Behavioral Economics: A New Lens for Understanding Genomic Decision Making

Scott Emory Moore, PhD, APRN, AGPCNP-BC, Holley H. Ulbrich, PhD, Kenneth Hepburn, PhD, FGSA, Bonnie Holaday, PhD, RN, FAAN, Rachel Mayo, PhD, Julia Sharp, PhD, and Rosanne H. Pruitt, PhD, APRN, FNP-BC

1Alpha Mu, Gamma Mu, Mu Rho, Phi Gamma, Post-Doctoral Fellow, Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH, USA
2Alumni Distinguished Professor Emerita of Economics, Clemson University, Clemson, SC, USA
3Professor, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, GA, USA
4Gamma Mu, Professor Emerita of Nursing, Clemson University, Clemson, SC, USA
5Professor, Department of Public Health, Clemson University, Clemson, SC, USA
6Associate Professor, Department of Mathematical Sciences, Clemson University, Clemson, SC, USA
7Gamma Mu, Professor, School of Nursing, Clemson University, Clemson, SC, USA

Abstract

Purpose—This article seeks to take the next step in examining the insights that nurses and other healthcare providers can derive from applying behavioral economic concepts to support genomic decision making. As genomic science continues to permeate clinical practice, nurses must continue to adapt practice to meet new challenges. Decisions associated with genomics are often not simple and dichotomous in nature. They can be complex and challenging for all involved.

Design—This article offers an introduction to behavioral economics as a possible tool to help support patients’, families’, and caregivers’ decision making related to genomics.

Methods—Using current writings from nursing, ethics, behavioral economic, and other healthcare scholars, we review key concepts of behavioral economics and discuss their relevance to supporting genomic decision making.

Findings—Behavioral economic concepts—particularly relativity, deliberation, and choice architecture—are specifically examined as new ways to view the complexities of genomic decision making. Each concept is explored through patient decision making and clinical practice examples. This article also discusses next steps and practice implications for further development of the behavioral economic lens in nursing.

Conclusions—Behavioral economics provides valuable insight into the unique nature of genetic decision-making practices.

Correspondence. Dr. Scott Emory Moore, 3107 Detroit Avenue, #306, Cleveland, OH 44113. sem167@case.edu.
**Clinical Relevance**—Nurses are often a source of information and support for patients during clinical decision making. This article seeks to offer behavioral economic concepts as a framework for understanding and examining the unique nature of genomic decision making. As genetic and genomic testing become more common in practice, it will continue to grow in importance for nurses to be able to support the autonomous decision making of patients, their families, and caregivers.

**Keywords**

Behavioral economics; decision-making; genomics; nursing

As genetics and genomics advance with the development of additional screening and testing procedures, it is imperative to understand how their expanding capacities can be integrated into and influence nursing practice. Further, as translational science comes to the forefront in genetics and genomics, scientists and clinicians alike must assess the social, ethical, and familial implications of the increased power, availability, and perplexing quandaries of genomic testing (Green, Guyer, & National Human Genome Research Institute [NHGRI], 2011). Over the past 20 years access to genomic information has increased in many ways, and there are a growing number of clinical and nonclinical (direct-to-consumer) applications (Boccia & Zimmern, 2015; Calzone et al., 2013). More specifically, clinical genetic testing can be used to screen for a disease or carrier status (e.g., aneuploidy, sickle cell), for help in supporting or confirming a diagnosis (e.g., alpha-1-antitrypsin deficiency), or to possibly guide treatment decisions (e.g., some cancers). The rapid growth of genetic testing requires diligent work in research and scholarship to ensure that the very best applications are understandable, safe, and equitably available for those affected (Green et al., 2011). Just as nursing care covers the entire lifespan, the future of genomics will range from cradle to grave.

With the amount of intellectual energy being focused globally on the inclusion of genetics and genomics in nursing education at all levels, the growing importance of genetics and genomics in nursing science research and practice is undeniable (Calzone et al., 2013; Kirk, Tonkin, & Skirton, 2014). It is imperative that nurses be able to understand and apply genetic and genomic information in their daily practice. Genetics and genomics are not equivalents; genetics refers more to a single gene approach, and genomics encompasses the entire genome and gene–gene interactions (Green et al., 2011; Lander, 2011). Nursing involvement with genomics includes activities such as direct, nurse–patient interaction (e.g., informed consent processes, specimen collection); patient, family, or caregiver education related to genomic testing decision making; or dealing with genomic testing results that may be ambiguous in the known clinical context. There are also the interactions with other healthcare professionals related to patient advocacy, interprofessional research collaboration, ethics, and treatment or intervention decision making. Nursing has maintained a high level of public trust globally, 89% of respondents having a high level of trust in nursing (GfK Verein, 2016). The relationships that nurses have with their patients and their patients’ families are imbued with trust, and they often rely on nurses for information and guidance when making difficult decisions (Joseph-Williams, Elwyn, & Edwards, 2014; Stacey et al., 2008).
The field of behavioral economics, the study of forces and principles behind the decision-making behaviors of humans, is growing rapidly (Ariely, 2009; Thaler, 2015). The field is highly focused on economic contexts; however, applications outside of a strictly economic environment are promising. Many opportunities for the application of behavioral economics have been aligned with incentivized health outcomes and health behavior changes (Hostetter & Klein, 2013; Hough, 2013). These concepts may also prove very useful in helping nurses and other healthcare providers better understand and support patient engagement in decision making in various situations. In the realm of genomic decision making there are several opportunities for the application of behavioral economics in clinical practice that bear exploration. Although recent articles have discussed behavioral economics and genomics, they have not fully explored the mechanisms related to genomic decision making (Blumenthal-Barby, McGuire, Green, & Ubel, 2015; Blumenthal-Barby, McGuire, & Ubel, 2014).

It is in the setting of the patient–nurse relationship where behavioral economics could prove to be valuable. Understanding the relationship as a continuum ranging from laissez faire to authoritarian approaches, behavioral economics, when applied to decision making, can offer a middle ground between these approaches (Bayles, 2010). Each participant enters into the patient–nurse relationship with an information asymmetry—the nurse brings the expertise and the knowledge of the clinical situation while the patient brings an abundance of knowledge about the context of their personal situation. Ethical and appropriate use of behavioral economics can help to navigate the middle ground, balancing the clinical and evidence-based knowledge of nurses with the very personal needs of the decision makers (Hough, 2013). Behavioral economic approaches can open the door to conversation, which will allow for the identification and elimination of the information asymmetry that often exists in genomic decision-making encounters. Behavioral economic approaches are key to better supporting the growing use of decision support intervention models like Shared Decision Making (Elwyn et al., 2012). In order to better prepare nurses to support the autonomy and self-determination that are key to best practices in decision support, this article aims, first, to introduce nurses to key behavioral economic concepts, and second, to explore next steps and practice implications for behavioral economics and genomic decision making for nurses and other healthcare professionals. While these concepts are new to nursing, they complement the many roles that nurses fulfill in the care of patients. Understanding these concepts of behavioral economics can help nurses to better support patients in a respectful and balanced decision-making process.

Genomic Decision Making in a Behavioral Economic Context

Several key framing concepts from behavioral economics are important for a better understanding of the unique and often complex nature of genomic decision making. Chiefly, it is important to understand the concepts of relativity, deliberation, and choice architecture to adequately contextualize genomic testing decisions within behavioral economics. These concepts are explored by providing current, literature-based practical examples to illustrate the types of genomic decisions that may be faced by patients and their families. These examples are relevant to nurses and healthcare professionals that are relied on by patients.
Relativity

Relativity, a central part of the human decision-making construct, allows for understanding the relative advantages of one option compared to others (Ariely, 2009). In exploring relativity, it is important to note that the comparison must be among similar and available alternatives. Genomic testing may offer similar alternatives; for example, healthcare providers and patients can choose among different panels of genetic tests offering a range of levels of information, including testing for additional (often related) genomic variations. This choice could be limited by insurance coverage and financial constraints, but sometimes a similar choice is available. However, genomic testing often has no alternative for relative comparison, and thus there is no comparable methodology that offers the opportunity to obtain the same level of information.

The initial question for those facing decisions about genomic testing is whether to test at all. Absent alternatives, the decision is between knowing or not knowing genomic-level information and the possibility of that genomic information changing the course of care. In applying relativity to these situations there is an increase in the amount of information that is needed, specifically the type, amount, and nature of the information provided by the proposed genomic tests and how the results may influence next steps in patient care.

There are situations where there are much more affordable and clinically expedient choices that can be made. One example is testing serum cholesterol levels rather than doing genetic testing related to familial hypercholesterolemia (FH). Current guidelines do not recommend genetic screening evaluation of patients for FH due largely to cost (Robinson, 2013). Since there are, currently, no gene-specific treatments related to treatment of FH, knowing the specific genotype has limited value, so treatment with lifestyle, statins, and close clinical monitoring is still recommended, regardless of genetics.

Another example is the use of regular colonoscopies rather than screening for familial adenomatous polyposis (FAP)-related genes. A finding of several polyps in a colonoscopy may lead to further testing, but does not establish a diagnosis of FAP. Patients tested for FAP-related genes might be able to better inform their colonoscopy screening intervals. Those with genetically confirmed increased risks for FAP would be served best not by general screening guidelines regarding regular use of colonoscopies, but by the use of more frequent screening from an earlier age (Syngal et al., 2015).

These two examples highlight how, in terms of relativity, comparison is very important in making genomic testing–related decisions. Currently, genomic testing information has limited influence on the course of treatment for FH; however, with FAP the screening trajectory for a patient with a confirmed increased genetic risk for FAP is different than one without increased genetic risk.

Just as relativity is built on comparisons, a related concept of importance is anchoring, the strong behavioral influence produced by first impressions (Ariely, 2009). While often
applied in an economic context, where initial prices are found to influence willingness to spend a certain amount of money on an item, the concept of anchoring can also be applied to healthcare decision making. If a patient or a family member has had a positive experience with genomic testing, then it might encourage them to engage in future genomic testing. If they have had a negative experience, then the opposite influence may be observed. Anchoring based on previous experiences may change the approach that decision makers take to addressing the options available.

**Deliberation**

Deliberation, the effort by an individual to identify alternatives, or new rules, for solving a problem, is important if practical problem solving or heuristics-based decision tactics have failed in supporting decision making regarding a dilemma (Gigerenzer & Gaissmaier, 2011; Mantzavinos, 2001). Heuristic decision making is the application of experiences of self or others to decision making. In deliberation as the mind seeks new alternatives, there is opportunity to address a problem through selection of one of several presented options or to apply the anecdotal knowledge of those who have encountered similar situations (Elwyn, Frosch, Volandes, Edwards, & Montori, 2010). This alternative is viable for decision making in genomic testing, but it is important to realize that, as with relativity, decisions are taken in context. The situation that one person faces in a diagnosis and testing decision is likely to differ, subtly or grossly, from anecdotal solutions. Contextually, genomic decisions are rarely identical from patient to patient, even within families. Even though test panels and results may be the same for several people, their lives and familial, environmental, emotional, and socioeconomic contexts vary, making the application of ready-made solutions difficult or impossible (Sweeny, Ghane, Legg, Huynh, & Andrews, 2014).

It seems relatively clear that there is limited potential for identifying a simple ready-made solution for decision making in genomics. In this regard, behavioral economics, when applied to the general situation of genomic testing decision making, may prove valuable in helping patients to make the best, most informed decision. The way to best shape these processes must rely heavily on choice architecture and requires a clear understanding of several of the dynamics at play (Thaler & Sunstein, 2008).

**Choice Architecture**

Choice architecture is the art of shaping decisions by designing choices within a framework that will encourage a certain choice. It is one mechanism that can be explored in attempting to best assist patients and families as they engage in genetic decision making. While it may seem like a limitation of autonomy, there is a clear difference between choice architecture and manipulation in that choice architecture merely provides guidance through information and support for decision making without attempting to limit a person’s autonomy (Sunstein, 2015). Nondirective counseling is central in the profession of genetic counseling, and it is imperative that nurses and other healthcare professions support patients without manipulating them. Choice architecture can address some of the external and internal contexts of decision making. Thaler and Sunstein (2008) offer some insight on choice architecture that, when applied to genomics, further supports the unique nature of the decisions to be made.
The application of choice architecture is very well suited to encouraging patient choices regarding wellness and preventive health. In such situations, choice architects employ “nudges” to frame decisions about the most appropriate route as the easiest one without limiting options. There are numerous ways to nudge decision makers, and often the processes are subtle because of their reliance on probable human behaviors; context is key. The scope and level of information involved in decision making in genomics requires further exploration when contemplating nudges and choice architecture. Understanding the unique nature of genomic information will help sharpen nudge methods but also improve our understanding of their applicability in aiding patient and family member decisions—and the ethical implications of employing such methods. Key nudge tactics that warrant further exploration in the setting of genomic testing decisions include default choices and mapping (Thaler & Sunstein, 2008).

**Default choices**—When no action is taken by the patient in genomic decision making, the result may be some kind of default choice. This path can be a slippery slope. Because the impact of genomic information can extend beyond the decision maker or patient, default choices should be respectful of all parties potentially affected. The sheer ability to obtain genetic testing is not a reason to do it, and the use of a strict default to test limits the autonomy that patients and decision makers must have. If choice architects were to use nudges in genomic decision making to prompt a default choice, then perhaps the safest default would be the null, no testing, choice, one with the potential to affect the fewest people and not to impose effects on others, inadvertently or not. There are some examples where the default to test is established in law, such as the use of newborn screening to test for a panel of specific genetic variants that can lead to various serious diseases (NHGRI, 2015). In this case, the default is set up to ensure early identification and intervention in patients with the selected genetic variants to ensure quality of life. Some of the selected variants have potential implications for other people beyond the patient (e.g., the tested child’s biological parents and other biological family members). The policy is designed to protect the perceived best interests of the child through early identification, early treatment, and improvement of outcomes. In other situations, such as where the proband is an older adult, a testing default choice is not a logical standard; it would be a nudge that discourages exploring other options. Because the implications of genomic testing results with regard to patient and family life are even less clear when testing in older populations, there is no clear path to a default choice for later life genomic testing.

**Mapping**—Mapping can be used as a way to nudge patients when making decisions regarding genetic testing. Mapping draws on a person’s knowledge and experiences to establish, by analogy to prior decision situations, a pathway to a decision in previously unexplored territory. However, as with most attempts to help shape a decision, there are some drawbacks. Not all genetic testing may lend itself directly to mapping, so it is important to be aware of the variables that may limit the ability to map out a decision pathway. These variables, fairly consistent in genomic decision making, include the context and timing of the decision, provider biases toward one type of testing or toward not testing at all, information asymmetry creating an increased patient dependence on nurses and other healthcare providers for appropriate information, and the social-emotional and financial
costs of genetic testing. Those patients and families considering genetic testing may need more time to make decisions, increased knowledge sharing between nurses and patients and families to limit information asymmetry, and an opportunity for deeper exploration of implications with patients to ensure that post-testing effects on patient and family lives are at least acknowledged if not mitigated in some way.

The BreastCARE intervention studies (Kaplan et al., 2014; Livuadais-Toman et al., 2015) provide an excellent example of how mapping might be helpful with genomics. BreastCARE sought to increase awareness and communication among patients and healthcare providers by using appropriate and validated measures of risk for breast cancer to structure a risk-assessment intervention. This strategy helped to increase communication of breast cancer–related information without increasing concern among patients. This intervention did not lead to a genomic testing decision per se, but it used existing knowledge to help shape the decision to speak with healthcare providers about breast cancer. Those who undergo this intervention may, in turn, need to be assisted in making the decision to seek testing for the genes associated with breast cancer, and this too could be mapped using a similar intervention.

Next Steps for Behavioral Economics and Genomic Decision Making

As genomic testing becomes more mainstream and as more people are faced with making decisions about testing and results, it will bring new challenges to old procedures and policies. Studies of decision-making processes and concerns will be crucial in adapting existing processes and developing new approaches. Understanding genomic decision making through a behavioral economic lens allows for the exploration of the nuanced factors at play in the rapidly emerging fields of genetics and genomics. While the personal and varied nature of genomic information makes restrictive and finely detailed descriptions of processes used in genomic decision making less likely, there is a need to have a clearer understanding of any processes that are undertaken.

Incorporation of behavioral economics elements can also help to create a more decider-friendly decision-making environment for those who are faced with difficult genomic testing decisions than the environment offered through the use of authoritarian approaches. There are a wide range of variables that each person will uniquely encounter, but there are also many commonalities that must be accounted for and further explored (Lerner, Li, Valdesolo, & Kassam, 2015). Nursing, based in holistic care, is uniquely equipped to inform the study of the decision-making processes as the complex intermingling of familial, contextual, emotional, environmental, and socioeconomic factors—all things that influence nursing care of patients. This unique nature makes studies seeking to identify ways to better support decision making imperative, and behavioral economics may be one path for reaching this goal. Exploring possible decision pathways or other tools that could be used to help patients contemplate the multiple variables of genomic testing is key for future steps in supporting patient decision making.

Contextual forces can disproportionately influence genomic decisions, resulting in a choice that may not fully reflect patient or family values or a full deliberation of the situation; nurses should be aware of these varied forces involved in decision making. Identifying the
importance of assessing the utility of options and awareness of situational perspective, Kahneman and Tversky elucidated some of the initial applications of concepts that underpin those discussed in this article (Kahneman, 2003; Kahneman & Tversky, 1979, 1992). There are numerous veins of inquiry related to behavioral economics and decision making that have relevance to health care; Game Theory, partially derived from the Nash Equilibrium, and other theories of conflict, bargaining, and outcomes, have also been applied to healthcare decision making (Djulbegovic, Hozo, & Ioannidis, 2015).

Behavioral economics does not rest solely on the belief that humans will always act rationally in a given situation, but rather accounts for contextual influencers such as emotions, cognitive biases, and other internal and external pressures (Ariely, 2009). This is growing in importance as patients are often turning to easily accessed resources for information, such as Internet resources of varied reliability, accuracy, and quality (Foster, 2016; Fox, 2008; Perazzo, Haas, Webel, & Voss, 2017). One behavioral economic concept that has been noted to shape decision making is present bias, or present-centeredness (Hostetter & Klein, 2013). Awareness of present bias is also important in understanding how decisions may be perceived. Understanding the value of information at the moment of testing and understanding the possible implications for future decisions of the patient and their family is imperative in genomic decision making.

It is important to consider how behavioral economic concepts can be applied in clinical nursing practice. Even before the blossoming of decision science as a part of nursing science, nurses have been a part of patient decision making (Pierce & Hicks, 2001). In the current patient-centered care environment, nursing has a unique role in patients’ decision-making processes. Relationships with patients and their families in times of both illness and wellness position nurses in contexts where important decisions are made. Often nurses are seen as sources of information and clarification when communication with other healthcare providers is limited. Nurses should seek to support decision making in a balanced manner, avoiding information asymmetry when at all possible and finding common ground from which to work. Behavioral economic concepts discussed here are important for informing nurses about how they can better support patient decision making within a shared or other decision-making model.

Interdisciplinary, collaborative exploration of decision making is an important part of assuring that patient decision making with regard to genomics is supported to the highest possible level. Understanding the core concepts of behavioral economics and choice architecture is key, and implementing these concepts to inform future studies will allow for improvement of the patient experience in genomic decision making. Nurses and other healthcare professionals must seek to better understand the context of the care that they deliver to their patients. The behavioral economic concepts described in this article offer a good start for better understanding decision making, specifically in a genomic context. Beyond the genomic focus of this article, nurses can benefit from further exploring these concepts and incorporating some of these approaches in supporting patients and families as they make difficult decisions.
These behavioral economic concepts do not replace the key concepts that underpin ethical practice and high-quality nursing, but are meant to complement nursing care. Patients are more than the sum of their complaints, diseases, or syndromes, and the process of diagnosis and treatment of illness is complex and multifaceted, possibly even more so when genomics are involved (Gorovitz, 2010). When engaging in supporting patient decision making, it is important that all parties involved fully understand the implications of decisions that they make, and these implications should be seen as a reason to further question processes. The use of behavioral economic mechanisms to support patient decision making is helpful in managing the complexities of these decisions through the use of information and expertise while still respecting autonomy. This is the essence of the marriage of behavioral economics with the nurse–patient relationship—the use of these approaches to overcome information asymmetry through thoughtful and deliberate support of patient decision making. Nurses will continue to provide high-quality care and support for patients, families, and caregivers; however, it is in that same vein that nurses must seek ways of understanding the new complexities of decisions faced by patients when deciding about genomic testing. While the question of whether to test or not may be dichotomous—either answer has effects on more people than just the patient at hand—nurses may be caught up in the mix as patients, families, and caregivers seek to reach a decision. Comfort, knowledge, and support are key aspects of the nursing care provided in times of need—nurses must remain unbiased and seek ways to bring balance in an unbalanced relationship between healthcare providers and patients.

Acknowledgments

Dr. Scott Emory Moore is a National Hartford Center of Gerontological Nursing Excellence Patricia G. Archbold Scholar and the recipient of the Oliver Kent and Bettye C. Cecil Fellowship in Geriatrics and Genetics from Clemson University. These two awards provided predoctoral support for the production of this publication. Dr. Scott Emory Moore’s postdoctoral training is supported by the National Institute of Nursing Research of the National Institutes of Health (T32NR015433 Multiple Chronic Conditions, Interdisciplinary Nurse Scientist Training; Principal Investigator, Dr. Shirley M. Moore). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References


<table>
<thead>
<tr>
<th>Clinical Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• National Institutes of Health, National Human Genome Research Institute. Genetic health professional education resources. <a href="https://www.genome.gov/17517037/health-professional-education/">https://www.genome.gov/17517037/health-professional-education/</a></td>
</tr>
</tbody>
</table>