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A Rare Family: Exploring Genetic Literacy in an Online Support Group

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Introduction

Over a decade ago, an international team of researchers completed the Human Genome Project, an initiative to sequence and map all of the genes in the human genome. The completed Human Genome Project ushered in a new era of biomedical research that is rapidly changing our understanding of genetics and how genes and environmental factors interact to create genomic conditions such as asthma and diabetes. Post-Human Genome Project technologies are also expanding our ability to diagnosis and treat genetic disorders. Given the sheer complexity of these discoveries, a major challenge of the "genomic era" is ensuring that members of the general public have the knowledge and skills necessary for integrating genetic information into health and medical decision-making (American Public Health Association, 2010).

Healthy People 2020 and the Institute of Medicine define health literacy as the "degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (National Research Council, 2004; U.S. Department of Health and Human Services, 2015). Essential components of health literacy include oral and print literacy, numeracy, and cultural and conceptual knowledge; the latter is influenced by sociodemographic factors and cultural understandings and approaches to concepts such as health care. Genetic literacy, a form of health literacy, has been defined in a number of ways (see Bowling et al., 2008, and Erby, Roter, Larson, & Cho, 2008, for examples). For the purposes of this paper, genetic literacy will be defined as the knowledge, skills, and attitudes necessary for an individual's understanding of genetic information and genetics-based health, behavior, technology, and services.

An individual who has attained some measure of genetic literacy should be able to critically evaluate genetic information, interpret personal genetic risk (i.e., the numeracy component of genetic literacy), advocate for and access appropriate programs and services, and make informed decisions concerning his or her health-related behaviors and genetic health. Such knowledge and skills are routinely required in the contexts of prenatal genetic testing and newborn screening (Lea, Kaphingst, Bowen, Lipkus, & Hadley, 2011), making genetic literacy potentially a vital component of sexual and reproductive decision-making.

The current qualitative research study is part of a larger research program that addresses how perception of genetic risk influences sexual and reproductive decision-making, including mate selection. The current study employs holistic content and narrative analysis of secondary data (electronic or e-mail posts) from an online support group for individuals

affected by a genetic disorder. Using grounded research techniques, the authors propose to explore the dynamics of an online support group to gain additional insights into specific psychosocial and environmental variables that affect individual genetic literacy, related perceptions of genetic risk, and sexual and reproductive decision-making.

Methods

Researchers in a number of disciplines are using narrative analysis as a method for exploring health-related theory, research, and practice (Harter, Japp, & Beck, 2005, p. 7). Beyond analyzing the linguistic turn of phrase or the unspoken meaning, narrative analysis also aids the researcher in discerning the "complexities that face contemporary health care participants: identity construction, order and disorder, autonomy and community, fixed and fluid experiences" (Harter et al., 2005, p. 8). In particular, illness narratives are useful for exploring how individuals understand complex concepts such as health and genetic risk, or communicate their subjective experience of an illness (Japp & Japp, 2005, pp. 107–108). Additionally, the illness narrative within the context of social networking subgroups, such as support groups, may reflect peer influences that impact members' social and health decision-making via co-constructed cultural and conceptual knowledge and perceptions of the illness/disorder (for more information on social networking and health, see Valente, 2010).

Sample and Setting

The Yahoo! Groups website contains thousands of special interest groups, including online support groups for individuals affected by genetic disorders. A search for genetic health-related support groups with only the term *genetic disorders* yielded 170 groups. Groups considered for inclusion in this study were (a) focused on human genetic disorders; (b) related to a single genetic disorder or syndrome; (c) "public access" groups (i.e., not moderators only or private membership groups to avoid researchers "impersonating" patients or family members with the genetic disorder); (d) for non-health professionals (e.g., only friends, family members, and other laypersons); (e) English language groups only; and (f) comprised of 30 or more active members. The authors used these specific criteria within the Yahoo! Groups search function to narrow the list of online genetic support groups to seven. To reduce the pool of candidate groups further, the researchers employed an additional criterion, frequency of postings. An active online group should generate enough postings, on average, to generate a "rich" sample of data for secondary

qualitative analysis. The support group selected for analysis had been active for several years at the time of study and generated more posts per month, on average, than the other six groups (18.7 messages vs. fewer than 5 messages).

Secondary analysis of group messages was limited to the period from January 1999 through December 2003, which is the half-decade predating completion of the Human Genome Project. This historic period was selected because the authors believe that post-Human Genome Project media and scientific reporting on genetic and genomic advances make it difficult to perform a baseline assessment of laypersons' discourse surrounding genetic and genomic issues and their genetic literacy. Participants' e-mail responses to the online support group were coded and analyzed for holistic themes and content. In addition, two posts specifically pertaining to genetic risk and sexual and reproductive decision-making were targeted for narrative analysis. These posts and the resulting responses, as well as those from the overall support group, underwent narrative analysis based on Symbolic Convergence Theory (Bormann, 1985).

Analytic Approaches

Holistic Content Analysis

Lieblich, Tuval-Mashiach, and Zilber (1998) describe a five-step process of holistic content analysis. The researcher reads the narrative "several times until a pattern emerges, usually in the form of foci of the entire story" (p. 62). After these initial readings, the researcher crafts an initial and global impression of the narratives (p. 62). Steps 3 and 4 of Lieblich et al. involve concentrating on content and themes of interest while using colors to track their appearance, disappearance, and reappearance throughout the narratives (pp. 62–63).

In lieu of using colors, this researcher took the text from the online group messages, selected narratives, and retyped these into a numbered line format. This method allowed the researcher to visually examine the texts and to follow along as themes appeared and reappeared. In step 5, the researcher followed each theme and wrote conclusions based on salience to the overall narrative and the ability of themes to address the major research questions (p. 63). Specifically, holistic content analysis allowed the researchers to explore support group members' writings related to a genetic disorder and related decision-making and to make inferences about their genetic literacy.

Symbolic Convergence Theory

Symbolic Convergence Theory (Borman, 1985) was born of the understanding that humans (referred to as *homo narrans*) are innate storytellers. Men and women tell stories to make sense not only of self but also of reality and the world around them (Clark & Sandoval, 2006). In doing so, they consciously or unconsciously create "socially shared narrations or fantasies" (Borman, 1985, p. 128; Clark & Sandoval, 2006), which correspond to the cultural/conceptual knowledge component of health or genetic literacy. This fantasy (consciousness or world view) need not be imaginary; fantasies often have their foundation in reality (Borman, 1985, p. 130; Clark & Sandoval, 2006).

Regardless of realism, fantasy gives groups a common symbolic language (Clark & Sandoval, 2006). As these fantasies are shared, individuals converge over "experiences, values and interpretations" (Clark & Sandoval, 2006). They also create preferences for certain types of fantasy scripts (dramatizations), exchange personal scripts for those that are more appealing, and seek out those that resonate with their own scripts (Borman, 1985, p. 130).

Narrative analysis with Social Convergence Theory involves exploring emerging fantasy themes and the nature of the group consciousness as revealed in the narrative (Clark & Sandoval, 2006). To uncover the essence of the group fantasy is to uncover their subjective, collective truth and motives for action. Borman (1985) describes the process of uncovering this theory in three parts. First, the researcher must locate "recurring communicative forms and patterns that indicate the evolution and presence of a shared group consciousness" (p. 129). Next, the researcher describes the dynamic tendencies in group communication that clarify why and how the group fantasy is created and sustained, and the impact that this fantasy has on shared "meanings, motives, and communication within the group" (p. 129). The final step involves determining why certain fantasies emerge at very specific points in time (p. 129).

For the purposes of this paper, the researcher modified the Social Convergence Theory (Borman, 1985) process. Overarching themes related to genetic literacy and sexual or reproductive decision-making, identified through holistic content analysis of messages posted to the online group and selected narratives, were used as evidence of an evolving group consciousness. The researcher then described this fantasy and used holistic themes from the text to determine how this fantasy was created and sustained. The impact of the fantasy on group meanings, motives, and decision-making became clear, as did the temporal context

for its formation, once this step had been performed.

Results

Demographics

Messages posted to the online support group (July 1999–December 2003) often contained demographic information, such as age, gender, and geographical location. The majority (84.4%) of the respondents who reported their age (n=32) were 25 years old or older. Most respondents (74.1%) were female (n=58). Of the respondents who indicated their age and gender (n=29), 72.4% were female with an average age of 31.2 years (range, 15–49 years). Males who indicated both age and gender had an average age of 37.1 years (range, 26–49 years). The majority (57.9%) of the respondents who reported their geographical location lived in the United States (n=38).

In addition to age, gender, and geographical location, the respondents often indicated their disorder status as carrier (i.e., having a trait for the disorder) or affected (i.e., having symptoms), number of biological children, and their children's carrier/affected status. A total of 26 female respondents indicated that they were carriers of or affected by the disorder. Of this number, seven female respondents had biological children, and each had at least one child affected by the disorder. An additional 12 female respondents who were not carriers/affected or did not indicate their status reported having at least one child who was a carrier of or affected by the disorder. A total of 13 male respondents indicated that they were carriers of or affected by the disorder. Of this number, two male respondents had biological children. One male respondent had at least one child affected by the disorder. It was unclear whether the other male respondent had a carrier/affected child. In addition, one male respondent who was not a carrier/affected reported having at least one child who was affected by the disorder.

Holistic Content Analysis and the Online Group: Global Impression

The online support group provides insight into the genetic literacy, attitudes, beliefs, and experiences of individuals who are affected by a genetic disorder. Messages fall into two categories: those from carrier/affected individuals and those from individuals (often family members or romantic partners) in relationships with a carrier/affected individual. Codes and emerging themes have been placed in tabular format for ease of reading and interpretation (**Table 1**). (Note that for ease

of reading, the messages in this table represent only a fraction of the messages that were analyzed.)

Holistic Content Analysis and Selected Narratives: Global Impression
The selected narratives were written by a non-carrier/affected mother of affected children (Ann) and a non-carrier/affected woman (Denise). Each woman is considering having a child with a carrier/affected husband. In Ann's case, she has two children (one is affected and the other will be tested) and is considering whether to have a third child. The majority of respondents who weigh in on these queries are pro-pregnancy, despite the genetic risks involved (**Table 2**).

Holistic Content

Social Impact of the Disorder
The social impact of having the disorder converges on three codes: a lack of or limited contact with others who have the disorder (n=11 codes); feelings of social isolation (n=2 codes); and the experience of being bullied as a child (n=6 codes). Several group members comment that they have never met or have met only small numbers of individuals with their disorder. When combined with feelings of social isolation and the experience of being bullied as a child, this factor appears to contribute very strongly to an individual's decision to join and become active within the group.

Physical Impact of the Disorder
The physical impact of the disorder can be distilled into three codes: life with chronic pain (n=8 codes); undergoing multiple surgeries (n=29 codes); and experiencing physical disabilities or limitations (n=7 codes). After impact due to genetics, this thematic area appears to be the largest. The genetic disorder varies in severity; however, the standard of care appears to be repeated surgical interventions with variable recovery times. Members reported having had as many as 40 surgeries over the course of their lifetime, beginning in infancy.

Emotional Impact of the Disorder
Group members represent a range of affective issues related to living with their disorder. Commonly expressed emotions include depression and loneliness (n=3 codes); poor self-esteem or body image (n=3 codes); positive affirmations that they would not be the persons that they are without the disorder (n=4 codes); feelings of guilt, shame, denial, and

embarrassment (n=5 codes); feeling different from others (n=3 codes); and counter-narratives (e.g., statements declaring that they "are ruled by the disease"; n=2 codes). Like the themes related to physical and social impact, this area appears to reinforce the individual's desire to join the group and strengthens the bonds between members.

Developmental Impact of the Disorder

Developmental impact of the disorder was the smallest thematic area. This may have been because the other holistic themes, such as social or emotional impact, more aptly captured the essence of this type of impact. Codes in this area included negative (message No. 107) and positive or neutral impact (messages Nos. 20, 60, 107, and 184) of the disorder on an individual's childhood or adulthood.

The Support Group as "Family"

Holistic content analysis revealed three codes: getting to know others whom they can identify with (n=23 codes); receiving comfort and encouragement (n=14 codes); and the desire to help others with the disorder (n=6 codes). This theme is covered more fully in the section on Symbolic Convergence Theory.

Genetics of the Disorder

As might be expected, codes related to the genetics of the disorder dominated messages to the online support group. These included the following: establishing the individual's genetic pedigree (n=60 codes); negative feelings associated with having "passed on" the disorder (n=7 codes); positive or neutral feelings associated with having inherited the disorder (n=2 codes); negative feelings associated with having inherited the disorder (n=2 codes); the pro-decision to have children (n=4 codes); the con- or neutral decision to have children (n=1 code); the "disease versus condition" definition (n=1 code); and stories of genetic misdiagnosis or misinformation (n=7 codes). This theme is also covered more fully in the section on Symbolic Convergence Theory.

Miscellaneous

This thematic area includes member requests for referrals, services, and advice (n=20 codes). Other than social interaction and support, this area contains the greatest benefits of membership. Members can pose questions related to symptoms, surgeries, and other aspects of life with the disorder. Because this disorder is rare and relatively unknown in the medical community, group members represent a substantial repository of

expert opinions and knowledge.

The Narratives

Ann (pseudonym) is a non-carrier mother of children who are affected by the disorder. (Her husband is the carrier/affected individual.) The question that she poses to the group centers on whether it would be selfish for her and her husband to have another child. Most responses to this question take the form of short, pro-pregnancy narratives. The respondents are informed of the risks involved, as are Ann and her husband; yet, the overall impression given is one of support for having a child. Respondents use phrases including "as long as we have good health insurance, I would probably have another child" (Charlene, lines 20–21) and "I am very glad that my parents had me … I consider myself lucky to have (the disorder)" (Barbara's 1st response, lines 52–56).

Similarly, Denise (pseudonym) is a non-carrier who is married to a carrier/affected individual. She and her husband are considering reproductive options and pose the question to the group. Like Ann's query, responses take the form of short, pro-pregnancy narratives. Respondents use phrases including "I had genetic counseling, not that it would have made a blind bit of difference to the outcome of the pregnancy" (Elaine, lines 8–10) and "children are wonderful and you will never regret having them" (Fran, lines 4–5). Only one respondent to either query places a qualifier on her response. Helen's pro-pregnancy narrative encourages Denise to consider the severity of her husband's disorder in making the decision. She states "(if) the family history of (the disorder) is not severe, then I would not hesitate … from your husband's attitude, it doesn't sound like (it) has been a big deal to him, so I'm guessing his family history isn't severe. In that I'd be inclined to agree with him (about having children)" (Helen, lines 56–62).

Meta-themes Emerging from Narrative and Holistic Content Analysis

The researchers read online group messages in an iterative fashion and considered how the findings from the narrative and holistic content analyses addressed the study's exploratory aims. In doing so, they applied a narrative framework, Symbolic Convergence Theory, to the emerging themes, which ultimately converged into overarching meta-themes (**Table 3**) that provided meaningful and actionable information.

Meta-theme 1: The Experience of Being a Carrier/Being Affected

The messages posted to the online group and the text of selected narratives highlight group members' collective experience and

cultural/conceptual knowledge as individuals affected by a genetic disorder. Evidence of what Japp and Japp (2005) refer to as "a core of four interconnected elements: the need to establish the legitimacy of suffering, the search for moral legitimacy, the search for medical legitimacy, and the search for public legitimacy" are vividly present (p. 109). The members find legitimacy for their individual struggles by posting to the group, participating in online chat sessions, reading newsletters, and, presumably, exchanging offline e-mails (Japp & Japp, 2005, p. 109). They freely dialogue about their multiple surgeries, life with chronic pain, genetic pedigrees, and life stories and experiences. The group is also a vehicle for advocacy-related activities and recruitment for charities and research studies that affect them as individuals and as group members.

Most importantly, the group is an electronic repository for the collective conscious, including its cultural/conceptual knowledge. Members can refer potential new members or post links at other sites for recruitment. These potential members can read older messages, chat with current members, view photos, and get exposure to the group. Once exposed to the collective, membership in the family is open and free-of-charge.

Meta-theme 2: The Rare Family

The online group provides members with "reinforcement and community" (Japp & Japp, 2005, p. 107). In this group, members have a forum that provides "catharsis, testimony, identity restructuring, and the ability to connect with others" (p. 107). This concept embodies the primary group fantasy: a socially constructed family of individuals affected by the disorder. Within the family, members find others who can identify with their feelings and experiences. Even members who are not affected can "experience the world of illness and prepare for the day when they (may) need to adjust to an illness of … one they love" (pp. 107–108).

The codes and themes revealed through holistic content analysis support this finding. A number of messages posted to the group contain elements of The Diagnosis Story or work to establish the sender's genetic pedigree. As a family member, individuals are free to ask or to offer advice and referrals for programs and services, which provides a mechanism for transferring cultural/conceptual knowledge about the disorder. Members also have ready access to almost 200 extended family members who sympathize when they undergo surgery, receive the results of their child's genetic tests, and fall in love. As one member wrote, "I felt as though I was caught inside some terrible storm with nothing to anchor me to the earth. I can see that I found my anchor in this group" (message No. 271).

Meta-theme 3: Genetic Health Decision-Making

Family, whether biological or socially constructed, does not always have a positive impact on health decision-making. A large body of literature on genetic and chronic health conditions reveals that family members and peers (i.e., social norming agents) wield a tremendous amount of power and influence over an individual's health knowledge, attitudes, behavioral intentions, and ultimately decision-making (Dancyger et al., 2011; Ganter et al., 2015; Kunz et al., 2014; McFadden, Bouris, Voisin, Glick, & Schneider, 2014; Peterson, Pirritano, Tucker, & Lampic, 2012). These health behavior decisions include those to undergo genetic testing or become pregnant (Dancyger et al., 2011; Peterson et al., 2012).

The responses to Ann's and Denise's inquiries provide evidence of a conflict of interest. On one hand, group members, particularly Barbara (the group's founder), are trying to create a safe, supportive environment. On the other, members are confronted with a challenge to the group's collective identity and their emerging cultural/conceptual knowledge: If one could choose not to have a child who was a carrier/affected, would one do so? The respondents' perception might also be that the outcome of this decision somehow invalidates or lessens their experience of the illness. It certainly calls into question their judgment under similar circumstances.

To act in a way that might be perceived as invalidating the group/family experience could prove to be the undoing of the group. After all, a family's role is to guide the growth and development of new family members. Ann's and Denise's decisions, and the decisions of others like them, may determine the ultimate fate of the family. Interestingly, the researcher found evidence of symbolic convergence in the formation of the group identity and the use of its cultural/conceptual knowledge in reproductive decision-making, but no evidence of its use in mate selection. The one time that this issue was broached to the group (messages Nos. 80–81), the member was encouraged "to (back) out of the relationship" if she did not feel that she could handle caring for potentially affected children. No comment was made concerning her ability to care for her future fiancé.

Discussion

Findings from the current qualitative study indicate that online health-related support groups can evolve into a socially constructed "family" of individuals affected by specific disorders. Within this online family, members find others who can identify with their feelings and lived experiences. Like biological families of origin, this online "familial" context may then exert particularly strong influences on members' social and

health decision-making via co-constructed cultural and conceptual knowledge of the disorder. In the context of genetic or genomic health, laypersons typically rely on personal experiences with illnesses or such cultural/conceptual knowledge in evaluating genetic risk or forming their understanding of genetic and genomic diseases, rather than on scientific or medical models (Walter, Emery, Braithwaite, & Marteau, 2004). When viewed through a scientific or medical lens, individuals with this cultural/conceptual knowledge may lack the genetic literacy necessary for informed and competent health decision-making.

A low level of health literacy is associated with reduced access to and utilization of health services and poorer health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Similarly, in an era of rapidly emerging and expanding genomic applications and technologies, individuals with limited genetic literacy are ill equipped to integrate genetic information into their health care. Yet, persons with limited genetic literacy, like those in the support group, will be increasingly called on to make decisions that have important consequences for themselves, as well as their "real-time" and online families (e.g., decisions to undergo prenatal testing for genetic disorders such as Down Syndrome or carrier testing for disorders such as Sickle Cell Disease and Huntington's disease). In addition to implications for individuals and family systems, such decisions may lead to complex and expensive encounters with various systems related to health care, education, and other support services. Thus, although online forums may provide psychosocial supports for their members within the forum, the same community may reinforce knowledge, attitudes, and behaviors that conflict with the accepted knowledge base and decision-making standards of health professionals and service providers (Japp & Japp, 2005; Geist-Martin, Ray, & Sharf, 2011).

Implications for Practice and Policy

Employing a systems approach (i.e., a framework for examining connections between different elements in a system—health care—and identifying and clarifying the patterns of interactions resulting from those connections, such as online forums dedicated to a specific genetic disease; Senge, 1990), we synthesized the themes and meta-themes from our study into three targets that have implications for practitioners and policymakers: information access, information processing, and action (Miller & Page, 2007). The first target—information access—refers to caregiver support information. For example, one health literacy issue is the impact of cultural and conceptual knowledge on decision-making (National Academies of Sciences, Engineering, and Medicine, 2015).

Training professional or peer facilitators would allow online support members to systematically explore how cultural understanding of concepts related to genetic illnesses affects their beliefs and values related to illness/disease, treatment, and care. Patients assessed as requiring care from medical or health professionals, such as orthopedic specialists, clinical social workers, or genetic counselors, could receive efficient referrals for care and services while continuing to participate in online group activities.

Another example of information access relates to referrals and patient advocacy under the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA). Many students who have genetic illnesses or disorders, from prekindergarten through grade 12 and college, may qualify for services and/or accommodations. Non-profit associations dedicated to patient support and advocacy should consider adding referral links with information on IDEA/ADA in addition to the more traditional medical and health referrals mentioned previously.

The second target—information processing—refers to professional development for health education and promotion practitioners. A number of recent studies have identified critical shortages of medical and health professional staff who have been adequately trained in genetics or genomics (Chen & Goodson, 2007). Health educators trained in genomics may provide a means for competently addressing patient information needs (Chen, Kwok, & Goodson, 2008). In particular, workshops, curricula, and materials based on genomic competencies are needed to increase health education practitioners' understanding and knowledge of genetics and genomics, as well as potential clients' cultural/conceptual knowledge, to address gaps in patient education and care services (Chen & Goodson, 2013).

Finally, the third target—action—refers to practitioner research, specifically action research. Action research allows health education and promotion practitioners a mechanism for improving the quality of their practice and services (Acosta & Goltz, 2014). Additionally, the action researcher permits practitioners to explore their own and their patients' cultural borderlands for the purpose of developing authentic communication bonds with their patients and caregivers. (The interested reader is also referred to Acosta, Goltz, & Goodson, 2015.)

Conclusion

With the completion of the Human Genome Project, the general public faces an increasing amount of highly technical information and access to social media, online forums, and social networking that are often

unsupported by knowledgeable health professionals. For this reason, laypersons must have the basic knowledge, skills, and attitudes to critically evaluate their own risk and access appropriate genetics-based technology and services. Understanding how laypersons interpret and communicate complex concepts such as genetic risk and inheritance are vital to helping health professionals change or develop programs that increase awareness and educate the general public. Furthermore, understanding how this information is used in real life may prove vital to assisting the general public with making fully informed reproductive and sexual health decisions. In order to do so, health professionals must understand the psychosocial and environmental variables that guide these decisions, as well as any potential barriers.

As this study demonstrates, qualitative methodologies lend themselves well to illuminating subjective experiences, meanings, and motivations. Additional analysis with Symbolic Convergence Theory is particularly useful for determining how groups think and why they behave in the ways that they do. Further qualitative research needs to be performed to understand the positive and negative impact that participation in a collective consciousness may have on sensitive decisions, such as those involved in sexual and reproductive health. Studies that test behavioral theories, such as the Health Belief Model, Theory of Planned Behavior, Game Theory, and Complex Adaptive Systems Theory, might also yield a deeper, richer understanding of this form of decision-making (Goodson, 2015; Honore, 2008).

References

Acosta, S., & Goltz, H. H. (2014). Transforming practices: A primer on action research. *Health Promotion Practice, 14*(5), 465–470. doi:10.1177/1524839914527591

Acosta, S., Goltz, H. H., & Goodson, P. (2015, online first). Autoethnography in action research for health education practitioners. *Action Research*. doi:10.1177/1476750315573589

American Public Health Association. (2010). *Strengthening genetic and genomic literacy* (Policy 201012). Retrieved from http://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/30/16/37/strengthening-genetic-and-genomic-literacy

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated

systematic review. *Annals of Internal Medicine, 155*(2), 97–107. doi:10.7326/0003-4819-155-2-201107190-00005

Bormann, E. G. (1985). Symbolic convergence theory: A communication formulation. *Journal of Communication, 35*, 128–138.

Bowling, B. V., Acra, E. E., Wang, L., Myers, M. F., Dean, G. E., Markle, G. C., … Huether, C. A. (2008). Development and evaluation of a genetics literacy assessment instrument for undergraduates. *Genetics, 178*(1), 15–22.

Chen, L-S, & Goodson, P. (2007). Entering the public health genomics era: Why must health educators develop genomic competencies? *American Journal of Health Education, 38*(3), 157–165. doi: 10.1080/19325037.2007.10598962

Chen, L-S., & Goodson, P. (2013). US health educators' likelihood of adopting genomic competencies into health promotion. *Health Promotion Practice, 14*, 44–52. doi:10.1177/1524839909348591

Chen, L-S., Kwok, O-M., & Goodson, P. (2008). US health educators' likelihood of adopting genomic competencies into health promotion. *American Journal of Public Health*, *98,* 1651–1657. doi:10.2105/AJPH.2007.122663

Clark, C., & Sandoval, C. (2006). *Symbolic convergence theory.* EHRD 656 (Narrative Analysis) lecture presented on October 4, 2006, at Texas A&M University, College Station, TX.

Dancyger, C., Wideman, M., Jacobs, C., Smith, J. A., Wallace, M., & Michie, S. (2011). Communicating BRCA1/2 genetic test results within the family: A qualitative analysis. *Psychology & Health, 26*(8), 1018–1035. doi:10.1080/08870446.2010.525640

Erby, L. H., Roter, D., Larson, S., & Cho, J. (2008). The rapid estimate of adult literacy in genetics (REAL-G): A means to assess literacy deficits in the context of genetics. *American Journal of Medical Genetics*, *146A,* 174–181.

Ganter, C., Chuang, E., Aftosmes-Tobio, A., Blaine, R. E., Giannetti, M., Land, T., & Davison, K. K. (2015). Community stakeholders' perceptions of barriers to childhood obesity prevention in low-income families, Massachusetts 2012-2013. *Preventing Chronic Disease*, *12*, 140371. doi:org.10.5888/pcd12.140371

Geist-Martin, P., Ray, E. B., & Sharf, B. F. (2011). *Communicating health: Personal, cultural, and political complexities.* Long Grove, IL: Waveland Press.

Goodson, P. (2015). Researching genes, behavior, and society to improve population health: A primer in complex adaptive systems as an

integrative approach. *Genetics, Health and Society, 16*, 127–156. doi:10.1108/S1057-629020150000016005

Harter, L. M., Japp, P. M., & Beck, C. S. (2005). Vital problematics of narrative theorizing about health and healing. In L. M. Harter, P. M. Japp, & C. S. Beck (Eds.), *Narratives, health and healing: Communication theory, research, and practice* (pp. 7–29). Mahwah, NJ: Lawrence Erlbaum Associates.

Honore, H. H. (2008). *Perception of genetic risk in sexual and reproductive decision-making (PGRID) by college students* (Doctoral dissertation). Texas A&M University, College Station, TX.

Japp, P. M., & Japp, D. K. (2005). Desperately seeking legitimacy: Narratives of a biomedically invisible disease. In L. M. Harter, P. M. Japp, & C. S. Beck (Eds.), *Narratives, health and healing: Communication theory, research, and practice* (pp. 107–130). Mahwah, NJ: Lawrence Erlbaum Associates.

Kunz, J. H., Greenley, R. N., Mussatto, K. A., Roth-Wojcicki, B., Miller, T., Freeman, M. E., & Lerand, S. (2014). Personal attitudes, perceived social norms, and health-risk behavior among female adolescents with chronic medical conditions. *Journal of Health Psychology, 19*(7), 877–886. doi:10.1177/1359105313481077

Lea, D. H., Kaphingst, K. A., Bowen, D., Lipkus, I., & Hadley, D. W. (2011). Communicating genetic and genomic information: Health literacy and numeracy considerations. *Public Health Genomics*, *14,* 279–289.

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation. Applied Social Research Methods Series, Vol. 47.* Thousand Oaks, CA: Sage Publications.

McFadden, R. B., Bouris, A. M., Voisin, D. R., Glick, N. R., & Schneider, J. A. (2014). Dynamic social support networks of younger black men who have sex with men with new HIV infection. *AIDS Care, 26*(10), 1275–1282. doi:10.1080/09540121.2014.911807

Miller, J. H., & Page, S. E. (2007). *Complex adaptive systems: An introduction to computational models of social life.* Princeton, NJ: Princeton University Press.

National Academies of Sciences, Engineering, and Medicine. (2015). *Health literacy: Past, present, and future: Workshop summary.* Washington, DC: The National Academies Press. Retrieved from http://www.nap.edu/catalog/21714/health-literacy-past-present-and-future-workshop-summary

National Research Council. (2004). *Health literacy: A prescription to end confusion.* Washington, DC: The National Academies Press.

Peterson, B. D., Pirritano, M., Tucker, L., & Lampic, C. (2012). Fertility awareness and parenting attitudes among American male and female undergraduate university students. *Human Reproduction, 27*(5), 1375–1382. doi: 10.1093/humrep/des011

Senge, P. M. (1990). *The fifth discipline: The art and practice of the learning organization.* New York, NY: Doubleday.

U.S. Department of Health and Human Services. (2015). *Healthy people 2020.* Retrieved from http://www.healthypeople.gov

Valente, T. W. (2010). *Social networks and health: Models, methods, and applications.* New York, NY: Oxford University Press.

Walter, F. M., Emery, J., Braithwaite, D., & Marteau, T. M. (2004). Lay understanding of familial risk of common chronic disease: A systematic review and synthesis of qualitative research. *Annals of Family Medicine, 2,* 583–594.

Table 1. Codes and Emerging Themes From Holistic Content Analysis

Message No.	Codes	Emerging Themes
11, 20, 41, 79, 91-92, 115–116, 132, 171, 195	Never met or talked to anyone/only a few others with disorder before	Social impact of disorder
43, 116	Social isolation	
107, 128, 132, 134–135, 137	Bullied as a child	
120, 138, 145–146, 148, 170–171, 180	Chronic pain	Physical impact of disorder
20, 36, 41–42, 44, 57–58, 60, 78, 85, 88, 92, 93, 101, 114, 118, 138, 145–146, 148, 151, 171, 173, 179, 193–195, 203, 205	Multiple surgeries	
92, 104, 111, 135–137, 153	Physical disabilities	
41, 116, 119	Depression and loneliness	Emotional impact of disorder
125, 126, 128,	Poor self-esteem (or body image)	
60, 85, 142, 157	"Would not be the person I am today"/"Thankful for life" (positive)	
105, 107, 114, 125, 153	Feelings of shame, embarrassment, denial, and/or guilt	
118, 119, 128	Felt "different"	
118, 136	Counter-narrative ("not going to be ruled by the disease")	
107	Impact on childhood/adulthood (negative)	Developmental impact of the disorder
20, 60, 107, 184	Impact on childhood/adulthood (positive or neutral)	

27, 44, 57, 88, 116, 119, 128, 132–133, 138, 141, 144, 146, 151, 173, 175, 179–180, 193–195, 203, 255	Getting to know others whom they can identify with ("you know you're not alone")	Support group as "family"
20, 27, 57, 116, 119, 128, 133, 138, 141, 151, 175, 195, 203, 255	Comfort and encouragement	
27, 41, 57, 60, 107, 255	Wanting to help others with the disorder	
11, 14, 19–20, 25, 27–28, 36, 41–44, 53, 57–58, 60, 78, 80–81, 85, 87–88, 90–92, 94, 97, 105, 107, 111, 114, 125, 129, 132–133, 138, 142, 144–145, 149, 153, 156–158, 168, 170–171, 173, 175–176, 179, 184, 187, 191–195, 203, 206	Establishing the genetic pedigree	Genetics of the disorder
81, 107, 156–157, 195, 203, 205	Feelings associated with having "passed on" the disorder (negative)	
107, 157	Feelings associated with having inherited the disorder (positive or neutral)	
116, 144	Feelings associated with having inherited the disorder (negative)	
81, 85, 158, 184	The decision to have children (pro)	
157	The decision to have children (con or undecided)	
238	"Disease versus condition"	
60, 111, 156, 157, 160–161, 184	Misdiagnosis/misinformation	
28, 36, 80, 96, 98, 106, 126–127, 146, 149, 153, 156, 164, 170, 184, 187, 190, 192, 204, 206	Miscellaneous (requests for referrals for services, advice, etc.)	

Table 2. Line-by-Line Coding for Narrative Analysis

Narratives	Lines of Narrative	Codes
Ann	1–3	• Establishing the family's genetic pedigree/role as the non-carrier mother of carrier/affected children
	4–9, 15–16	• The Diagnosis Story
	3, 8–9	• Accessing genetic services and technology
	4–7	• Initial diagnosis of genetic risk (imperfections of the diagnostic process and risk communication)
	5	• Attitude toward disorder
	8–9	• Knowledge related to genetic inheritance
	10–14	• Guidance/support from "experts"
Barbara's 1st response	1–5, 16–18	• Establishing the family's genetic pedigree
	3–21	• Initial diagnosis of genetic risk (imperfections of the diagnostic process and risk communication)
	16–18	• Social norms
	22–27, 39–46	• The Diagnosis Story
	25–27, 31–38, 45–46, 52–58	• Attitudes related to disorder
	28–30, 41–44	• Corrected knowledge of genetic risk
	39–40, 62–65	• Accessing genetic services and technology
	45–46	• Perceived seriousness of disorder
	47–49	• Sexual and reproductive decision related to carrier/affected status
	50–51, 54–55	• Perceived severity of disorder
	57–61	• Support of family and friends
Charlene's response	1–8	• Establishing the family's genetic pedigree/role as the non-carrier mother of a carrier/affected child
	4–6, 30–34	• Perceived severity of disorder
	9–12	• The Diagnosis Story

	13–18	• Accessing genetic services and technology
	19–24	• Potential sexual/reproductive decision
	25–29	• Psychosocial variables (e.g., religion) impacting sexual and reproductive decision
	35–40	• Knowledge related to genetic inheritance
	39–40	• Request for guidance/support from "experts"
Denise	3–6	• Potential sexual/reproductive decision
	4	• Establishing the family's genetic pedigree/husband's role as a potential carrier/affected father
	6	• Perceived seriousness of disorder
	7–9	• Attitude toward disorder
	7–9	• Role as potential non-carrier mother
	10–14, 17–19	• Request for guidance/support from "experts"
	13	• Knowledge related to genetic inheritance
Elaine's response	1–6, 15–19, 43–49	• Establishing the family's genetic pedigree/role as the carrier/affected mother of non-carrier/affected children
	7–10	• Accessing genetic services and technology/sexual and reproductive decision related to carrier/affected status (pro)
	11–14, 32–38	• Corrected knowledge of genetic risk/accessing genetic services and technology
	14	• Knowledge related to genetic inheritance
	15–19, 54–60	• Perceived severity of disorder
	20–25, 26–28, 54–60	• Coping as a strategy for living with disorder
	29–31, 43–49	• Support of family and friends
	32–35	• Guidance/support from "experts"
	39–42, 50–53, 61–63, 64–68	• Attitude toward disorder
	50–53, 54–60	• Perceived seriousness of disorder
	64–68	• Empowerment as a strategy for living with disorder
Fran's response	1–3, 9–13	• Establishing the family's genetic pedigree/role as the non-carrier mother of an affected, adopted child

	4–8, 14–16	• Attitude toward parenting
	7	• Attitude toward disorder
	8	• Love and support as a strategy for living with disorder
	9–13	• The Diagnosis Story
Gladys's response	6–14, 26, 44–49	• Establishing the family's genetic pedigree/role as a carrier/affected individual
	6–17	• Social norms
	14–17, 31–33, 46	• Perceived severity of disorder
	18–25, 40–43, 44–49, 53–54, 57–59	• Perceived seriousness of disorder
	26–43, 36–43, 50–54	• Differing experiences of disorder
	31, 37–39, 53–54, 56–59	• Attitude related to disorder
	34–35	• Sexual and reproductive decision related to carrier/affected status (family member, con)
	52	• Lack of knowledge related to disorder
	56–59	• Sexual and reproductive decision related to carrier/affected status (self, pro)
Barbara's 2nd response	1–4, 31–39	• Establishing the family's genetic pedigree/role as the carrier/affected mother of a non-affected child
	1–4	• Initial diagnosis of genetic risk (imperfections of the diagnostic process and risk communication)
	5–7	• Corrected knowledge of genetic risk
	8–16, 23–24	• Attitude toward disorder
	15–16, 33	• Perceived severity of disorder
	15–16	• Perceived seriousness of disorder
	17–24	• Guidance/support from "experts"
	20–22	• Love and support as a strategy for living with disorder
	35–39	• Attitude toward parenting
Helen's response	3–6, 7–12, 26, 43–46	• Establishing the family's genetic pedigree/role as a carrier/affected individual
	7–18	• Social norms
	13–14, 19–24, 31–33, 36–39	• Perceived severity of disorder

	13–18, 34–35, 41–42	• Perceived seriousness of disorder
	25–30, 40, 54–57, 58–62	• Sexual and reproductive decision related to carrier/affected status (self, pro)
	27	• Attitude toward disorder
	28–30	• Knowledge related to genetic inheritance
	47–53	• Accessing genetic services/improved technology

Table 3. Meta-themes Emerging From Holistic and Narrative Analysis

The experience of being a carrier/being affected • The archetypal survivor-illness narrative • The social, physical, emotional, and developmental experience of living with a genetic disorder
The rare family • The supportive, nurturing "Net" family • A family "constructed" or composed of "like-minded" people who understand one another's experience • An information, referral, and advice resource
Genetic health decision making • The archetypal survivor-illness narrative, when applied to sexual and reproductive decision making, results in a pro-pregnancy/having-children stance. This holds true despite the relatively high genetic risk for having an affected child.