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Self-Regulation Principles Underlying Risk Perception and Decision Making within the Context of Genomic Testing

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Abstract

Advances in theory and research on self-regulation and decision-making processes have yielded important insights into how cognitive, emotional, and social processes shape risk perceptions and risk-related decisions. We examine how self-regulation theory can be applied to inform our understanding of decision-making processes within the context of genomic testing, a clinical arena in which individuals face complex risk information and potentially life-altering decisions. After presenting key principles of self-regulation, we present a genomic testing case example to illustrate how principles related to risk representations, approach and avoidance motivations, emotion regulation, defensive responses, temporal construals, and capacities such as numeric abilities can shape decisions and psychological responses during the genomic testing process. We conclude with implications for using self-regulation theory to advance science within genomic testing and opportunities for how this research can inform further developments in self-regulation theory.

Keywords

Self-regulation; decision making; genetic testing; genomic testing; risk perception

Introduction

Advances in research on self-regulation processes have yielded important insights into how cognitions and emotions shape risk perceptions and risk-related decisions. Self-regulation

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refers to the processes through which individuals direct their thoughts, emotions, and actions to achieve desired outcomes and minimize harms. Self-regulation theory has proven valuable in advancing knowledge of the dynamics guiding complex, risk-related decisions about health and other important life issues (Baumeister, 2016; Cameron & Leventhal, 2003; Carver & Scheier, 1998; Latham, 2003; Mann, de Ridder, & Fujita, 2013). In this article, we use a self-regulation framework to identify new and novel directions for further inquiry within the context of genomic testing, a clinical arena where individuals must grapple with complicated risk information and make potentially life-altering decisions. At the same time that self-regulation theory can advance our understanding of genomic-testing decisions, genomic testing in turn can offer a rich environment within which scientists can advance self-regulation theory by examining how people respond when faced with the demands of making complex decisions with potentially high stakes.

Genomic testing is a general term that includes single-gene testing for mutations that confer disease risk, multi-gene panel testing for variants in numerous genes that incur risk for multiple conditions, and exome sequencing of all protein-coding genes in one's DNA. With rapid advances in genomic testing, healthcare providers increasingly implement precision medicine by using genetic information to inform disease-treatment and prevention decisions. For example, adults with a family history of disease might undergo testing for elevated risk of cancer, cardiovascular disease, Alzheimer's Disease, and other common conditions; pregnant women routinely accept prenatal screening; and health care providers increasingly use genetic testing to target treatments to client responsiveness (e.g., using the Oncotype DX test to determine whether a woman with breast cancer should undergo chemotherapy or radiation).

Genomic testing offers new promise for improving disease prevention and control, but its use is complicated. First, genomic-test results largely convey probability and ambiguity, and so individuals must make decisions based on their subjective risk interpretations. Individuals also need to manage emotions aroused by disease threat, uncertainty, and the positive or negative implications of results. In addition, genomic testing often involves a complex series of decisions along a temporal spectrum of screening, diagnosis, treatment, and ongoing health management. Decisions about whether to undergo genomic testing, whether to pursue screening or other consequential actions (e.g., terminating a pregnancy), and how to manage disease risk over time are a few examples. Finally, because an individual's genomic-risk information is not only personally relevant but also relevant to relatives for whom results might reveal information about their risk, the individual undergoing testing must also decide whether and how to share results with others. Genomic testing is an arena in need of further psychological research to better understand and improve decision making, adaptive behaviors, and well-being.

In the following sections, we present a self-regulation framework and discuss how it can inform our understanding of decision making within the genomics context. We first introduce genomic testing and offer a case example illustrating the complexities of testing decisions. Next, we present general principles of self-regulation theory. Then, using the case example to illustrate key points, we discuss how principles related to risk representations, emotion regulation, defensive responses, temporal construals, and capacities such as numeric

abilities can shape decisions and psychological responses during the genomic-testing process. We focus on these self-regulation constructs because they are particularly relevant to how people process risk information about immediate and longer-term threats. We conclude with implications for using self-regulation theory to advance the science of genomic testing and, in turn, how genomic-testing research can advance self-regulation theory.

Genomic Testing: Introduction and a Case Example

Genomic testing is expanding quickly, and numerous options are available to clients in prenatal, pediatrics, and adult disease settings. Tests range from those used conventionally in healthcare settings (e.g., most pregnant women with insurance or other financial resources undergo prenatal screening) to tests that are available but not yet implemented widely (e.g., exome sequencing). Tests also vary considerably in the degree of risk conferred by a genetic variant. For example, a positive result from a genetic test for Huntington's disease indicates with 100% certainty that it will develop (barring early death from other causes) whereas a predictive (ApoE) result for non-hereditary Alzheimer's Disease confers about a 13% risk for the disease and genomic tests for diabetes or macular degeneration confer lifetime risks of up to 20%. To illustrate the complexities inherent in genomic testing, we describe a hypothetical case example: Louise, who was faced with the decision of whether to undergo testing for genetic risk of cancer.

High-risk cancer testing: The case of Louise

Louise was diagnosed with breast cancer at age 30. She underwent surgical removal of the tumor followed by chemotherapy. At the age of 41, Louise was diagnosed with endometrial cancer and underwent a hysterectomy and radiation therapy. Her maternal grandmother had breast cancer in her fifties but no other relatives have had any type of cancer. Following her hysterectomy and radiation therapy, Louise's internist referred her to a high-risk cancer clinic for genetic counseling. The counselor conveyed to Louise that a genetic cancer risk may exist in her family because of the early onset of Louise's and her grandmother's cancers and the rarity of endometrial cancer in the general population. The counselor informed Louise that she had a slightly increased risk of carrying a *BRCA1* or *BRCA2* variant. These variants can confer up to an 85% lifetime risk of breast cancer and up to a 70% lifetime risk of ovarian cancer. Endometrial cancer does not typically occur in *BRCA1/2* carriers, but risk of endometrial cancer is elevated in hereditary non-polyposis colon cancer (HNPCC) families who also have higher risks for colon and other cancers. The counselor explained to Louise that she has less than a 5% chance of carrying a *BRCA1/2* mutation and less than a 10% chance of a HNPCC mutation. The counselor then explored how anxious Louise felt about regular mammography and colonoscopy. Louise found both screenings anxiety-provoking but thought she would feel better once she learned the results because they would alleviate her worries about new or recurrent cancer. It had not occurred to her that a cancer gene might be in her family, and she became concerned about her children and other relatives getting cancer. She expressed worry about how her relatives would respond to that possibility.

The genetic counselor helped Louise deliberate about whether to undergo genetic testing. The counselor suggested she consider multi-gene panel testing for both hereditary breast and ovarian cancers and HNPCC syndromes as well as other cancer genes that increase risk. She explained that it was more likely that no cancer gene variant would be identified through the panel testing, in which case she would recommend that Louise follow the usual screening guidelines for endometrial and breast-cancer survivors. The counselor also informed Louise that there was a significant chance of finding a genetic variant of unknown significance (VUS), which would leave her with uncertain results. When a VUS is found, patients typically follow a conservative screening regimen until further interpretation of the results becomes available.

Louise had to decide about predictive panel testing, an emotionally-charged decision given the implications for herself and her family. The decision was also cognitively difficult as she faced unfamiliar and complex information, much of it probabilistic. The decision was even more distressing because of her self-perception of not being a “numbers person.” She felt uncertain about whether to proceed with panel testing and chance receiving an uncertain result. Although she was undergoing recommended cancer screenings already, she expected that receiving an uncertain result would lead her to pursue more frequent screening to quell her rising anxiety about possible future cancers.

Louise’s testing outcome

Louise ultimately decided to undergo testing and was found to have a pathogenic variant in the *BARD1* gene. This variant increases her risk for developing breast cancer to an uncertain degree. Whether it increases risk of other cancers is also unclear. The genetic counselor described it as likely explaining much of her medical and family cancer history. This discovery of a previously unknown genetic risk factor in the family might change Louise’s risk perceptions or her feelings about her risk. It might also influence her sense of control over managing the risk. It certainly reinforced concerns about her children and other relatives developing cancer. A VUS was also found in another cancer gene on the panel. The counselor explained that this VUS is an uninterpretable variant that could be benign or it could pose an indeterminate risk. Louise was bothered by this uncertain result as it suggested the possibility that her cancer risk could be even higher. As she anticipated prior to testing, she felt that she should undergo additional cancer screening until the VUS could be properly interpreted.

Challenges of genomic testing exemplified by the case of Louise

Individuals such as Louise often face complex genomic-testing options requiring consideration of numeric risk probabilities, implications for relatives, and options for risk control such as screening or prophylactic surgeries. Panel test results identifying an unexpected variant in a cancer gene can result in further uncertainty about how to manage one’s future health risk. Given the high degree of uncertainty, Louise might not feel that she can rely on her counselor’s or physician’s advice. As such, she might choose to pursue unnecessary, additional screening to assuage her anxiety and other negative emotions. Panel testing thus creates a demand for better risk information and clinical services to help individuals make informed, value-based decisions that are consistent with client preferences.

Yet to date, few studies have examined how best to inform patients about test options when choices are preference-based versus recommended and how individuals make decisions to undergo testing or act on the results. A self-regulation framework can provide a roadmap to guide psychological science in finding solutions to these problems.

A Self-Regulation Framework of Risk Perception and Decision Making

Self-regulation encompasses the processes through which mental representations of situations develop, activate emotions, and interact with emotions to shape decisions for goal pursuit (Carver & Scheier, 1998; Leventhal et al., 2012; Mann et al., 2013). These processes shape decisions and behavior through stages of setting goals, planning and enacting strategies to achieve these goals, appraising feedback to determine progress toward goal attainment, and revising goals and actions accordingly. Appraisals of good or poor progress can elicit emotions that independently influence goal-setting and goal pursuit.

Figure 1 displays our framework for the self-regulation of illness risk. This model incorporates processes for understanding and making decisions about illness risk by integrating the Common-Sense Model (Cameron, 2008; Cameron & Jago, 2008; Leventhal et al., 2012) with constructs delineated by Temporal Self-Regulation Theory (Hall & Fong, 2007) and defensiveness processes (van't Riet, & Ruiter, 2014; Weibe & Korbel, 2003). Although this framework is not inconsistent with other theoretical models of self-regulation for behaviors in general (e.g., Carver & Scheier, 1998) or those requiring self-control (Baumeister, 2016), it focuses on self-regulatory processes specific to understanding and responding to health threats. The model identifies interactive motivational systems targeting: (1) management of the threat itself; and (2) management of emotional representations, or construals of emotions elicited by the threat and, in particular, fear-related emotions that are common reactions to threat.

Risk representations play critical roles in shaping decisions to engage in protective behaviors as well as activating emotions and emotion-regulation efforts (Cameron, 2008; Leventhal et al., 2012). Within the context of managing health threats, risk information activates an illness risk representation involving five key attributes: (1) identity (illness label and associated symptoms and signs); (2) cause, or factors contributing to illness development; (3) timeline, including beliefs about onset and duration; (4) consequences, including physical and psychosocial outcomes; and (5) control/cure, including beliefs about protective behaviors and treatments or fatalistic beliefs that the illness is uncontrollable. These representational contents form the basis of risk perceptions such as perceived likelihood (based on identity, cause, and timeline beliefs) and severity (based on consequences and control beliefs; Cameron, 2008). They direct decisions to engage in protective behavior and are revised as the outcomes of these actions are appraised. Protection motivations are also promoted by representational coherence, or the extent to which representational attributes are consistent with themselves and with representations of protective behavior so that they provide a clear understanding that "makes sense".

Risk representations elicit emotional reactions such as fear or worry, and construals of these experiences can prompt emotion-regulation efforts (e.g., cognitive reframing, distraction

activities, or expressing emotions to others). Fear-related emotions can also elicit defensiveness and trigger efforts to avoid threatening information, cognitively minimize the degree of risk or harm, or respond with reactance. These emotional reactions also shape representations; for example, they can highlight information for further consideration and, as "feelings of risk," they can act as information to drive risk perceptions (Slovic, Peters, Finucane, & MacGregor, 2005; Loewenstein, Weber, Hsee, & Welch, 2001). Further, they can spur efforts to consider objective health risks more closely and either use that information in later judgments or decisions (Evans, et al., 2015; Peters, Lipkus, & Diefenbach, 2006) or minimize the risks akin to what researchers have called "motivated cognition" (Kunda, 1990).

Temporal construals also shape how people respond to risk information (Hall & Fong, 2007; 2013). Temporal construals refer to the psychological distance between one's current experience and alternative experiences, with greater value or worth placed on immediate, concrete, or highly probable events and less value applied to future, abstract, or highly improbable events. For many health decisions such as whether to get tested for illness risk, the temporal proximity of costs and benefits differs such that costs (e.g., discomfort, inconvenience, or worry about results) are immediate whereas benefits (e.g., to long-term health through risk management) may not be experienced until further into the future. For risky behaviors (e.g., avoiding a health care visit), the benefits are often immediate with the costs occurring in the distant future. Because people tend to value immediate contingencies more (Loewenstein, Read, & Baumeister, 2003), short-term costs of protective behaviors can de-motivate these behaviors despite appreciation of long-range health benefits. Thus, substantial self-regulation efforts may be required for better health.

Finally, self-regulation theory addresses the role of self-regulatory capacity in decisions and actions (Hall & Fong, 2007, 2013). Self-regulatory *capacity* is the ability to engage in goal-directed efforts. It is influenced by biological capacities such as physiological energy, cognitive functions such as numeracy and willpower, and social/environmental constructs such as social norms or test availability. While self-regulatory capacity can directly influence decisions, it can also shape representations. For example, numeric skills can influence interpretations of risk information such as probability estimates in ways that produce a cascade of effects that ultimately guide decisions about prevention behaviors or screening tests.

In the following sections, we consider how specific aspects of this self-regulation framework relate to genomic-testing perceptions and decisions, referring to the case of Louise to illustrate these points. In each section, we highlight research directions that are particularly promising in advancing the parallel goals of: (1) understanding how to promote effective self-regulation and decision making within the genomic-testing arena; and (2) using genomic-testing issues to develop and test self-regulation theory as it applies to complex decision making in situations high in risk and uncertainty. We begin with mental representations and their role in guiding genomic-testing perceptions and decisions.

Genetic Risk Representations and Representation-Behavior Coherence

Mental representations of disease risk guide how people interpret information about genomic testing and which aspects of the information they accept, reject, or misconstrue. For example, beliefs that genes are a primary cause of disease tend to foster views that genomic tests are relevant and important (Marteau & Weinman, 2006) and provide accurate estimates of disease risk (Michie et al., 2002). Genomic-testing information can also modify risk representations. For example, information that a genomic test can determine disease risk tends to intensify beliefs that the condition is caused primarily by genes (Marteau et al., 2004). Considering the case of Louise, if her counseling session caused her to believe that her cancer risk is determined largely by genetics, she might be more motivated to undergo testing and to accept the results as valid indicators of her risk, even in the circumstance that her genes were unlikely to be the underlying cause of her cancers.

Risk representations also shape representations of protective actions by means of "IF-THEN" risk-action links (Cameron, Marteau, Brown, Klein, & Sherman, 2012; Marteau & Weinman, 2006). For example, a common-sense link between a risk representation and action representations for heart disease might be, "IF lack of exercise causes heart disease, THEN regular exercise will reduce the risk of heart disease." This is a coherent risk-action link between a causal risk belief and a protective action (Marteau & Weinman, 2006), in which individuals expect that risk attributes (e.g., lack of exercise as a cause) will point directly to the actions needed to control the risk (e.g., regular exercise). Coherent risk-action links are critical in motivating protective behavior (Bishop, Marteau, Hall, Kitchener, & Hayek, 2005; Cameron et al., 2012).

Belief that a disease is caused by genetic variants can lead to specific types of risk-action links (Marteau & Weinman, 2006). For example, individuals could exhibit a genetic essentialist bias to perceive genetic outcomes as immutable and unchangeable (Cheung, Dar-Nimrod, & Gonsalkorale, 2014; Dar-Nimrod & Heine, 2011). This cognitive bias can lead to assumptions of "genetic fatalism" such as the "IF-THEN" link: "IF breast cancer is caused by genetic mutations, THEN there is nothing that can be done to reduce my risk". This fatalistic belief could make it difficult to accept information that disease risk nonetheless can be reduced through treatment or behaviors such as diet or exercise (van Maarle, 2003; Shiloh, Rashuk-Rosenthal, & Benyamini, 2002). Beliefs that behaviors such as physical inactivity ("laziness") and alcohol use are genetically determined can also reduce perceived self-efficacy in altering these behaviors and behavior change motivations (Beauchamp, Rhodes, Kreutzer, & Rupert, 2011; Dar-Nimrod, Zuckerman, & Duberstein, 2013), although they might also spur seeking early professional help (Dar-Nimrod et al., 2013). Alternatively, individuals often assume that biological processes affected by genes can be controlled with biologically-based treatments such as medication or surgery (Marteau et al., 2004; Wright et al., 2003); for example: "IF breast cancer is caused by genes, THEN surgery and chemoprevention can reduce my risk". This risk-action link could increase use of pharmacological or surgical measures and undermine health-protective behaviors (Senior & Marteau, 2007). For Louise, this IF-THEN link could motivate the use of chemoprevention medications such as tamoxifen while lessening confidence that exercise, a healthy diet, or limited alcohol use will protect her from cancer.

These tendencies to form “IF-THEN” links can make it difficult for individuals to develop mental models of gene-behavior interactions that motivate behavioral means of risk reduction. Communications, however, that clearly explain the links among a genetic variant, physiological disease processes, and protective actions can instill coherent risk-action links that, in turn, increase motivations to engage in health-protective behavior (Bishop, Marteau, Hall, Kitchener, & Hayek, 2005; Cameron et al., 2012). For example, members of melanoma-prone families who receive genetic counseling with explanations of how sun protection can reduce melanoma risk report either no change or increases in their beliefs that they can control their risk through sun protection (Aspinwall et al., 2015). Further, people who endorse genetic causes of disease are sometimes *more* likely to endorse behavioral causes for conditions with gene-behavior links that are easily recognized and understood (Lippa & Sanderson, 2012; Sanderson et al., 2013; Wang & Coups, 2010). With obesity, for example, the considerable media attention on the integrated roles of genes, low metabolism, and high-caloric diets as causal factors could foster understanding of how dietary changes could reduce the genetic risk of obesity.

Research is needed to explore factors that foster understanding of the joint influences of genetics and behaviors on disease risk, and how appreciating genetic-behavior dynamics can promote protective behaviors. Moreover, research is needed on how people’s values, beliefs, and traits affect their comprehension of genomic-testing communications and shape their risk representations and IF-THEN action links. More broadly, as the science on gene-environment interactions grows, so will the need for research on how to convey these relations in genomic-testing communications.

Emotion Regulation

As reflected in the case of Louise, genomic testing can create strong emotions. These emotions vary across individuals, diseases, and specific genetic results. Although people may experience positive emotions (e.g., relief and hope after negative test results; Eijzenga, Hahn, Aaronson, Kluijt, & Bleiker, 2014), we highlight situations in which negative emotions may result as they tend to be more disruptive and demand greater self-regulatory efforts.

Individuals can experience an array of emotions throughout the genomic-testing process. Individuals offered genomic testing can experience anxiety about decision making (Farrell et al., 2011) and those waiting for test results often experience worry and dread (Mendes et al., 2011). Individuals who receive results indicating heightened risk can experience anxiety and depressed affect, particularly when the disease cannot be prevented or controlled (Gritz et al., 2005; den Heijer et al., 2013). They can experience anger over their fate, shame from perceived stigma, and guilt over passing a genetic risk to their children (Eijzenga, Hahn, Aaronson, Kluijt, & Beiker, 2014; Vodermaier, Esplen, & Maheu, 2010). Those learning of low risk can experience guilt over being spared when other family members have the genetic risk (Smith, West, Croyle, & Botkin, 1999). People with heightened genetic risk often report that managing emotions is a primary concern (Eijzenga et al., 2014). Distress dissipates in the months following testing for a majority of test takers (Graves et al., 2011; Hamilton, Lobel, & Moyer, 2009), suggesting that many regulate their emotions successfully. How

these emotions are managed in the short and longer term can shape testing decisions and protective behaviors as well as interactions with family, friends, and health care providers, all of which can influence health and quality of life (DeSteno, Gross, & Kubznaski, 2013).

Self-regulation theory identifies common strategies for managing emotions in a five-stage, emotion-generative process (Cameron & Jago, 2008; DeSteno et al., 2013). We consider how these strategies might influence genomic-testing decisions and experiences. In the initial stage of situation selection, individuals can act to increase the chance of entering situations that lead to desired emotions and avoiding situations eliciting undesired emotions. Concerns about negative emotions could lead to decisions to decline testing, skip family get-togethers where discussions of genetic risk might arise, and avoid screenings (e.g., colonoscopies). For example, Louise might have chosen to decline the panel test to avoid any prospect of bad news and instead pursue aggressive screening that might not be indicated.

The second stage, situation modification, involves attempts to alter the environment to shape one's emotions. Examples include bringing a support person to the genetic-test visit, insisting that family members not discuss genetic risk, or selecting a reassuring doctor to perform detection exams. The third stage of attentional deployment involves efforts to decrease or increase focus on an emotionally-evocative issue. It can manifest as avoidance, such as attempts to push thoughts about genetic risk out of one's mind or avoid information about it. For example, Louise might have found the stressfulness of the testing decision to be so aversive that she distracts herself by talking with friends, immersing herself in other activities, or delaying her decision. Conversely, attentional focus can manifest as vigilant monitoring for information to reduce uncertainty or find solutions. For example, pregnant women offered prenatal genomic testing might actively search the Internet for information about the test, probabilities of mutations, abortion procedures, or support services for children with genetic disabilities. Rumination about disease risk and self-monitoring for disease-related symptoms also represent attentional-focus behaviors.

The fourth stage involves cognitive change, or efforts to reappraise the situation to alter emotional experiences such as to reduce anxiety or generate hope. Individuals at heightened genetic risk often report reappraising by revising life priorities, generating optimistic construals, and focusing on the present rather than the past or future (Appleton, Fry, Reis, Rush, & Cull, 2000; Bakos et al., 2008). Among breast cancer survivors receiving *BRCA1/2* test results, for example, mutation carriers have reported higher levels of benefit-finding (e.g., greater appreciation of life and gains in personal strength) relative to non-carriers (Low, Bower, Kwan, & Seldon, 2008). For Louise, the identification of the gene variants could have led to greater appreciation of her life and a positive self-identity as a survivor with psychological fortitude.

The final stage, response modulation, includes efforts to alter experiential and behavioral aspects of emotions. Intrapersonally, it can include using mindfulness, leisure activities, or substances such as alcohol to relax or dull negative emotions. Interpersonally, it includes efforts to shape emotional communications with others through suppression or sharing. Individuals with heightened genetic risk may hide their feelings from their family to avoid

causing them distress. These suppression tendencies can have deleterious effects such as prolonged distress, relationship difficulties, exacerbated treatment side effects, poor adjustment, and faster disease progression (Chapman, Fiscella, Kawachi, Duberstein, & Muening, 2013; DeSteno et al., 2013; Schlatter & Cameron, 2010). Conversely, the benefits conferred by emotional expression (Booth, 2012; Pennebaker & Chung, 2007) suggest that it could improve emotion regulation and its associated psychosocial and health benefits within the context of genomic testing. Louise could benefit from sharing her feelings with her genetic counselor and her family or from using expressive writing to explore her feelings about her testing decision.

The nature and complexity of emotions experienced across the stages of genomic testing highlight the opportunities for advancing research on emotion regulation. Questions remain about how the five emotion-regulation strategies, when used during counseling and within relationships, influence testing decisions, decision satisfaction, treatment choices, and quality of life. Other fruitful topics for research include the role of mixed or changing emotions on single-shot testing decisions or those made over time. These findings could be applied to generate tools to assist individuals in managing their emotional experiences during the testing process.

Defensive Responses

Defensive responses reflect one form of motivated cognition, which refers to reasoning that is biased by the desire to reach specific conclusions (Kunda, 1990; Molden & Higgins, 2005). Health messages conveying a heightened genetic risk for disease can be threatening to one's self-identity, and these feelings of threat can elicit unconscious motivations to defensively protect the self by distorting or rejecting threat information (Leventhal, 1970; van't Riet & Ruiter, 2013; Wiebe & Korbel, 2003). With respect to Louise, the anxiety-provoking prospect that the panel test results would indicate the need for frequent mammograms or colonoscopies could trigger defensiveness. She might be even more defensive if she exercises infrequently and expects her counselor to recommend regular exercise based on her results.

Various forms of defensive responses can manifest in the context of genomic testing. Defensiveness can motivate information avoidance, such as declining opportunities to meet with a genetic counselor or receive genetic information (Taber et al., 2015a). People are particularly likely to defensively avoid situations involving receipt of risk information when they do not know its contents or valence and when they expect it to change their attitudes, affect, or behavior in undesirable ways (Sweeny, Melnyk, Miller, & Shepperd, 2010).

If people do receive risk information, they can instead cognitively minimize the degree of risk or reject its accuracy (McQueen, Vernon, & Swank, 2012). Minimization represents a major barrier to the effective provision of risk information and behavioral recommendations (Croyle et al., 2006; Liberman & Chaiken, 1992; Schuz, Schuz, & Eid, 2013) and thus poses a particular threat within the context of genomic testing. For example, after Louise learned about the variant in the BARD1 gene and the VUS, she might have convinced herself that this risk was not so high that frequent screenings or exercise changes were necessary.

Minimization can also have consequences for family members. Individuals who respond defensively to genomic-testing information may not provide crucial information to relatives to prompt them to seek testing or engage in healthier behaviors (van den Nieuwenhoff et al., 2007). If Louise responded defensively, she might not have discussed the panel-testing decision with her family even though testing would provide information about their cancer risks.

Another defensive response likely to occur in this context is reactance, in which people perceive recommendations to change behaviors as a threat to their personal freedom or identity and thus continue to engage in risky behaviors (Brehm, 1966). Given that reactance occurs when people feel that their autonomy and identity are threatened (Miller, Lane, Deatrick, Young, & Potts, 2007), researchers can consider strategies to identify aspects of testing information that most threaten an individual's sense of self and implement strategies for reducing that threat. For example, if the prospect of prophylactic mastectomy threatens Louise's sense of femininity, a counselor might focus on decisions surrounding reconstructive surgery, which might reduce her defensiveness. Further, people are less likely to engage in reactance when they believe they can choose how to act (Miller et al., 2007). With Louise, the counselor made clear that she could choose whether to proceed with testing and that she would have options for managing test results – a standard practice in genetic counseling that is likely to reduce reactance.

Importantly, little is known about whether these defensive responses actually reduce protective behavior over time. Defensive responses might lead to *increased* health behaviors if they successfully reduce negative emotion or motivate acceptance of behavioral recommendations as one strategy for reducing the fear of getting a disease (van't Riet & Ruiter, 2013). Louise, for example, might initially react poorly to news that she is at genetic risk for cancer, but could accept her risk over time. She might even embrace the test as a means of illuminating the risk patterns within the family and encourage her family to seek testing and engage in screening and other protective behaviors. Much research on defensive processes has been conducted in laboratory settings in which participants are told of a hypothetical or fictitious disease risk and then debriefed that they are not truly at risk afterward (e.g., Ditto & Lopez, 1992; Jemmott, Ditto, & Croyle, 1986). Less work has examined how defensive responses unfold over time (Wiebe & Korbel, 2003; van't Riet & Ruiter, 2013). The context of genomic testing allows researchers to examine how defensive processes change over time in the context of meaningful decision making.

Self-affirmation to reduce defensive reactions

Theory and research point to strategies to reduce defensive responses and hasten acceptance of threatening information, such as that conferred by genetic risk. Self-affirmation is one promising technique (Cohen & Sherman, 2014). It is based on the premise that people aspire to see themselves (and have others see them) as high in integrity and consistency (Steele, 1988). When faced with a personal threat (e.g., failure to achieve a goal or messages that threaten certain lifestyle behaviors), one can manage the threat by affirming important values that bolster one's sense of integrity. For example, when exposed to threatening messages about their health behaviors (e.g., graphic warning labels for cigarettes; articles

about the dangers of alcohol abuse), people are less defensive and more likely to change their behavior when self-affirmed in advance (e.g., Harris & Epton, 2009; Reed & Aspinwall, 1998). Although most research provides self-affirmation opportunities experimentally – usually by asking participants to complete value scales or write essays about cherished values (McQueen & Klein, 2006) – people often engage in spontaneous self-affirmations, and some people more than others (Harris, Napper, Griffin, Schüz, & Stride, 2016; Taber et al., 2015b).

The threats inherent in the genomic-testing process open up numerous possibilities for self-affirmation strategies to be implemented to improve decisions. For example, smokers who learn that they have a high genetic risk for lung cancer might respond less defensively if they also have opportunities to reflect on cherished values (Crocker, Niiya, & Mischkowski, 2008). A likely related intervention approach used by genetic counselors is to query and explore important relevant values during the sessions. In the case of Louise, the counselor might lead her to elaborate on important values and activities. Little work has examined how such self-affirmation strategies might influence engagement with genetic information, but preliminary evidence suggests a beneficial role (Taber et al., 2015b).

Temporal Construals

As noted earlier, perceived temporal proximity of costs and benefits associated with genomic testing and risk-reducing behaviors can shape risk representations (e.g., timeline, consequences, and control beliefs), emotions, decisions, and outcome appraisals. But temporal proximity is only part of what determines psychological distance, or the perceived divergence from one's immediate experience along the dimensions of time, space, social perspective, and hypotheticality (Liberman & Trope, 2014). Psychological distance is also determined by the level of abstraction at which an object or event is construed. High-level, abstract construals are perceived as psychologically distant, with low-level, concrete construals perceived as psychologically near. Research demonstrates that individuals guided to make more high-level construals about objects and events are more willing to receive unpleasant but useful feedback about themselves (Freitas, Salovey, & Liberman, 2001). Further, creating abstract mental representations can lead to better self-regulation, and high-level construals can improve self-control (Fujita, Trope, Liberman, & Levin-Sagi, 2006). These findings point to new research directions concerning how people self-regulate in the context of genomic testing. In particular, research can test whether encouraging people to process genomic-test information at higher levels of construal could reduce defensiveness, thereby increasing openness to learning about genetic risk and behavior modifications.

A dimension of psychological distance that is particularly relevant to genomic testing is hypotheticality as reflected in the degree of risk; i.e., low versus high probability of disease (Liberman & Trope, 2014). Low hypotheticality (e.g., low disease likelihood) fosters high-level, abstract construals whereas high hypotheticality (high disease likelihood) promotes low-level, concrete construals (Wakslak & Trope 2009; Todorov, Goren, & Trope, 2007). Similarly, genetic risk information that is presented as uncertain (e.g., a VUS) versus certain (e.g., definitive presence of a *BRCA1/2* mutation) is likely to be construed at a high level versus low level, respectively.

Understanding the psychological distance of risk estimates are also important because dimensions of psychological distance are automatically associated; if an object is near versus far on one dimension then it tends to be perceived as similarly near vs. far on another dimension (Trope & Liberman, 2010). Individuals also expect unlikely events to happen further in the future than likely events (Wakslak, 2012), suggesting that the degree of risk conferred may influence beliefs about timeline, disease threat salience, and need for immediate action. Thus, whether a risk estimate is certain or uncertain, or high or low, might influence whether an individual prioritizes proximal or distal outcomes. Because effective self-regulation and adherence to behavioral recommendations often require prioritizing distal outcomes, encouraging abstract mindsets and focusing on other high-level constructs might promote effective decision making and self-regulation. For Louise, if her counselor frames the test results to emphasize the low probabilities and high uncertainties linked with the variants, Louise might adopt a high-level, abstract mindset that makes her more open to learning about treatment alternatives and considering lifestyle changes such as exercise. Future research can examine how the abstract versus concrete nature of an individual's mindset at the beginning of genetic counseling influences subsequent decisions about testing and protective action, and whether interventions to change mindsets can promote favorable outcomes. Researchers can also explore how the influence of genetics on health outcomes is construed from a temporal perspective, such as whether abstract or concrete construals shape timeline perceptions of when in the future a genetic predisposition might lead to disease onset.

Numeric Competencies

Self-regulation theory points to cognitive capacity as a critical factor influencing decisions and actions in the context of managing risks (Hall & Fong, 2007). Abilities with numeric information represent one such cognitive capacity relevant to the highly numeric domain of genomic testing. Numeracy difficulties are ubiquitous within the genomic-testing domain, as people often have difficulty interpreting risk estimates (Fagerlin, Zikmund-Fisher, & Ubel, 2011; Windschitl, 2002). They are also generally insensitive to small and moderate increments in genetic risk probabilities (Bruine de Bruin et al., 2000; Cameron, Sherman, Marteau, & Brown, 2009) and instead tend to interpret the "gist" of risk probabilities in terms of whether they indicate low risk, high risk, or a "50-50" chance (likely reflecting a sense of uncertainty as in "who knows?").

Objective numeric competency, a facet of intelligence (Cattell, 1950), has been associated with the processing of numeric health information and, in turn, risk representations and decisions. Individuals who are less objectively numerate understand numeric information less well and tend to make worse decisions than the more numerate (Peters et al., 2006; Schwartz, Woloshin, Black, & Welch, 1991). For example, those higher in objective numeracy are more likely to use numeric information in decisions whereas the less numerate are more likely to use non-numeric and emotional sources of information such as anecdotes from family or the media and the positive or negative frame in which information is presented. Those lower in objective numeracy tend to be less sensitive to differences in risk probabilities, presumably due to their lower ability to draw affective meaning from numeric

information (Peters et al., 2006; Petrova, van der Pligt, & Garcia-Retamero, 2014) although such differences have not been examined within the context of genomic testing.

Research also has revealed distinct roles for objective and subjective numeracy (independent of general intelligence) in the processing and use of numbers in judgments and decisions (Peters & Bjalkebring, 2015). Subjective numeric competency, or perceptions of one's numeric capabilities, influences motivations to attend to numeric health information and confidence in one's appraisals in ways that may shape risk representations and decisions. Controlling for objective numeracy, individuals lower (versus higher) in subjective numeracy appear to have more negative emotional reactions to number-related tasks and find them less attractive. In the genomic-testing domain, Miron-Shatz, Hanoch, Doniger, Omer, and Ozanne (2014) found that higher subjective (but not objective) numeracy was associated with greater willingness to pay for direct-to-consumer genetic tests. In addition, those higher in subjective (but not objective) numeracy expressed greater preferences for providing and receiving numeric information rather than just words in health communications (Anderson, Obrecht, Chapman, Driscoll, & Schulkin, 2011; Couper & Singer, 2009). For example, physicians higher in subjective numeracy were more likely than those lower in subjective numeracy to use numbers when conveying Down syndrome screening results (Anderson et al., 2011).

Louise, who views herself as "not a math person," is likely low in subjective numeracy and may value genomic testing less simply because she does not like numbers and is uncomfortable using them (Gurmankin, Baron, & Armstrong, 2004). Such emotional preferences to avoid numeric information could have led her to choose not to get the panel testing, particularly given the complexity of the results involving multiple genes and risk patterns. Other individuals who believe themselves good at math may have stronger preferences to undergo testing simply because they like numbers and like to receive them. Yet this preference could prove problematic if they are not objectively numerate enough to understand the numbers. If Louise is as poor with numbers as she believes, then she might not have a clear sense about the "goodness" or "badness" of her 10% chance of carrying an HNPCC mutation. Consequently, she might have relied more on her worry about cancer recurrence in making her testing decision without deliberating carefully about her chances of having a variant.

Research on the roles of objective and subjective numeracy in responses to genomic testing information can provide new insights into how these facets of cognitive capacity influence decisions requiring the comprehension and use of complex risk information. This research could inform our understanding of which individuals are likely to misinterpret and misuse genomic risk information and how they tend to do so. The findings could guide the development of tools to help those low in objective or subjective numeracy manage the self-regulatory demands of making genomic testing decisions and understanding the implications of test results.

Conclusion

A self-regulatory perspective can provide novel insights into the complex cognitive and emotional processes guiding decision making in the genomic-testing arena. Examples throughout this paper argue for the importance of using self-regulation theory to frame studies of genetic counseling and to promote informed choices about genomic testing and the subsequent use of results to promote health and well-being. Specifically, we have identified the potential for theory and research on risk representations, emotion regulation, defensiveness, temporal construals, and numeric competencies to shape the self-regulation processes guiding genomic-testing decisions and experiences. The new research directions suggested throughout this paper are likely to accelerate advances in self-regulation theory on the one hand and genomic testing research and practice on the other. The self-regulation framework presented here can guide research that, in turn, can be used to revise and extend it.

We have used Louise's example of panel testing for cancer risks to illustrate the complexities of genomic-testing decisions faced by an individual proceeding through the testing process. The complexities and possibilities for research extend far beyond this example. The wide variety of genomic tests provides an array of research targets ranging from prenatal screening to genetic tests for obesity, addiction, and disease susceptibility to tests used to tailor treatment to the genetic blueprint of the patient. Decision dynamics also vary according to the nature of the disease, degree of risk conferred by the genetic profile, potential for disease prevention, and treatment options for disease control or cure. Factors such as cultural beliefs and community environments, personality characteristics such as conscientiousness and optimism, and clinical factors related to medical history and access to care will also influence decisions and thus require research to inform genetic counseling and support. These empirical insights can critically inform health information provided not only through clinical practice but through social media as well. With the exploding use of social media, health care agencies are increasingly facing the challenges of providing genomic-testing consumers with online information and support that best inform decisions, facilitate emotion regulation, and increase adaptive behaviors.

We have focused on decision making regarding genomic testing, but future research can help connect this work with the literature on how both personalized genetic feedback and general attitudes about the role of genetics drive lifestyle behaviors. Despite evidence thus far that genetic test results may have little impact on daily health behaviors (e.g., Bloss et al, 2011; for reviews, see Bloss et al., 2013; Marteau et al., 2010; Hollands et al., 2016), there is much more to be learned about for whom, in what situations, and for what diseases providing genetic risk information might lead to behavior change (Graves, Hay, & O'Neill, 2014).

Finally, more work is needed to integrate the roles of social processes into self-regulation theory; the genomic-testing arena offers rich opportunities to develop and test hypotheses on social dynamics shaping complex decisions involving high risk and uncertainty. Genomic testing inherently involves relationship dynamics as test results have potent implications regarding the risk of other family members and can lead to family members needing testing. Social values and norms are likely to play an important role, as they can influence

representations (e.g., by shaping beliefs about social consequences) or directly influence behaviors (e.g., if individuals succumb to social pressures despite their personal beliefs). Evidence of genetic essentialist biases (to believe that genes confer homogeneous characteristics among those who possess them) suggests the potential for genomic information to shape social identities and dynamics through stereotyping and labelling effects (Cheung et al., 2014; Dar-Nimrod & Heine, 2011). These social categorizations could critically influence not only self-perceptions and personal behaviors but perceptions of family members and family dynamics as well. The self-regulation framework recognizes the role of facilitative and inhibitory influences within the social environment, but specific hypotheses need to be developed and tested. Broadening a self-regulation perspective to include social processes can provide a more comprehensive framework for understanding decision making and experiences in genomic testing and other life domains.

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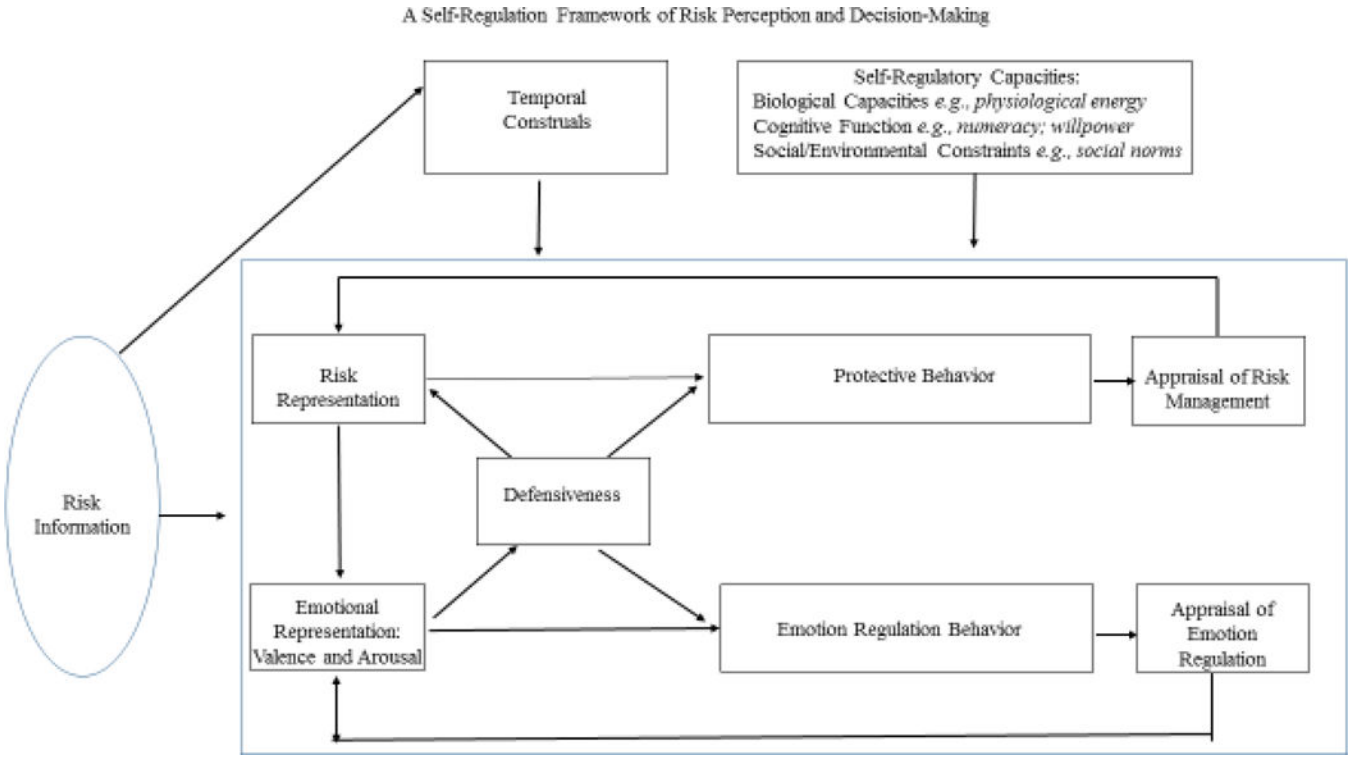

Figure 1.

This model is an expanded version of the Common-Sense Model of the self-regulation of illness (Leventhal et al., 2010) and illness risk (Cameron, 2008; Cameron & Jago, 2008). It incorporates the constructs of temporal construals and self-regulatory capacities from Temporal Self-Regulation Theory (Hall & Fong, 2007) as well as defensiveness (van't Riet, & Ruiter, 2014; Weibe & Korbel, 2003). The upper arm represents regulation of the threat itself and the lower arm represents regulation of emotional arousal. Protective behavior incorporates decisions and actions for risk management' emotion regulation behaviour incorporates decisions and actions for emotion regulation. For simplicity, the figure does not depict the distinction between intentions and behaviors but it is acknowledged that self-regulatory capacities, defensiveness, and temporal construals can intervene to create intention-behavior gaps.