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How Can Psychological Science Inform Research About Genetic Counseling for Clinical Genomic Sequencing?

Cynthia M. Khan,
Department of Health Behavior, University of North Carolina-Chapel Hill, 312 Rosenau Hall, CB#7440, Chapel Hill, NC 27599-7440, USA

Christine Rini,
Health Behavior, Lineberger Comprehensive Cancer Center, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Barbara A. Bernhardt,
Translational Medicine and Human Genetics, University of Pennsylvania, Philadelphia, PA, USA

J. Scott Roberts,
Health Behavior & Health Education, Center for Bioethics and Social Sciences in Medicine, University of Michigan-Ann Arbor, Ann Arbor, MI, USA

Kurt D. Christensen,
Genetics, Department of Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston, MA, USA

James P. Evans,
Genetics, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Kyle B. Brothers,
Family and Geriatric Medicine, University of Louisville School of Medicine, Louisville, KY, USA

Myra I. Roche,
Genetics, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA; Pediatrics, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Jonathan S. Berg, and
Genetics, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Gail E. Henderson
Social Medicine, Center for Genomics & Society, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Cynthia M. Khan: ckhan@med.unc.edu

Abstract

Next generation genomic sequencing technologies (including whole genome or whole exome sequencing) are being increasingly applied to clinical care. Yet, the breadth and complexity of

Correspondence to: Cynthia M. Khan, ckhan@med.unc.edu.

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sequencing information raise questions about how best to communicate and return sequencing information to patients and families in ways that facilitate comprehension and optimal health decisions. Obtaining answers to such questions will require multidisciplinary research. In this paper, we focus on how psychological science research can address questions related to clinical genomic sequencing by explaining emotional, cognitive, and behavioral processes in response to different types of genomic sequencing information (e.g., diagnostic results and incidental findings). We highlight examples of psychological science that can be applied to genetic counseling research to inform the following questions: (1) What factors influence patients' and providers' informational needs for developing an accurate understanding of what genomic sequencing results do and do not mean?; (2) How and by whom should genomic sequencing results be communicated to patients and their family members?; and (3) How do patients and their families respond to uncertainties related to genomic information?

Keywords

Communication; Genome sequencing; Patient understanding; Psychological; Psychosocial

Next generation genomic sequencing technologies (including whole genome or exome sequencing) have considerable potential as clinical tools because they simultaneously analyze millions of gene variants (Bick and Dimmock 2011; Facio, Lee, and O'Daniel 2014). Yet, a substantial portion of the genetic variation that genomic sequencing uncovers is of uncertain significance due to current limitations in knowledge about genetic causes of disease (Berg, Khoury, and Evans 2011). Genomic sequencing can also yield incidental or "secondary" findings—genetic information that is unrelated to the main reason for which sequencing was conducted (Lohn, Adam, Birch, and Friedman 2014). Incidental findings vary greatly in their clinical validity and utility, and recommendations for returning this information will likely change with advances in genomic science (Green et al. 2013). The increased interest in genomic sequencing has also raised discussions regarding informed consent, protection of privacy, and security of health records (Burke et al. 2013; Green et al. 2013; McGuire et al. 2008; Presidential Commission 2012).

Much of the concern surrounding return of sequencing information focuses on (a) what, when, how, and by whom this information should be communicated and (b) how it may be understood and used by patients and their family members (Berg et al. 2011; Biesecker, Burke, Kohane, Plon, and Zimmern 2012; Cho 2008). Genetic counselors will be on the frontlines of translating genomic sequencing to clinical care and grappling with these issues in their practice and conducting research to develop best practice guidelines (Bernhardt 2014; Hooker, Ormond, Sweet, & Biesecker, 2014; Mills and Haga 2013; Ormond 2013). The aim of this paper is to provide some examples of how psychological science can inform multidisciplinary research on the above issues, and ultimately, provide an empirical basis for genetic counseling practice.

Psychological science encompasses many areas of specialization that can offer explanations for emotional, cognitive, and behavioral responses to sequencing information (See Table 1; King 2008; Patenaude, Guttmacher, and Collins 2002; Tercyak, O'Neill, Roter, and McBride

2012). For example, cognitive psychologists have investigated how people process information and make decisions; social psychologists have investigated how people influence each other's feelings, thoughts, and behaviors; health psychologists have investigated how people cope with stress; and clinical psychologists have investigated causes of and treatments for emotional distress. Psychological and behavioral processes have been investigated using people's self-reports in surveys and qualitative interviews as well as observations of their physiological responses (e.g., heart rate) and behavioral responses (e.g., information seeking) in laboratory and field settings. The variety of methods used in psychological science necessitates quantitative statistics and qualitative analyses to investigate psychological and behavioral processes. This diversity of research areas, methodologies, and analyses in psychological science enables genetic counseling research to address a wide range of practice questions related to clinical genomics.

We organize our discussion of applying psychological science to genetic counseling research around three critical questions that were identified by clinicians and researchers in the Phase 1 Clinical Sequencing Exploratory Research Program consortium (Baylor College of Medicine, Brigham and Women's Hospital, Children's Hospital of Philadelphia, Dana-Farber Cancer Institute, University of North Carolina, Chapel Hill, University of Washington; for more information about the consortium, see http://www.genome.gov/27546194):

1. What factors influence patients' and providers' informational needs for developing an accurate understanding of what genomic sequencing results do and do not mean?
2. How and by whom should genomic sequencing results be communicated to patients and their family members?
3. How do patients and their families respond to uncertainties related to genomic information?

Q1: What Factors Influence Patients' and Providers' Informational Needs for Developing an Accurate Understanding of What Genomic Sequencing Results Do and Do Not Mean?

Qualitative research suggests that people often anticipate some level of personal utility from learning sequencing information (Facio, Brooks, Loewenstein, Green, Biesecker, and Biesecker 2011; Miller et al. 2014; Sapp et al. 2014). Yet, people's understanding of the relationship of genetics to health appears to be based more on personal experiences and prevailing cultural views than scientific or clinical knowledge (Condit 2010). At the same time, the shortage of genetics specialists relative to the growing demand for clinical genomics (Bernhardt 2014) means that the remaining gaps are likely to be filled by providers with variable levels of training in genetics and genomic medicine (Feero and Green 2011). National surveys reveal that although most physicians recognize the potential benefits of genetic information for clinical care, many are ill-equipped to order genomic sequencing due to limitations in their genetics education and training and lack of awareness

of available testing resources (Haga, Burke, Ginsburg, Mills, and Agans 2012; Stanek et al. 2012).

People have different informational needs for understanding their genomic sequencing information (Schmidlen, Wawak, Kasper, García-España, Christman, and Gordon 2014). Knowing how and what to communicate about gene variants, disease risk, and health implications has proven challenging (Biesecker et al. 2012; Lautenbach, Christensen, Sparks, and Green 2013) and will be further complicated by the return of incidental findings (Bernhardt 2014; Facio et al. 2014; Hooker et al. 2014). Research is needed to clarify factors that shape the informational needs of patients and providers for understanding genomic sequencing information. Elucidating such factors could, for instance, inform guidelines for communicating different types of sequencing information to patients; inform health care provider education and training; and help genetic counselors anticipate patients' needs for support systems or clinical services. Some examples of factors whose investigation could be informed by psychological science include patients' and providers' expectations for sequencing information; emotions surrounding sequencing information and subsequent decision-making; and ability to derive meaning from sequencing information.

Patient and Provider Expectations

How might patients' expectations influence their responses to sequencing results? How might providers' expectations influence their interpretation and communication of sequencing information? Expectations are characterized as beliefs about the probability of future outcomes (e.g., personal and social costs and benefits to engaging in a certain behavior; Bandura 2004) that develop largely as a result of personal and vicarious experiences (Olsen, Roese, and Zanna 1996). Notably, what people *expect* to happen may be distinct from what they *hope* will happen (Leung, Silvius, Pimlott, Dalziel, and Drummond 2009). People's hopes for future outcomes are posited to reflect their preferred outcomes, which may or may not correspond with their expected outcomes. For example, a patient may expect *and* hope to get a positive result from genomic sequencing; or *expect* an uninformative result but *hope* for a positive result. The implications of the discrepancies between hopes and expectations are not yet clear.

Psychological research has shown that expectations can influence how people process information. When people have strong expectations for an outcome, they are likely to exhibit a confirmation bias—they tend to seek and attend to information that is consistent, rather than inconsistent, with their expectations (Bandura 2004; Hart, Albarracín, Eagly, Brechan, Lindberg, and Merrill 2009; Higgins and Bargh 1987; Johnston 1996). However, research suggests that confirmation biases can be attenuated. For example, when people evaluate information, diverting their focus from their expectations to the information itself can make their attitudes less polarized (Hernandez and Preston 2013) and decrease biased information-seeking (Jonas, Traut-Mattausch, Frey, and Greenberg 2008). Patient and provider expectations for sequencing outcomes could affect their psychological and behavioral responses to sequencing information. For example, patients who strongly expect to find a definitive genetic explanation for their condition may question the veracity of a negative or uninformative sequencing result. One potential implication of this response is

that patients may hesitate to follow medical recommendations that are based on unexpected sequencing results. Providers who strongly suspect a genetic cause for a disorder in their patient could, for example, give more clinical significance to uncertain diagnostic findings than warranted.

Emotions Surrounding Sequencing

How do patients' emotions surrounding different types of sequencing information influence their understanding and subsequent health decisions? How might providers' emotions surrounding sequencing information influence their willingness to order sequencing? Emotions are largely characterized as feelings of pleasure (e.g., happiness, relief) or displeasure (e.g., sadness, anger) in response to an event or experience (Barrett Feldman, Mesquita, Ochsner, and Gross 2007). Discussions surrounding the potential for patient distress in response to sequencing information typically focus on patient emotions as *outcomes* (Biesecker et al. 2012; Cho 2008). Psychological research highlights the importance of also investigating emotions as potential *predictors* of responses to sequencing. For example, anxiety is shown to increase people's attentiveness to threatening information (Vuilleumier 2005). Negative emotions (e.g., anxiety, depression) are also shown to motivate people to take action to blunt their distress or to avoid the source of distress (Frijda 1986). Patients' emotional responses to their sequencing information could affect how they process and seek genetic information. For example, patients who are distressed by their diagnostic sequencing results may avoid seeking further information and/or avoid discussions involving genetic information. In fact, evidence suggests that patients' negative emotions can undermine communication of genetic information to family members and uptake of genetic testing by at-risk family members (Landsbergen, Verhaak, Floor, and Hoogerbrugge 2005). Compared to less distressed patients, patients who are highly distressed may also be less willing to learn incidental information (e.g., if they fear it could raise additional health concerns).

Positive or negative feelings about an activity or event can also serve as “information” that influences people's risk perceptions and health decisions (Peters, Lipkus, and Diefenbach 2006; Slovic, Peters, Finucane, and MacGregor 2005). Specifically, evidence suggests that people's judgments of an activity (e.g., cancer screening) are based, in part, on their positive or negative feelings about it. When people have positive feelings about activities, they view them as having high benefit and low risk; negative feelings about an activity have the opposite effects. People's feelings about an activity are theorized to precede and shape their beliefs about risk and benefit (Slovic et al. 2005).

Patients' feelings about receiving different types of sequencing information (e.g., negative diagnostic results; positive, but non-medically actionable incidental findings) may affect their decisions about whether or not to learn certain types of sequencing information. For example, patients who have positive feelings about genetic information may want to learn ‘all the information’ they can from their genomic sequencing. Patients who feel less positively may be more selective about what information they want to learn. Likewise, providers' feelings about, for example, the possibility of needing to return incidental findings from diagnostic genomic sequencing (e.g., sequencing results for adult-onset diseases in

minors) may influence their willingness to order genomic sequencing for diagnostic purposes. Providers who have negative feelings about returning incidental information may be less willing to order genomic sequencing than providers who feel less negatively.

Further, when anticipating future emotional responses to an outcome (affective forecasting), people often overestimate the intensity and duration of their emotional responses to a future event (Wilson and Gilbert 2003). Affective forecasting has been used to highlight biases that can systematically shape patients' medical decisions and provider recommendations. First, patients may place greater weight on how they think their lives will be different than on what may actually stay the same after a medical diagnosis or decision. Second, patients may not recognize how their current emotional or physical states influence their expectations (Halpern and Arnold 2008; Winter, Moss, and Hoffman 2009). Third patients and providers may underestimate how quickly patients make sense of events and adjust their personal values to new situations (Halpern and Arnold 2008; Rhodes and Strain 2008; Wilson and Gilbert 2003). Affective forecasting could have implications for patient willingness to learn —and provider willingness to order or return—different types of sequencing information. For example, patients who expect to be distressed by their genetic information may be more anxious about learning incidental findings out of fear of prolonged worrying afterwards. Conversely, patients who expect to feel more empowered may seek to learn incidental findings, believing that being “forewarned is forearmed.” Likewise, providers who fear prolonged distress or maladaptive health care decisions in patients may be hesitant to order genomic sequencing or return incidental findings.

Making Meaning from Complex Information

How do patients and providers infer health implications from complex sequencing information that is presented in the form of probabilities, patterns of inheritance, and degrees of penetrance? Psychological research suggests that patients and providers are unlikely to incorporate all of the different pieces of information regarding the sequencing output (or its caveats) into their interpretation of findings. For example, people often simplify complex information by drawing on personal experiences and anecdotal knowledge of other people's experiences or by comparing their situation to what they think of as a “typical situation” (McDowell, Occhipinti, and Chambers 2013; Tversky and Kahneman 1974). People also generally simplify complex information into a bottom-line meaning, or “gist” (Reyna 2008). Gists are also informed by context and personal experiences (e.g., “Mom and her sisters died from cancer, and my brother had it; cancer runs in the family; my cancer must be genetic”). However, when simplification of complex health information is based on inaccurate representations of situations, patients run the risk of maladaptive medical decision making (Senay and Kaphingst 2009) and providers run the risk of making ineffective or harmful recommendations (Enkin and Jadad 1998). Such simplifications are especially problematic because patients may base medical decisions more on their perceptions of their condition than their actual results from medical testing (Reyna 2008; Vos et al. 2012).

Examples of Research Directions for Q1

Research on such topics as expectations, emotions (and anticipated emotional responses), and derivation of meaning could inform an empirical basis for determining how to address

patients' and providers' informational needs. For example, research on expectations could include investigating factors that may shape patient and provider expectations to identify subgroups of patients and providers likely to need tailored genetics education and assistance with comprehension of sequencing information. Research on patients' emotions surrounding sequencing could include investigating patients' emotional responses—or anticipated responses—to different types of sequencing information and their effects on patient comprehension and subsequent health decision making. Research could also investigate provider assumptions about patients' feelings and beliefs about different types of sequencing and their effects on provider recommendations for genomic sequencing and provider communication of sequencing information. Finally, research on patients' and providers' inferences about health implications from sequencing information could include investigating how they develop a gist understanding of sequencing information to identify areas of misunderstanding.

Q2: How Should Genomic Sequencing Results be Communicated to Patients and Their Families, and from Whom Should this Communication Come?

The breadth and complexity of sequencing information create considerable difficulties for patient-provider communication and informed decision making by patients. These difficulties are further compounded by the interplay among the public's perceptions and fears about genetic information, poor health literacy, and the inability of health care systems and providers to keep up with advances in genomic science and medical technologies (Feero and Green 2011; Johnson, Case, Andrews, and Allard 2005; Lea, Kaphingst, Bowen, Lipkus, and Hadley 2011). Research is needed to develop guidelines for streamlining communication of different kinds of sequencing information (e.g., diagnostic, incidental; medically actionable, non-medically actionable) and develop empirically-based patient education strategies that maximize comprehension and informed decision making (Haga, Mills, and Bosworth 2014). Some examples of where psychological science could inform the second overarching question include research on communication formats for sequencing information (e.g., text, numbers, graphs); communication strategies (e.g., message framing, narratives, tailoring); and impact of the provider of sequencing information.

Communication Format

How can genetic counselors present genomic sequencing information in ways that are accessible to patients? A major challenge to communication and comprehension of sequencing information is that different people will have different needs for comprehending sequencing-related details (Schmidlen et al. 2014). For example, low patient literacy (i.e., inadequate knowledge and skills to search, comprehend, and use information from text or numbers; Kutner, Greenberg, Jin, Paulsen, and White 2006) has led to calls to investigate ways to communicate genetic information that take into account patient literacy levels (Lea et al. 2011; McBride, Koehly, Sanderson, and Kaphingst 2010). Reviews suggest that communication formats that can decrease literacy demands include presenting numerical information in tables, pictographs, and natural frequencies; avoiding overly complex

terminology when possible; limiting the range of information presented; starring or otherwise highlighting key points in text; and using videos to highlight important information (McCaffery et al. 2013; Trevena et al. 2013). Likewise, genetic counselors may benefit from using health literacy or genetic/genomic testing knowledge assessments to determine patients' informational needs and tailor their communication of sequencing information accordingly.

Communication Strategies: Message Framing

How can genetic counselors frame sequencing information in a way that promotes clinically appropriate decision making by patients? Health messages that encourage an action can be framed in terms of gains (benefits) from engaging in the action or losses (costs) from *not* engaging in the action (Gallagher and Updegraff 2012; Rothman and Salovey 1997). For example, smoking cessation can be framed in terms of a gain, “If you stop smoking, you'll reduce your chance of getting another heart attack” or in terms of a loss, “If you *do not* stop smoking, you'll *increase* your chance of getting another heart attack.” A recent review of health framing studies found that for actions intended to prevent illness (e.g., smoking cessation), people were on average more likely to take action in response to a gain framed message than to a loss framed message (Gallagher and Updegraff 2012). By contrast, for actions intended to detect illness or risk (e.g., mammograms), people were marginally more likely to take action in response to loss framed messages than gain framed messages (Gallagher and Updegraff 2012).

Framing effects could influence patients' responses to medically actionable sequencing information by, for example, influencing uptake of surveillance activities (e.g., when high genetic risk warrants action), treatment (e.g., when finding an explanatory gene variant leads to a diagnosis), or information sharing (e.g., discussing findings with other health care providers or family members). However, it is unclear how framing effects would influence patient responses to sequencing information that is not medically actionable (i.e., gene variants for conditions that are not preventable or do not have a well-defined treatment). Further, evidence suggests that framing effects on health decisions vary by patient literacy, health beliefs, and perceived difficulty of adhering to a recommendation (Rothman and Salovey 1997).

Communication Strategies: Narratives

How effective are narratives—relative to traditional genetic counseling interactions—for helping streamline communication of sequencing information? Narratives can be constructed to relate the same messages as more traditional didactic forms of health communication, but in a story format that describes scenes, characters, and conflict; raises unanswered questions or unresolved conflicts; and provides resolution to those questions and conflicts (Hinyard and Kreuter 2007; Kreuter et al. 2007). Stories within narratives may be fictional or non-fictional, and they may be based on firsthand experience, secondhand stories of others, a position of a group, or culturally common themes (Hinyard and Kreuter 2007). Evidence suggests that narratives can facilitate health information processing and understanding, promote learning (e.g., by modeling desired behaviors), overcome resistance to enacting health behaviors, and help people understand the psychological and social

implications of health decisions (Green and Brock 2000; Kreuter et al. 2007; Murphy, Frank, Chatterjee, and Baezconde-Garbanati 2013). The use of narratives to promote understanding of genomic sequencing information and informed decision making (e.g., as online or written decision aid materials) could be a promising supplement to traditional genetic counseling interactions. However, it is currently unclear how narratives compare to traditional clinician-patient interactions in helping patients understand and make decisions based on complex and often nuanced sequencing information.

Communication Strategies: Tailoring

How can genetic counselors tailor genomic sequencing information to the patient and how does such tailoring affect patient understanding and health decisions? A review suggests that people are more likely to attend and respond to health information if its relevance is tailored to them (Noar, Benac, and Harris 2007). The efficacy of tailoring can be explained by various psychological mechanisms, including increased attention (and, by extension, comprehension) and greater perceived relevance to personal goals, circumstances, and experiences (Hawkins, Kreuter, Resnicow, Fishbein, and Dijkstra 2008). In turn, information perceived as more personally relevant is more likely to be carefully processed (e.g., greater attention to information content; greater integration of information with the person's own knowledge and experience; Petty and Wegener 1999).

There are numerous ways genomic sequencing information could be tailored. For example, information could be tailored to individual differences such as patients' *need for cognition*, which reflects the degree to which people prefer to think deeply and prefer to get more detailed, elaborate explanations over briefer and simpler explanations (Cacioppo and Petty 1982). Recommendations for applying genomic information to health decisions could also be tailored to the individual's values, goals and life stage. Additionally, tailoring information to patients' level of health literacy could promote understanding of complex sequencing information. However, tailored approaches can be difficult to implement in some settings because up-front assessments are needed to guide tailoring, and providers have to be flexible in their style of communication (Noar et al. 2007). Nonetheless, research has documented effective ways to develop tailored print materials (Noar et al. 2007), and interactive web-based software programs can facilitate baseline assessment and customized feedback (Krebs, Prochaska, and Rossi 2010).

The Impact of the Provider of Sequencing Information

How might patients' comprehension and subsequent use of genomic sequencing information vary in response to receiving them from different health care providers (e.g., genetic counselors, specialist, family physician)? As applications of genomic sequencing become widespread, there will be corresponding increases in the diversity of settings in which sequencing results are communicated (Bick and Dimmock 2011; Berg et al. 2011). Patients are more likely to trust health information from providers who are known to them and who they perceive as understanding their background and motivations (Kreuter and McClure 2004; Lewis et al. 2000). Yet, the lack of uniformity in genomics education and training across health care professions (Feero and Green 2011) may cause some providers to refer patients and families to specialists with more expertise in genome medicine.

It is currently unclear how patients would comprehend and make informed health decisions from sequencing information they received from different providers. Psychological science research on persuasive messaging suggests that people's receptivity to messages from different sources is influenced by a combination of source, message, and recipient factors. For example, for people who are highly motivated to attend to a message, evidence suggests that source credibility or expertise matters more when the message is ambiguous or neutral than when a message clearly favors a certain position (Chaiken and Maheswaran 1994). Evidence also suggests that when people disagree with a message, they scrutinize strongly argued messages from experts more than strongly argued messages from non-experts (Clark, Wegener, Habashi, and Evans 2012). However, when they agree with the message, people may scrutinize weakly argued messages more from non-experts than experts. These findings suggest that the difference a provider's expertise makes on patient responses to sequencing information could depend on factors such as the clarity of information provided or the degree to which the information meets patients' expectations or hopes.

Examples of Research Directions for Q2

Investigating such areas as communication formats, communication strategies (e.g., framing, narratives, tailoring), and impact of the provider of sequencing information could inform development of guidelines for communicating different types of sequencing information in ways that promote comprehension and informed decision making. For example, research on communication formats could include comparing the effects of visual aids, decision aids, and different communication mediums (video, online) on patient comprehension and decision making across different levels of literacy. Research on framing could include comparing the effects of gain framed to loss framed communication of diagnostic and incidental sequencing information on patient understanding and health decisions. Research on narratives could include investigating the relative efficacy of supplementing traditional didactic clinician-provider communication with narratives. Research on tailoring could include comparing the effects of different tailoring methods (e.g., by health literacy, need for cognition) on patient health decisions and the feasibility of applying tailoring across different clinical contexts. Finally, research on providers of sequencing information could include investigating how patient comprehension of genomic sequencing information—and subsequent health decisions—vary as a function of the health care provider returning results.

Q3: How do Patients and their Families Respond to Uncertainties Related to Genomic Information?

In health contexts, uncertainty is a multidimensional construct that is characterized as feeling a sense of ignorance because of the probable nature of health risks and the ambiguity and complexity of health information (Han, Klein, and Arora 2011). Uncertainty in health contexts can arise from limitations in scientific knowledge (e.g., limited evidence about a treatment's efficacy), limitations within health care systems (e.g., treatment accessibility), and patients' illness uncertainty (Han et al. 2011). Patients' illness uncertainty is characterized by an inability to make sense of illness-related events because patients are unable to identify the cause of their illness, define their illness, or make predictions about their future health (Han et al. 2011; Mishel 1990). Although illness uncertainty is thought to

be anxiety-provoking (Sweeny and Cavanaugh 2012), some patients may capitalize on it to allay distress from the *certainty* of negative health outcomes (Mishel 1990; Case, Andrews, Johnson, and Allard 2005). However, when patients view illness uncertainty as threatening or as a barrier to their goals, it can elicit distress (e.g., anxiety, depression) (Baum, Friedman, and Zakowski 1997; Case et al. 2005; Mishel 1990) and impede decision making and communication of health concerns with others (Baum et al. 1997; Hamilton et al. 2013; Johnson Wright, Afari, and Zautra 2009; Neville 2003). Such effects of illness uncertainty may depend on the source of uncertainty. For example, decisional implications of uncertainty about the probability of a treatment's efficacy appear to be distinct from decisional implications of uncertainty from a lack of information or conflicting expert opinions and scientific evidence (Hamilton et al. 2013).

Genomic sequencing can potentially reduce patients' illness uncertainty by identifying the cause of a previously unexplained or undiagnosed condition. However, genomic sequencing will also perpetuate illness uncertainty by yielding genetic information (diagnostic, incidental) with unclear clinical validity and utility; probabilistic health implications; and clinical implications that are likely to change over time with advances in genomic science (e.g., uncertain diagnostic results may be later re-classified as positive or negative results) (Berg et al. 2011; Green et al. 2013). Some examples of how psychological science could inform research on the third overarching question include clarifying how patients cope with uncertainty from sequencing information individually (e.g., their personal responses) and with others (e.g., processing information by talking with others) and their effects on patient psychological and behavioral responses to sequencing information. Such research could, for instance, inform the development of educational and support resources for patients and families (McClellan et al. 2013); guidelines for communicating sequencing information; and testable models for anticipating patient decisions about learning different types of sequencing information as well as their responses to receiving that information.

Individual Ways of Managing Uncertainty

How might patients respond to uncertainty in their sequencing information? In one study, responses to uncertainty from sequencing information by research participants were found to stem from their personal beliefs about the extent to which uncertainty in sequencing information is expected or normal (Biesecker et al. 2014). Participants with more optimistic attitudes or greater tolerance for ambiguity in sequencing information were more likely to view uncertainty as a source of opportunity. In contrast, participants who viewed uncertainty negatively or as something unexpected from sequencing information were more likely to perceive uncertainty in sequencing information as distressing or question its veracity. These findings suggest that patients who are more tolerant for uncertainty in sequencing information may be more likely to remain hopeful about the clinical possibilities of genomic sequencing technologies than patients who are less tolerant of uncertainty.

When uncertainty is deemed stressful, patients may engage in various efforts to manage their stress. One line of research on stress management suggests that people manage stress by either seeking or avoiding information related to the stressor. Some people tend to be *monitors* who actively seek information (e.g., scouring the Internet for relevant content),

believing that “knowledge is power” (Miller 1987). Other people tend to be *blunters* who avoid such information, perceiving that “ignorance is bliss”. Evidence also shows that that monitors are more likely than blunters to ask questions and express emotions during clinic encounters, have longer clinic encounters, and experience more post-decisional regret about treatment decisions (Timmermans, van Zuuren, van der Maazen, Leer, and Kraaimaat 2007). Another line of research suggests that patients may manage anxiety they experience before receiving uncertain health information (e.g., results from a tumor biopsy) by adjusting their expectations for positive outcomes, planning ways to manage distress in case of bad news, or finding ways to distract themselves from thinking about the impending health news (Sweeny and Cavanaugh 2012). Thus, such factors as individual differences in coping preferences and patient attempts to brace for potentially unpleasant health information could have important implications for how they respond to sequencing information. For example, relative to blunters, monitors may be more tolerant of uncertainty in their sequencing information and experience less distress in response to diagnostic results and incidental findings. Yet, blunters may be more likely to brace for potentially undesirable sequencing information and take precautionary measures to cushion themselves from distress.

Interpersonal Ways of Managing Uncertainty

How might family and community social dynamics influence patient responses to uncertainty surrounding sequencing information? Responding to illness uncertainty can extend beyond the individual patient to include family members. This is especially true of genetic information, where one family member's testing or sequencing results can impact how other family members view their own risk for illness (Dancyger, Smith, Jacobs, Wallace, and Michie 2010; McBride et al. 2010). Families often manage distress by encouraging disclosure of distress and engaging in collective efforts to comfort each other and generate potential solutions (Berg and Upchurch 2007; Mickelson, Lyons, Sullivan, and Coyne 2001). This shared coping often occurs when family members share a sense of responsibility for helping each other through difficult situations (Mickelson et al. 2001). These kinds of collaborative family social dynamics could, for example, facilitate exchange of disease-risk information within families and encourage uptake of genetic counseling or testing services by at-risk family members (Dancyger et al. 2010; Peterson 2005).

However, family members can also undermine each other's attempts to manage uncertainty by avoiding or otherwise discouraging disclosure of distress. For instance, family members may be uncomfortable with their loved one's distress or they may want to avoid family conflict regarding genetic information (Peterson 2005; Lepore and Revenson 2007). Under such circumstances, families may develop patterns of interaction that discourage discussion of personal fears and concerns. Further, some patients may prefer to keep their fears and concerns to themselves. For example, they may want to protect family members from distress, avoid discussion of difficult topics, or avoid negative experiences they had in the past when sharing their distress with others (Lepore and Revenson 2007; Peters et al. 2011; Peterson 2005). Such “social constraints” could, for example, reduce the likelihood that patients share important information related to family disease risk and hinder their ability to understand and make sense of their sequencing information.

In addition, the ways in which patients and families respond to uncertainties related to genomic sequencing information could be shaped by their larger social network and surrounding community. When people have limited direct experience on which to base their expectations for future events or outcomes, they may refer to the experiences of others (Bandura 1997; 2004). By extension, patients and unaffected or at-risk family members may look to the experiences of their friends, co-workers, neighbors or fellow members of religious or civic organizations to inform their beliefs about genetics and its health implications. Further, people turn to social media (e.g., Facebook, Twitter) to increase health knowledge, supplement provider communication, exchange social support and advice, learn or share a health status, and share illness-related experiences (Antheunis, Tates, and Nieboer 2013; Thackeray, Crookston, and West 2013). However, patients and their family members may need education about the potential risks of sharing sequencing information through social media (Prince and Roche 2014). For example, they may not realize that sharing sequencing information through Facebook could inadvertently undermine their or their family members' legal privacy protections from employers and insurers.

Examples of Research Directions for Q3

Investigating patients' individual and interpersonal coping processes surrounding sequencing information could provide a more nuanced understanding of patient and family responses to uncertainty in sequencing information. For example, research on individual coping processes could include investigating the effects of individual differences in patients' coping preferences (e.g., tendencies to be a monitor or blunter in response to distressing information or general coping styles) on patients' psychological responses to sequencing information, communication of sequencing information with others (e.g., family members, health care providers), and application of sequencing information to health decisions. Research on social dynamics surrounding genomic sequencing information could include investigating the effects of patient preferences for disclosure or shared decision making with close family members, friends, and other extended social network members on patient-level and family member-level psychological and behavioral outcomes. Finally, another research direction could be to investigate the effects of family and extended network social dynamics on patient psychological and behavioral responses to sequencing information as a function of the type of sequencing information returned (e.g., diagnostic results, incidental findings).

Conclusions

Next generation sequencing technologies offer considerable potential for the explanation of unexplained or difficult-to-diagnose diseases. However, current technological capabilities and demands for clinical translation seem to outpace current knowledge about the clinical validity and utility of many of the gene variants obtained from genomic sequencing. Multidisciplinary research aimed at developing guidelines for applying sequencing technologies is currently underway, and the need for such research will only increase with continuing advances in genomic science and medicine. The experiences and research of genetic counselors are crucial to meeting this need.

Questions about communicating sequencing information and helping patients and families understand it can be addressed, in part, by applying research from psychological science to genetic counseling research. For example, psychological studies in cognition, communication, and decision making suggest that expectations, emotions, and biases in thinking about complex and uncertain information can shape patient-provider understanding and communication. Psychological studies on cognition, social processes, health, and communication suggest that patients' literacy, preferences for information, perspectives on their health, and views of different providers are important factors to consider when communicating sequencing information. Psychological studies on social processes and health also suggest that patient and family responses to uncertainties in genomic information may be shaped by individual or family differences in communication and coping preferences.

The cited examples of psychological science, as well as the examples of research directions, reflect a small subset of psychological theory and research. The breadth of psychological research on emotional, cognitive, and behavioral processes span well over a century, making an exhaustive review of all of the potential applications of psychological science to clinical translation of genomic sequencing impossible. At the same time, this breadth provides a rich basis for advancing scientific understanding of patient-provider communication and patients' and families' psychological and behavioral responses surrounding the complexities of genomic sequencing. Additional examples of psychological science that were not discussed but could also inform genetic counseling research include (but are not limited to) the literature on illness representations (Marteau and Weinman 2006), stigma (Major and O'Brien 2005), locus of control (Cheng, Cheung, Chio, and Chan 2013), and cognitive dissonance (Harmon-Jones, Amodio, and Harmon-Jones 2009).

Findings from the psychological science research cited in this paper come from a variety of study contexts (e.g., field research, laboratory settings) and participant populations (e.g., cancer patients, healthy young adults). The degree to which such findings will replicate in the context of clinical genomics is an empirical question. Yet, it is possible that the psychological, social, and behavioral implications of sequencing information are much like those of other health (e.g., cancer risk) or social (e.g., predicting someone else's behaviors) contexts in the sense of being complex, ambiguous, and having unclear long-term implications. The richness and breadth of psychological science offers a significant resource for genetic counseling research to investigate ways to maximize the benefits and minimize the harms of clinical genomic sequencing. Further, the range of different types of research methodologies (e.g., quantitative survey research, qualitative observational studies) employed in psychological science demonstrate the value of implementing multiple research methods to address a wide range of research questions. We hope that the examples of psychological science in this paper will generate innovative research that addresses critical questions about clinical applications of genomic sequencing technologies and inform genetic counseling practice.

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Table 1

Examples of different areas of psychological science (King 2008)

Area	Description	Examples of research
Cognitive	Investigating attention, consciousness, information processing, and memory	Learning, decision making
Social	Investigating social interactions, relationships, perceptions of oneself relative to others, and attitudes	Social support, discrimination
Health	Investigating psychological factors affecting health, lifestyle behaviors, and health care	Stress and coping, illness management
Personality	Investigating enduring individual characteristics	Personality traits, motivation
Developmental	Investigating factors contributing to human development	Language development, aging and memory
Clinical	Investigation and treatment of clinical disorders	Mental disorder treatments, classification of mental disorders