Biomedical and behavioral research: Appendix: Vol 1. Belmont Report*
- Faden, R. R., & Beauchamp, T. L. (1986). *A History and Theory of Informed Consent*. New York: Oxford University Press.
- Kessler, S. (1981). Psychological aspects of genetic counseling: Analysis of a transcript. *Am J Med Genet*, 8, 137–153.
- Kessler, S. (1992). Psychological aspects of genetic counseling: VII. Thoughts on directiveness. *J Genet Counsel*, 1(1), 9–17.
- Kessler, S. (1997). Psychological aspects of genetic counseling. XI. Nondirectiveness revisited. *Am J Med Genet*, 72, 164–171.
- Lippman, A. (1991). Prenatal genetic testing and screening: Constructing needs and reinforcing inequities. *Am J Law Med*, 17(1–2), 15–50.
- Lippman-Hand, A., & Fraser, F. (1979). Genetic counseling: provision and reception of information. *Am J Med Genet*, 3, 113–117.
- McAllister, M. (2003). Personal theories of inheritance, coping strategies, risk perception and engagement in hereditary nonpolyposis colon cancer families offered genetic testing. *Clin Genet*, 64(3), 179–189.
- McConkie-Rosell, A., & Sullivan, J. A. (1999). Genetic counseling-stress, coping, and the empowerment perspective. *J Genet Couns*, 8(6), 345–357.
- Michie, S., Bron, F., Bobrow, M., & Marteau, T. M. (1997). Nondirectiveness in genetic counseling: An empirical study. *Am J Hum Genet*, 60(1), 40–47.
- Murray, T. H. (1996). *The worth of a child*. Berkeley/Los Angeles/London: University of California Press.
- Rapp, R. (1999). *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge.
- Rogers, C. (1951). *Client-Centered Therapy: Its Current Practice, Implications and Theory*. Boston: Houghton Mifflin.
- Rothman, B. K. (1986). *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York: Viking.
- Savulescu, J., & Momeyer, R. W. (1997). Should informed consent be based on rational beliefs? *J Med Ethics*, 23(5), 282–288.
- Shiloh, S. (1996). Decision-making in the context of genetic risk. In T. Marteau & M. Richards (Eds.), *The Troubled Helix: Social and Psychological Implications of the New Genetics*. New York: Cambridge University Press.
- Somer, M., Mustonen, H., & Norio, R. (1988). Evaluation of genetic counseling: Recall of information, post-counseling reproduction, and attitude of the counselees. *Clin Genet*, 34(6), 352–365.
- Spriggs, M. (1998). Autonomy in the face of a devastating diagnosis. *J Med Ethics*, 24(2), 123–126.
- Spriggs, M. (2005). *Autonomy and patients' decisions*. Maryland, Lexington Books.
- van Zuuren, F. J. (1997). “The standard of neutrality during genetic counseling: An empirical investigation.” *Patient Educ Couns*, 32(1–2): 69–79.
- Veach, P. M., Truesdell, S. E., LeRoy, B. S., & Bartels, D. M. (1999). Client perceptions of the impact of genetic counseling: An exploratory study. *J Genet Couns*, 8(4), 191–216.
- Weil, J. (2003). Psychosocial genetic counseling in the post-nondirective era: A point of view. *J Genet Couns*, 12(3), 199–211.
- White, M. T. (1997). “Respect for autonomy” in genetic counseling: An analysis and a proposal. *J Genet Couns*, 6(3), 297–313.
- Yarborough, M., Scott, J. A., & Dixon, L. K. (1989). The role of beneficence in clinical genetics: nondirective counseling reconsidered. *Theor Med*, 10(2), 139–149.