THE ISSUE IS

Occupational Therapy and Genetic Information: Considerations and Cautions

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The structure of deoxyribonucleic acid (DNA), the material of which genes are composed, was discovered in the 1950s. The components and functions of DNA continue to be explored through the Human Genome Project, a collaboration of scientists worldwide with the shared goal of mapping the entire human blueprint. By early 2000, the mapping of some 3 billion bits of sequenced information that influence human function was nearly completed. Unraveling genome information across the population and among individuals generates vast amounts of new knowledge about the heritability of traits and conditions and/or vulnerability to physical and behavioral circumstances that affect ability to function and participate.

New genetics is certainly about reproduction, birth, and development, but is also about one’s lifetime and lifestyle. Genetic testing and diagnostic technologies are likely to influence and perhaps alter personal and cultural health beliefs and options. More than Mendelian genetics is now becoming understood, and technology is enabling careful viewing of genes with greater precision and purpose. New genetics and genomic medicine (Guttmacher & Collins, 2002) make each of us more aware of genetic possibilities and personal health risks due not only to family history but also to interactions between lifestyle choices and genetic make-up. With this new knowledge come justified concerns about ethical and legal issues and implications for health care practices and policies. Researchers with the Human Genome Project recognized concerns for practitioner education and ethical issues and remain dedicated to addressing implications of new genetics and related technology.

The purpose of this paper is to bring attention to the changing and growing genetic and genomic knowledge base and to address implications of this new knowledge for occupational therapy education, practice, and research. The Preamble to the 2000 American Occupational Therapy Association (AOTA) Code of Ethics declares that AOTA and its members “are committed to furthering the ability of individuals, groups, and systems to function within their total environment” (AOTA, 2000). The environment is comprised of all internal and external forces acting on an individual. Although the influence of heredity was recognized in the 19 century, the increasing ability to decode genetic information draws greater attention to genetic influences on many aspects of human life and well-being. Occupational therapy personnel are obligated to learn and incorporate rapidly changing information about genetics into client evaluation and intervention.

Evidence suggests that occupational therapy practitioners must commit to learn and apply genetic information to practice (Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000). Therapists often have low levels of confidence in their abilities to provide genetic-based evaluation and intervention services (Kyler & Thomas, 2000). Literacy about genetics implies several things. Included is an understanding of different types of genetic disorders and familial patterns of inheritance. Knowledge about consequences of genetic conditions on performance components, areas, and contexts, and implications of genetic conditions in promotion of health and prevention of disease and disability are critical to practice and research. Genetic literacy also includes recognition of ethical, legal, and social dilemmas for individuals, practitioners, and society as a whole.

The ways in which occupational therapy personnel deal with genetically linked conditions take many forms. They include evaluations that provide identification of symptoms signifying a genetic condition, interventions that address the physical, cognitive, and psychosocial manifestations of genetic conditions; and education of clients and families regarding genetic counseling, testing, and research (Taugher, Dudgeon, Hirschel, Low, Pickering, & Kyler 1999). Attention to the influence of genetic factors in health promotion and disease prevention is important to occupational therapy practice. Potential exists for expanded roles for occupational therapy personnel in management of genetic conditions that are present but presymptomatic or for which an individual has a predisposition. Occupational therapy personnel should prepare to provide services and to offer anticipatory guidance to persons, families, and groups involved with lifestyle decisions that affect and are affected by genetics and genomic medicine. Clinical practice strategies and research focusing on ameliorating stresses or effects of negative contributory factors need to be explored.

Occupational therapy assessment and intervention for an inherited condition may not differ in kind from management afforded other illnesses or injuries that contribute...
to disabilities. Nevertheless, occupational therapy personnel bring the unique perspective of focusing on the dimensions of daily life activity and participation. Physicians with genetics training advise on symptoms that are present or potential and genetics counselors assist families in making choices about reproduction and other life issues. Occupational therapy personnel can enhance the work of these practitioners and also directly help individuals and family members in dealing with the day-to-day issues related to occupation or those that may manifest in the future. Occupational therapy intervention or consultation or both can include such issues as short-term and long-term life planning, community reentry skills, health and fitness activities, energy conservation and joint protection techniques, vocational choices, uses of adaptive/assistive technology, and inclusive environmental design. In addition, for those conditions influenced by environmental factors, interventions focused on wellness behaviors and fitness are as important as injury and disability prevention.

Increasing ability to identify genetic causes and predisposition to conditions affecting function draws attention to the ethical, legal, and social issues impacting those we serve. Advances in genetic studies increase the availability of genetic testing and advising about genetic heritage. Although many aspects of new genetics are positive, further understanding and testing of the human genome also creates dilemmas for individuals, families, and social or cultural groups. Humankind has a history of discrimination against those who differ from the majority, even when the individual cannot be held responsible for her or his differences. We must be proactive in assuring that the recipients of our services obtain full access to the benefits normally offered in our society, even with the revelation of genetic information or suspicion of genetic disorders.

Further, we need to assure that neither occupational therapy personnel nor the recipients of our services view information revealed through genetic testing as the sole determinant of health and well-being. In his book, *The Mismeasure of Man*, Stephen Gould (1981) alerted us to the hazards of biological determinism, noting that human beings make a habit of reification (i.e., converting abstract concepts into entities and assigning serial ranking status to these concepts). By way of illustration he cited such flawed scientific and social movements as determining intellectual capacity on the basis of brain size and head measurement in the 19th century and preoccupation with intelligence testing in the 20th century. Perhaps in the 21st century, it will be genetics. It is important that we not lose sight of the multiple dimensions responsible for human function. Both nature and nurture impact all actions of living beings, including physical, sensory and cognitive development, health and fitness, and talents and interests.

Of critical importance in any discussion of new genetics is the recognition of serious and controversial issues arising from modern science and medicine’s capacity to view, make judgments, and perhaps modify individual genetic makeup. Occupational therapy practitioners are no different from other segments of society. We are not exempt from vulnerability to genetic disorders affecting our family members or ourselves. Neither are health care professionals exempt from discrimination and stigmatization based on inherited traits or potentialities. We are responsible for knowing what is happening around us and within us, as well as how that will affect our clients, families, and communities. Scientific breakthroughs influence public policies and opinions about incorporating genomics into clinical care. Occupational therapy personnel are responsible for using professional expertise to influence rational and ethical applications of genetic knowledge and to offer support and advocacy for groups representing those with genetic disorders that may have limited capacity to be self-determining. Current and future circumstances necessitate national and international dialogue about clinical and ethical issues relating to genetics and genomic medicine. Occupational therapy practitioners must seek opportunities to participate in these dialogues at societal, professional, and individual levels.

Continued competence in this evolving area is mandated and moves outside of traditional medical or educational settings may be necessary for occupational therapists to bring lifestyle information to those that have particular challenges linked to genomics. Occupational therapy personnel are obligated to stay informed and vigilant about new genetics and implications for consumers, our profession, and society as a whole. Occupational therapy practitioners should refer to their ethical obligations as health practitioners to do what is best for the recipients of occupational therapy services. Guidance in making decisions can be drawn from placing new attention on familiar ethical principles. These include respecting the autonomy of persons, including their capacity to self-determination and rights to privacy and confidentiality. It also means being beneficent and maximizing the well-being of individuals and families, particularly by avoiding, preventing, or minimizing harm. Ethics also drives us to seek justice and equitable access and fairness in use of resources within society. No one needs to be left out or left behind as genetics changes medical understanding and options, as well as public health awareness and related programs. ▲

References


