Mapping Metaphor:
A qualitative analysis of metaphorical language in discussions of receiving exome and whole genome sequencing results

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Abstract

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The rapid integration of genomics into clinical care, growing interest in offering genetic results to research participants, and consumer enthusiasm for personalized genomics requires greater understanding of how individuals conceptualize and communicate about genetic information, preferences for genetic information, and individual genetic results. Metaphors such as the “genome as a blueprint” have been well studied in public discourse; however, the applicability of these metaphors to the translation of personal genetic information is largely unknown. I performed a qualitative analysis of metaphorical language in 40 interviews and 13 focus groups in which participants (n=109) were asked to discuss their preferences for and expectations about receiving genetic results from whole genome or exome sequencing. I identified several salient conceptual metaphors in which participants compared genetic information to physical objects such as tools, weapons, and goods in boxes. Dichotomies and tensions within these metaphors suggest the importance of agency and different loci of control. In some cases, genetic information empowered individuals to act (e.g., a weapon in their arsenal) while in other cases it overpowered them (e.g., they are bombarded by genetic information). Participants used metaphors such as storing results in a “lockbox” or unintentionally opening “Pandora’s box” to describe the potential benefits and harms of incidental sequencing results. Metaphors comparing whole genome sequences to formal documents or reports (e.g., a credit report) raised questions of authorship, ownership, and interpretability, and resonated with well-known genetics metaphors in the public domain (e.g., blueprint, recipe, book of life). These results have practical implications for understanding and perhaps influencing how research participants and patients perceive the desirability, utility, and actionability of genetic information. Furthermore, these findings suggest that increased awareness of and attention to metaphorical language may serve to improve communication between stakeholders when discussing genetic information.

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Sarah Nelson, May 31st, 2014

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Introduction

Over the past decade, advancements in genetic technologies have made obtaining genetic information easier, cheaper, and faster than ever (Wetterstrand, 2013). Rather than examine only a limited subset of genes or variants at any given time, sequencing either across the entire genome or the protein-coding portion thereof, known as the “exome,” has become increasingly common. Thus across both research and clinical settings, an unprecedented amount of genetic information is now being produced. The increase in volume and complexity of genetic data intensifies the need for accurate and innovative ways to communicate about genetic information within and between multiple stakeholder groups.

Broadly speaking, conversations about genetic information occur in three key domains: public discourse, healthcare, and research. In public discourse, lay persons interact with genetic information through media reports of research findings; policy issues — e.g., ongoing debates surrounding federal regulation of direct-to-consumer genetic testing company 23andMe (Klein, 2013); technological advancements; and even celebrity news (Jolie, 2013). In healthcare, genetic information is slowly but steadily being integrated into many different clinical scenarios (Manolio et al., 2013). Indeed, in the future it is likely that a wide variety of healthcare professionals will discuss genetic risk information with patients, rather than primarily genetic counselors and medical geneticists. For example, primary care may become a “home base” for such conversations, especially about genetic risk for common, complex diseases (Lautenbach, Christensen, Sparks, & Green, 2013). Last, individual genetic results are discussed with participants in genetic research studies, initially in the informed consent procedure (McGuire & Beskow, 2010) and then, potentially, if and when individual results are returned to participants.

Genetic sequencing and the rapid pace of translating genetic information into clinical applications is increasing the demand for means to convey complex genetic information, particularly about principles used in medical decision-making, such as actionability and uncertainty. Actionability is the extent to which preventive or therapeutic clinical action can be taken to alter the course of disease (Fabsitz et al., 2010) and is a pivotal factor in ongoing debates about whether and when to return results to patients (Burke et al., 2013; McGuire, McCullough, & Evans, 2013; Wolf et al., 2012) and research participants (Burke, Evans, & Jarvik, 2014; Murphy Bollinger, Bridges, Mohamed, & Kaufman, 2014; Wolf, 2013). In the context of whole genome or exome sequencing (WGS/ES), uncertainty usually refers to a lack of definitive knowledge about either the probability of illness given the presence of known risk variants and/or whether certain variants are even associated with disease risk (Gray et al., 2014). Studies have shown that “uncertainty” can have multiple definitions (Han, Klein, & Arora, 2011), which may differ between providers and patients (Han, 2013). These and other nuances of genetic sequencing data call for refined communication tools if genetic technologies are going to positively impact human health in a way that honors personal preferences while maximizing clinical benefit.

Research purpose

Examining how people use metaphor when discussing and seeking to understand personal genetic information is an important starting point to identify ways to address the communication needs described above. People use language to accomplish far more than just “saying” things. Language in general, and therefore metaphor as a specific type of language, is also used to build identities, assign significance, and make relationships between people and things in the world (Gee, 2010). More than just a linguistic flourish, metaphor is an essential part of how we understand the world — it works deeper than just words to influence both thought and action (Lakoff & Johnson, 1980, p. 3). For many years, rhetoricians and communication experts have been studying metaphor in public discourse about genetics (reviewed below). However, few have studied how individuals use metaphor when referring to personal genetic information, a context that has become particularly important due to the volume of genetic information made available through sequencing. In this thesis project, I examine research participants’ use of metaphor when asked to discuss the possibility of receiving personal genetic information, specifically in deciding on their preferences for and expectations about receiving results from WGS/ES. The purpose of this analysis is to increase awareness of and attentiveness to metaphorical language as a foundation to ultimately improve communication of genetic information between stakeholders.

In the following sections I will further introduce metaphor, review the literature on metaphor in public discourse about genetics, and situate the present study as a bridge between the scholarship on genetics metaphors in public discourse and the translation of individual genetic information.

Background

Introducing metaphor

Aristotle first established the study of metaphor in his 4th century BC works *The Poetics* and *The Rhetoric*, in which he wrote "metaphor consists in giving the thing a name that belongs to something else" (cited in Black, 1954, p. 284) and "the greatest thing by far is to have a command of metaphor" (cited in Richards, 1936, p. 89). Metaphor can generally be thought of as a descriptive, explanatory, and potentially creative comparison between two things or ideas: the "vehicle" and "tenor" (terminology from Richards, 1936). The vehicle is the more concrete and/or familiar thing or idea used to help describe or explain the more abstract and/or less familiar tenor. At face value, vehicle and tenor may seem quite dissimilar. However, upon further examination and reflection, aspects or elements of the vehicle help bring to light and explain similar aspects of the tenor.

There are essentially two perspectives on how metaphors are thought to be used by speakers/writers: the rhetorical and the cognitive (Cameron, 2013). Beginning with Aristotle, the rhetorical perspective holds that metaphors are "thoughtful and deliberate constructions" intentionally and often artistically used by the speaker/writer, i.e., the "poetic use" of metaphor (2013, p. 343). More recently, the cognitive perspective has reconceptualized metaphors as reflective of deeper, internalized ways of thinking. In these "prosaic" uses of metaphor (2013, p. 343), the speaker/writer is usually either unaware or only superficially aware of the metaphorical patterns in their language (Schmitt, 2005, p. 260). The cognitive perspective was established with Lakoff and Johnson's seminal publication in 1980, *Metaphors We Live By*. In this book, they argue that instead of being mere linguistic decoration, metaphors are essential to our ways of thinking and acting and are thus pervasive in everyday life (1980, p. 3). In fact, Lakoff and Johnson characterize our entire conceptual system as "fundamentally metaphorical in nature" (1980, p. 3). Thus from the cognitive perspective, metaphor is an essential part of how we understand the world, shaping perception, thought, and action — often implicitly, outside of our awareness.

Lakoff and Johnson created a systematic way of understanding several different aspects of metaphor. First they introduced the idea of the *metaphorical concept* (or, equivalently, a conceptual metaphor): the underlying metaphorical framework in which different linguistic expressions are embedded. For example, in their classic example the metaphorical concept ARGUMENT IS WAR manifests across different expressions, such as to “attack a position,” “gain ground,” or “win” an argument (1980, p. 7). Metaphorical concepts are like containers in which many different details and subcategories may be located. The different ways metaphorical concepts can be expressed are referred to as *linguistic expressions*. For example, Nerlich and Hellsten (2004) have identified different linguistic expressions of a common genetics metaphor, the BOOK OF LIFE: “DNA as text,” “annotating” the genome, and “reading” and “writing” genetic information. Notably, various linguistic expressions may lead to differing implications, also referred to as entailments, commonplaces, or “the material consequences” (Gronnvoll & Landau, 2010) of the metaphor being used. Which entailments are drawn out in any given use of a metaphorical concept will necessarily focus attention on some aspects of a concept while hiding others (Lakoff & Johnson, 1980, p. 10). Thus metaphor can simultaneously illuminate and obfuscate. As Ceccarelli has written, “metaphor selects some aspects of a subject to emphasize, while deflecting our attention from other aspects of that subject” (2013b, p. 16). Therein lays both the power and danger of metaphor, in that it can both enhance and detract from clear understanding, depending on which entailments follow from the metaphors that are used and on the positionality of both speaker/writer and listener/reader.

Metaphor in public discourse about genetics

Historically, metaphor has played an important role in public discourse about science and technology, including the field of genetics. Nerlich and Hellsten have argued the importance of metaphor in translating science outside of the scientific community, in serving to “connect various scientific and non-scientific discourses” and to “open up a common ground for the different participants of the debate” (2004, pp. 257–8). This process of translation is crucial because the ethical and social issues that arise from the integration of science and technology call for an extended role of non-scientists, beyond just being recipients of science news. Rather, “research and technical innovations have to be legitimised in the marketplace, in policy-making, in ethical debates and amongst the publics as citizens and as consumers” (Hellsten, 2005, p. 286). In addition to translating science to non-scientists, metaphors are also used within scientific communities to process and conceptualize different models and theories (P. Ball, 2011; Keller, 1995). Thus metaphors influence and shape discourses about genetics both within and beyond the scientific community. Accordingly, communications and rhetorical scholars have studied genetics metaphors in many domains: in popular media such as newspapers and magazines, in academic publications, and in the public speeches of scientists and politicians. Next I review key features of these studies: (1) metaphorical shifts over time, (2) multiple meanings of metaphor, and (3) rhetorical uses of metaphor.

Several shifts in metaphors over the past century have been described, often reflecting changes in scientific understandings of genes and genomes. In *The Meanings of the Gene*, Celeste Condit chronicles the gene in public discourse across the 20th century, from early breeding metaphors to the genome as blueprint metaphor introduced in the early stages of the Human Genome Project (HGP). She argues that genetic metaphors have been used to connect "social interests, social fears, and scientific discoveries" (1999b, p. 218). By tracing the evolution of and transition between four primary metaphors: stock/breeding, atomic particles, codebook, and blueprint, she explores how changes in metaphors over time reflected changes in general understandings about the nature of genetics. For example, the change from codebook to blueprint as a guiding metaphor during the 1980's reflected a shift in focus from individual genes to the entire genome. The change "accompanied a refocusing of scientific vistas from the individual genes to the 'genome,' and this involved a more holistic look at the complicated role of DNA in creatures and cells" (1999b, p. 20). The introduction of the blueprint metaphor also reflected an increasing commercialization of genetic technologies — thus the blueprint as a "manufacturing" metaphor (1999b, p. 159). Condit also notes that the transition from a codebook to a blueprint metaphor reflected a growing understanding of the genome as a flexible entity that can be altered by the environment (e.g., the way the realization of a building is influenced by the builder and the materials), in contrast to the more fixed, deterministic genome implied by a codebook (1999b, p. 161).

Following Condit's book, others scholars have further examined how metaphors change over time in response to evolving understandings of genetics. Nerlich and Hellsten (2004) examined "metaphorical shifts" in public discourse about the HGP by comparing articles in one scientific and one non-scientific publication (the journal *Nature* and a UK newspaper, respectively) from 2000 to 2003. They determined that when the completion of the HGP revealed far fewer genes than expected (~30,000 vs. an expected 100,000), the earlier, more "programmatic" metaphors, such as code or blueprint, were rendered insufficient to capture "effectively the complexity of the gene-protein-environment interaction" (2004, p. 257). However, the new metaphors introduced by journalists and scientists during this time, such as “genome salad” and “litter,” failed to gain widespread traction. The authors attribute this relative failure to the enduring nature of the earlier metaphors, and also partly to the awkwardness of the newly proposed ones. While the metaphorical containers endured, however, the meaning and usage did shift: they were “adapted to fit into the new post-genomic era” (2004, p. 266). In a follow-up study focusing specifically on the BOOK OF LIFE metaphor, Hellsten (2005) again observed that while old metaphors persist, different aspects were drawn out at as the field turned from genetics to genomics to post-genomics. For instance, after completion of the HGP, the book metaphor was extended to highlight the importance of annotating the book — of understanding how genes function in addition to knowing where they are located. She concludes that metaphors with “both a long history of use and that are flexible enough to allow for new formulations” are more readily taken up as tools of communication (2005, p. 295).

The studies described above show how metaphors can be both reflective of and resistant to change. On the one hand, metaphorical shifts often reflect evolution of scientific understanding. On the other hand, some metaphors endure despite dwindling scientific support for their relevance. In exploring this persistence over time, Hellsten (2008) characterizes some metaphors in the biosciences as “bridges over time:” in addition to bridging divides between scientific and lay understandings they can also link past to present (and indeed, future). In this work, Hellsten examines metaphors with a “temporal disconnect” between vehicle and tenor, such as a car engine having “horsepower.” Such metaphors operate at societal levels, drawing upon shared historical and cultural discourses and indeed serving as “carriers of cultural knowledge across generations of metaphor users” (2008, p. 16). This function “places metaphors at the level of social groups (instead of individuals, as asserted by Lakoff and Johnson) and at the level of discourses” (2008, p. 18). The take home message from this study of metaphors as “bridges over time” is that while culturally salient and cohesive, these same metaphors may also “sometimes hinder our creative imagination toward alternative, innovative solutions” (2008, p. 13).

In addition to shifting across time, the meanings of metaphors can also vary with context. Condit and colleagues have shown how a metaphor can have a broad set of potential meanings initially, which are then filtered down based on specific contexts (Condit et al., 2002). In examining people’s interpretation of and preferences for the blueprint and recipe metaphors of the genome, they found the recipe metaphor to be no less deterministic than blueprint, contrary to the expectations of some media critics. Specifically, they observed people's different understandings and preferential uses of metaphor to be products of a three way interplay between (1) the "concrete referent" (e.g., "baking bread" in the recipe metaphor); (2) their "emotional valence" toward the metaphoric vehicle, or the metaphor's affective qualities; and (3) the familiarity of the vehicle: i.e., individuals have a preference for vehicles with which they are more familiar (2002, p. 313). They explain their findings via Joseph Stern's theory of metaphor, which depicts the interpretation of metaphor as a "dual process of production and filtration" (2002, p. 303). This research shows that metaphors do not have innate meanings and thus serves as a cautionary tale against making simplistic predictions about how a given metaphor will be perceived and adopted in social usage.

Rhetorical scholars have critically examined genetics metaphors in public addresses made by prominent scientist and politicians, revealing how metaphors are used to shape and promote scientific and political agendas. For example, Leah Ceccarelli has studied both the historical development and recent usages of the "frontier" metaphor by American scientists. Ceccarelli underscores how the frontier, as both myth and metaphor, has been "pervasive" in American culture in general and in scientific discourse in particular (2013b, p. 2). When the frontier metaphor was brought to the biological sciences, instead of a spatial, physical frontier to be colonized/explored/conquered, biological bodies (like the human body and its genome) became "spatialized" as a frontier (2013b, p. 11). As a "terministic screen," the metaphor shapes (essentially limits) how we view the nature of science (rugged, individualistic, progressive) and who we think should practice it (i.e., white men) (2013b, p. 3).

Unfortunately the frontier metaphor is at odds with several key components of contemporary science, namely its highly collaborative nature — indeed, collaborations on a global scale are increasingly necessary for successful scientific endeavors — and its rightful inclusion of many female scientists (2013b, pp. 5–6). Many of the metaphor's shortcomings were recognized by one of its users: Francis Collins, who, as head of the National Human Genome Research Institute (NHGRI) at the time, was a major leader of the HGP. Ceccarelli (2013a) specifically examines the use of the frontier metaphor in Collins's public addresses, including his 2000 speech at the White House press conference announcing the draft completion of the HGP. Collins's use of the metaphor "carries all the troubling entailments that scholars identified in earlier examples of public discourse about the [HGP]" (2013a, p. 98), suggesting that scientific progress is predicated on ideas of ownership and individualism. His use of the metaphor, Ceccarelli argues, undermined his concurrent efforts “to portray science as an international cooperative endeavor that disregards economic self-interest to serve the needs of all “ (2013a, p. 98). Ultimately Ceccarelli concludes that, through its use by not only Collins but many other public scientific figures as well, the metaphor is too ingrained to be cast off completely at this point. Nevertheless, she warns that scientists and their supporters in the public sphere “should become aware of its pitfalls” (2013b, p. 28).

The literature reviewed above reveals a well-developed understanding of how metaphor can function — to aid or hinder — public discourse about genetics. The data points in these studies have mostly been news media reports, audience studies, and speeches/public addresses of scientists. The sources of these metaphors are arguably the *public genome*, or the genome in the abstract. While metaphors such as the genome as a blueprint have been well-studied in public discourse as a vehicle for conceptualizing genetics, the applicability of these metaphors to the translation of personal genetic information (the *personal genome*) is largely unknown. Some work has been done on this front: for instance, Gronnvoll and Landau (2010) have demonstrated that lay audiences tend to use different metaphors when grappling with the connection between genes and disease than those used by scientists. Parrott and colleagues (2004; 2012) have examined public perceptions of the role of genes in health and found that common frameworks used to explain illness causation in health messaging may not work well when communicating about genes and health. Studies such as these suggest the need for further exploration of metaphor’s “untapped potential” (Gronnvoll & Landau, 2010) in communicating and translating personal genetic information.

The present study is an effort to further bridge between genetics metaphors in public discourse and in individuals discussing personal genetic information, to examine both the utility and limitations of the literature reviewed above as actual people and patients increasingly encounter genetics in research and clinical settings. This undertaking is of particular importance as the genetics community seeks to successfully integrate genomics into clinical care. Indeed, in 2012 the NHGRI stated “genomic medicine can *metaphorically* be viewed as a key ‘destination’ for attaining NHGRI’s mission— improving human health through genomics research” (NHGRI, 2012, emphasis added).

The realization of genomic medicine, however, requires more than just uncovering the genetic basis of disease. It calls for understandings and innovations in the development and delivery of genetic information and applications into clinical use. A key part of this delivery process is effective, bi-directional communication: between clinician and patient, between the research community and clinicians (e.g., disseminating research findings), and between the research community and the general public (i.e., establishing both genetic literacy and health literacy in would-be patients). It is known from decades of genetic counseling that probabilistic, often uncertain, genetic risk information can be difficult to convey (Lautenbach et al., 2013) and that metaphors can be helpful in this endeavor (GCCCT, 2010; S. Jamal, MSc, LCGC, CCGC , personal communication, Dec. 8, 2013). In the decades to come, the challenges and opportunities for communicating about genetic information are likely to expand, as WGS/ES become more commonplace in research and in medicine.

In an effort to respond to the opportunities and challenges just described, I have undertaken an analysis of metaphorical language used by research participants when asked to discuss the possibility of receiving personal genetic information, specifically in deciding on their preferences for and expectations about receiving results from WGS/ES. In the following chapters I will describe the research methodology and methods used to carry out this analysis; present the conceptual metaphors I identified; and draw out conclusions and implications for future communication of genetic information in public, research, and clinical settings.

A methodology is a set of principles guiding the choice of research methods whereas methods are the actual actions taken during a research project (Carter & Little, 2007). In short, methodology justifies methods. In this chapter, I describe the methodology and methods I adopted to examine the use of metaphor by research participants asked to discuss the possibility of receiving results from WGS/ES.

Methodology

While my project was informed by several different qualitative research methodologies, I used discourse analysis as the central organizing methodology. Discourse analysis is the study of "language-in-use" or how language is used to "say things, do things, and be things" (Gee, 2010, p. 3). Gee anchors discourse analysis in an examination of how language is used to accomplish seven "building tasks:" *significance, activities, identities, relationships, politics, connections*, and *sign systems and knowledge* (2010, pp. 17–19). He describes these tasks as areas or things language is used to establish in the world (2010, p. 28). For example, the building task of *significance* is accomplished when words render certain things either more or less important; the task of *identities* is accomplished when language is used to perform certain social roles (2010, p. 3).

By conducting a discourse analysis, I have assumed a social constructionist view of reality, in which truth and meaning are constructed or built in accordance with (and thus specific to) a certain time, place, and context. Gee describes this as "situated meaning," where the meaning of language is dependent on the context in which it is spoken or written. Personal, social, and cultural histories may affect both how a speaker/writer constructs her meaning and how a listener/reader comprehends that meaning. Thus meaning is "*negotiated* between people in and through communicative social interaction" (Gee, 2010, p. 104). Because all meaning is context-specific and negotiated, in this project I have not assumed that "researcher and participant necessarily mean the same thing when they use the same words" (Starks & Trinidad, 2007, p. 1375). Rather, I have captured and integrated as much context as possible so that I can make reasonable arguments about the function of my participants' language.

Appropriateness of methodology to the research aim

My study is aimed at understanding how research participants use metaphor when asked to discuss the possibility of receiving personal genetic information, specifically in deciding on their preferences for and expectations about getting results from WGS/ES. This goal is well-suited to discourse analysis in that it seeks to uncover what language is doing in a specific context. The particular type of language I am interested in is metaphor: creative yet very functional comparisons between two things or ideas that influence perception, thinking, and action (Lakoff & Johnson, 1980, p. 3). Metaphors are involved in many of Gee's building tasks of language, most notably *connectio*n and *significance*. A metaphor at its core is a *connection* or comparison between two things: a tenor — the subject being explained, and a vehicle — the thing or idea helping to describe or explain the tenor (Richards, 1936). The choice of vehicle and which of its characteristics are featured in the metaphor will serve to highlight some aspects of the tenor while obscuring others (Ceccarelli, 2013b; Lakoff & Johnson, 1980), thus building (or removing) *significance*.

Discourse analysis also focuses on how language functions specifically in social contexts, another feature that makes it a good methodological choice for this metaphor project. Metaphor as social discourse has been well characterized by science communications expert Iina Hellsten and colleagues (Hellsten, 2008; Zinken, Hellsten, & Nerlich, 2008). They have explained "discourse metaphors" as those that draw upon shared socio-cultural knowledge, or "cultural commonplaces" (Zinken et al., 2008, p. 6), and thus show a social "situatedness" (Zinken et al., 2008, p. 2) rather than being solely a reflection of individual cognition. Furthermore, Zinken et al. discuss how metaphors have "social costs and benefits" (2008, p. 5), much in the same way Gee has described all language as political, "where social goods are always at stake" (Gee, 2010, p. 5).

Metaphor also resonates with three other fundamentals of discourse analysis: *situated meanings*, *intertextuality*, and *figured worlds*. First, metaphors are prime examples of *intertextuality*, when "one spoken or written text alludes to, quotes, or otherwise relates to another one" (Gee, 2010, p. 208). Second, studying metaphor requires attention to *situated meanings*, as Condit and colleagues have shown that even genetics metaphors assumed to be uniformly used and understood (e.g., the blueprint and recipe metaphors) are "activated" differently based on context (2002). Last, metaphors have much in common with *figured worlds*, which Gee explains to be "simplified, often unconscious, and taken-for-granted theories or stories about how the world works that we use to get on efficiently with our daily lives" (2010, p. 76). This depiction of figured worlds aligns with Schmitt's description of metaphor: "Metaphors provide schemes, which bundle together the fullness of details, making them clearer and more manageable. In doing this, they make perception more automatic and ease the energy required to understand” (2005, p. 366). Thus like a heuristic or mental short-cut, metaphor is a miniature type of figured world in that it is often a convenient placeholder for more complex and difficult-to-understand phenomena. For example, a human genome is an abstract and potentially difficult to understand entity. In comparison, a “blueprint” is a more familiar and tangible object that people can use to more easily perform a mental simulation of what a genome might be or encompass.

Positionality

I come to this work as a public health genetics researcher-trainee interested in understanding the social and ethical dimensions of genetic information. My upbringing (middle class), academic training (biology, public health genetics), professional experience (quantitative human genetics research), sex (female), and race (white) all influence how I see and interpret data. Specifically, there may be metaphors that resonate differently in specific cultures and communities of which I am not a part. However, rather than attempt to cancel myself out of the analytic process, I have strived to uphold the quality of my research by recognizing and reflecting upon my biases, a practice Finlay (2002) calls “reflexivity;” consulting with my peers and mentors along the way; and maintaining an “audit trail” of decisions made and actions taken throughout my project (i.e., via memos, discussed further below).

Methods

Data sources

My dataset comprises transcripts from interviews and focus groups previously conducted as part of an ongoing joint research initiative of the University of Washington Department of Pediatrics and Seattle Children’s Research Institute. This larger research program encompasses several aims, including (1) to investigate willingness to participate in WGS/ES research studies, (2) to understand attitudes and preferences around receiving results from such studies, and (3) to develop tools and strategies for return of results. Prior to initiating my thesis work, I was added to the two IRB protocols under which these data were collected (“Informed Consent for Whole Genome Studies” and ”Usability testing of a web-based portal for return of genetic results”) and was thus approved by the University of Washington Human Subjects Division to access these transcripts for my specific research project. Below I briefly describe, separately for focus groups and interviews, the specific research aims and context, participant recruitment and composition, and content of the protocol (i.e., focus group or interview guide).

Focus groups were conducted to explore attitudes around participating in and receiving individual results from WGS/ES research studies, with an emphasis on exploring these attitudes in parents and across different racial and ethnic groups. My analysis includes 13 focus groups conducted between May and August 2012, with the exception of one held in September 2011. Four of these groups were composed of exclusively self-identified African Americans, three were exclusively self-identified non-African American, and six were mixed. All participants were adults living in the Seattle/King County area recruited with a variety of community and clinic-based advertisements (for details, see Yu, Crouch, Jamal, Bamshad, & Tabor, 2014; Yu, Crouch, Jamal, Tabor, & Bamshad, 2013). Focus groups were held at a variety of locations, including schools, community centers, and clinics. They were all moderated by a lead researcher accompanied by a research assistant and — for some of the latter focus groups — a genetic counselor also on the research team. In these focus group discussions, participants were asked about two broad topic areas: (1) willingness for themselves and/or their children to participate in a genetic sequencing study and (2) what types of genetic results they might want (or not want) to receive back from such a study. Prior to opening up discussion on these topics, the moderators first provided relevant background information such as explaining what genetic sequencing is and what kinds of results may be generated from it.

A second component of my dataset is a series of **interviews** from two related studies: the Preferences Setting Study (PSS) and the My46 Usability Study in African Americans (MUAA). A key aim of these interviews was to help guide the research team's development of a web-based tool for self-guided management or return of results, called "My46" (http://www.my46.org). With the My46 web interface, individuals can choose among different categories of results to receive from sequencing, such as risk for different types of diseases (e.g., disorders of the blood, brain and nervous system, or heart and lungs), carrier status, and medication response. During the interviews, participants used the My46 web tool to set their individual preferences, under the hypothetical scenario that their whole genome or exome was being sequenced in a research study. Interviews proceeded in three stages: pre-task interview, individual use of the web tool ("web task"), and post-task interview. The MUAA interviews included two additional components: reviewing a sample report and watching a short informational video on sickle cell disease.

All interviews were conducted by the same lead researcher during two different time periods: the PSS interviews between May and August 2012 and the MUAA interviews between July and August 2013. The PSS and MUAA interviews were carried out with similar protocols and are thus primarily distinguished by the time period conducted (i.e., PSS functioned like a pilot study for MUAA) and the focused recruitment of African Americans for the MUAA study. Note some individuals participated in both a focus groups and an interview, in part because of the overlapping time frames of the different studies. Further demographic details of all interview and focus group participants are presented in the chapter on results (see Table 1).

Notably for my research project, in neither the focus groups nor interviews was there any explicit discussion or elicitation of metaphor from the participants. While some metaphorical language may have been used by the moderators and/or in the My46 website content, there was no explicit discussion of metaphor per se*.* Rather, my secondary use of these datasets relies on natural or unsolicited uses of metaphor by participants. There are both advantages and disadvantages to this situation. An advantage is that, as Cameron has observed, metaphor use in spontaneous conversation, while “often low key and conventionalized,” can also be “revealing of [the speaker’s] ideas, attitudes, and values” (2013, p. 347). A disadvantage is that because metaphor was not an original target of focus group or interview questions, only rarely were follow-up questions used to clarify or expand upon participants’ metaphors. Thus my analysis is limited in the inferences that can be made regarding authorial intent and broader contexts that may be influencing metaphor use, whether consciously or subconsciously.

Data analysis

During data analysis, I iteratively read over transcripts using the general framework of directed content analysis (Hsieh & Shannon, 2005). Specifically, I first read through all the transcripts looking for a very general a priori code of “metaphor:” any metaphor pertaining to genetics, health, or decisions about those things. I attempted to code only **live metaphors**: those acting as “explanatory comparisons or active analogies” rather than being purely descriptive (Condit, 1999b, p. 160). This criterion was meant to exclude dormant metaphors that have become conventionalized or literalized to the point that the vehicle has come to literally represent the tenor[1]. Note that this criterion did not preclude keeping well-worn genetics metaphors in the analysis, which could potentially still be live. For example, there may be some uses of the “blueprint” or “recipe” metaphor among participants that are sufficiently activated by surrounding text to warrant further attention. Ultimately, in my initial coding pass I reserved a backup code, “metaphor-potential,” to track passages that seemed neither purely comparative nor purely descriptive. This backup code was also applied when the metaphorical tenor was not clearly pertaining to genetics or health but still seemed potentially related. All coded passages (n=189), whether coded with the primary code “metaphor” or the auxiliary “metaphor-potential” code, were then reviewed for adherence to the criteria of (1) live metaphor and (2) relevance to the tenors of interest. Those that did not adhere were not carried forward into the next stages of coding and analysis.

In subsequent stages of analysis, I grouped metaphors into more refined categories according to both vehicle and tenor. When grouping individual instances of metaphor, I drew upon systematic metaphor analysis, an approach to the analysis of metaphor in qualitative data developed by German social science researcher Rudolf Schmitt (2005). This method can be distilled into three steps (Nerlich & Hellsten, 2009): (1) closely reading text to identify metaphor use, (2) collecting all metaphorical expressions and their surrounding context, and (3) sorting these expressions into conceptual metaphors, which can be thought of as the larger underlying metaphorical frameworks. For example, the classic example given by Lakoff and Johnson is the conceptual metaphor ARGUMENT IS WAR (1980, p. 4). While a speaker may directly state this metaphorical understanding, it is more common for him to state specific entailments of the metaphorical concept, such as someone winning an argument or there being two sides to a disagreement. Overall, the process of grouping metaphor according to metaphorical concepts and/or key ideas was one of decontextualization and recontextualization (Ayres, Kavanaugh, & Knafl, 2003): a

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[1] Here I consider dormant metaphors to be those where the vehicle has come to literally represent the tenor, most likely through extensive and continued use. Dormant metaphors can be thought of as literal uses of figurative language. For example, early representations of DNA as code were active analogies to either Morse code or computer code. More recently, referring to DNA as a code has mostly lost its metaphorical origins: DNA is now literally understood to be a code (e.g., DNA “codes for” proteins). Another example of a dormant metaphor, which I noted frequently in this dataset, is the “passing on” of genes. As an active metaphor, this could be a comparison between intergenerational inheritance of genes and the passing on of other physical objects, such as family heirlooms. However, because people so often speak of “passing on” genes, that phrase has come to literally describe how genes are transferred from parent to offspring. Note I use the term “dormant” rather than “dead” because the metaphorical roots of these expressions can still be potentially drawn out or “awakened” if brought to the speaker/user’s attention. For example, one could “awaken” the DNA as code metaphor by comparing the current movement to make genetic data widely and publicly available (e.g., Ball et al., 2014) to similar calls for open source software in the computing world (e.g., DiBona & Ockman, 1999).

feedback loop between zooming in on particular cases and stepping back to articulate general emerging themes. All transcripts were coded and analyzed within the qualitative analysis software ATLAS.ti (v7.1).

Memoing

Throughout the planning and execution of my project, I kept research journals or “memos” to serve as a written track record or “audit trail” of how the research was unfolding (Birks & Mills, 2011, p. 41). In addition to the concrete purpose of codifying a record of decisions made and actions taken, memoing serves a more abstract purpose of fostering an analytic and reflective frame of mind in the researcher (Jeon, 2004, p. 253), facilitating insight and cohesive thinking to help connect dots that might otherwise remain separate. I kept one grand memo where I recorded (1) relevant conversations I had with my peers, mentors, and friends; (2) notes from meetings with my committee members; and (3) personal reflections on the research project as a whole. Additionally, in ATLAS.ti I kept memos for different phases of coding — i.e. a coding memo and analysis memo.

Results

Below I present the conceptual metaphors I identified by grouping and thematizing the passages coded as metaphor. Overall, I identified approximately 160 metaphors across 53 transcripts from focus groups and interviews with 109 unique study participants. Basic demographic information for these participants is presented in Table 1. Table 2 contains example quotes for each of the conceptual metaphors described below. Following the convention of linguistics, I have written conceptual metaphors in small caps. In excerpted quotes, underlined phrases indicate the linguistic expressions of the metaphorical concept.

Genetic information as tools and weapons

Next I present a pair of related conceptual metaphors consistent with the contextual focus of parent group discussions and interviews on receiving genetic results: GENETIC INFORMATION IS A TOOL and GENETIC INFORMATION IS A WEAPON. In both concepts, genetic information is portrayed as a physical object with practical utility to carry out some concrete action in the world. In other words, these metaphors relate to what genetic information is actually used to *do*.

Participants' expressions of GENETIC INFORMATION IS A TOOL highlighted the utility of receiving genetic information. For example, one focus group participant spoke of receiving sequencing results as having "one additional piece of information to add to the toolbox" (P08-02, white female). The reference to a toolbox invokes the idea of a set or suite of tools; this participant seems to view genetic results as just one of those tools. Another example of GENETIC INFORMATION IS A TOOL is from an MUAA interview participant as she considers receiving results for her child:

> [Receiving genetic information] gives you tools and fuel and information on, on if there was any pro- you know any issues that had to be dealt with, you could work it out with your child and I mean you could, you just could work together and um, and just be armed. (MUAA13, African American female)

She goes on to say that genetic information is "empowering" and that "it just gives you something to work with." The double comparison to "tools and fuel" underscores the utility of genetic results as something you can do something with, or "work with." Being "armed" with information is also an expression of the GENETIC INFORMATION IS A WEAPON conceptual metaphor. The participant's invocation of both conceptual metaphors demonstrates how the two cluster together in portraying genetic information as a useful object that can be used to *do* or *accomplish* things.

I classified several passages as representing the conceptual metaphor GENETIC INFORMATION IS A WEAPON. Different expressions of this underlying metaphor show contrasting loci of control: when control is located within the individual, where they use the weapon, versus when control is external to the individual and the weapon is used against them. First, I present examples of the former construction, where the weapon is used by the individual. For example, one PSS interview participant very consistent about wanting to know all of her genetic results stated, “I want to be armed with information” because “if I have more information then I can plan better” (PSS24, Asian American female). Additionally, in the passage below a focus group parent’s explanation of why she would rather know her child’s genetic results than her own contains several expressions of this conceptual metaphor:

> I have already made the decisions that I’ve made, and this could be a piece of information for them to make-to-to have in their arsenal for decisions that they’re going to make in their lives and if they’re going to go through this, then it’s-I would say that it wouldn’t be fair for me to choose for them, like I would want them to be able to have the information to choose to use it or not. (P02-01, white female)

Similarly to a toolbox containing tools, an arsenal contains weapons: items or pieces of information. In addition to the metaphorical entailment of the nature of information being like a weapon, this passage also includes a clear use for the information — to aid decision making — and a clear choice for putting the information to that use or not.

In contrast to the above examples of weapons used *by* individuals, participants’ also expressed GENETIC INFORMATION IS A WEAPON in terms of weapons used *against* individuals. In this construction, the individual is “hit” by genetic information as if it is a weapon wielded by an external force. For example, one focus group participant spoke of not wanting to be “blindsided” by her genetic results:

> I mean people could be very blindsided and you know and really. I mean, if you know, they do this voluntarily, they know they’re getting their genome, but like, "What? I had no idea that I could possibly be positive for that." You know what I mean? Kind of thing that just maybe, could hit somebody pretty hard. (P06-01, white female)

“Getting hit” came up in other focus groups as well, including during discussions of how participants would want genetic information returned, for example, by their doctor or through the mail:

> I’m trusting you to present it back to me in a way that’s not gonna just…knock me off my feet, you know. (P09-03)
> 'Cause it can be quite a wallop all at once, but uhm... yeah, or so much information it’s just meaningless like you don't even know what do. (P06-02, white female)

Participants' comments suggest that the timing and delivery of genetic information could affect whether one is hit by it or not. Given all at once, it can knock someone over and/or become "meaningless" because of the sheer volume and potential complexity of a whole genome or exome sequence.

Other references to being hit by genetic information included one MUAA participant who spoke of not wanting to be "bombarded" with too much information (MUAA24, African American female). Bombardment invokes an idea of war, of continuous and heavy attack via shells or missiles. Thus there are weapons involved in this expression of the conceptual metaphor GENETIC INFORMATION IS A WEAPON, but again they are being used against rather than by the individual. This theme of bombardment or shelling with information also arose in a PSS interview. Here he describes not wanting to know certain types of genetic risk information for his children:

> No, I guess if they have developed some type of deadly disease, I don't think I would care to know… like I said, [I] may become a <u>shell shocked victim</u> due to new information such as that. (PSS21, African American male)

Becoming "shell shocked" would imply being stunned to the point of immobility or incapacitation, signifying that the genetic risk information could be too much to handle.

Notably, I categorized another set of metaphors about being "hit" where the tenor was not genetic information but rather unexpected life events or disease onset. In these metaphorical expressions, participants portrayed genetic information as something that could *prevent* one from being hit by these other unexpected occurrences. The idea of being "blindsided" came up again in this context:

> I think preparation is better than [being] <u>blindsided</u> because you can--- you can always make a plan but you--- you--- it's harder to work on the fly. (P07-02, white female)

Similar to this focus group participant, some interviewees also expressed wanting to know genetic risk information because of the advantage afforded by knowing and preparing in advance:

> You don't want to get, you know, you don't want to get <u>hit in the head</u>, <u>in the back</u> out of nowhere. It's better to expect it than not expect it. (PSS16, Asian American male)

Getting "blindsided" or hit "in the head, in the back out of nowhere" emphasizes surprise, or lack of forewarning or expectation. That is, they cannot *see* what hits them — for example, a disease or condition. Thus in this context, genetic information provides that forewarning or expectation and is thus desirable. These different contexts of being hit — e.g., by the genetic risk information or because of the lack of it — therefore have different implications for whether or not individuals want to receive genetic results.

Genetic information as light and dark

Next I present another set of metaphorical concepts where participants describe genetic information in terms of light, dark, clouds, and/or shadows. These metaphors speak more to the affective quality of genetic information, or how it makes one feel, in contrast to the previous grouping of weapons and tools that appealed to what genetic information can do — i.e., its utility as an object. Imagery of light and dark touches upon very deep-seated, primal notions of good and evil, particularly in Western culture. Indeed, Osborn (1967) has characterized light-dark metaphors as "archetypal," due to their lasting and universal appeal; "persuasive potency;" and groundedness in salient human experiences, such as the transition from night into day. Taken alone, metaphors comparing knowledge to light and ignorance to darkness might appear literalized to the point of dormancy. However, I have chosen to draw out or activate this set of conceptual metaphors because of their resonance with less common vehicles such as clouds and shadows. Each of these vehicles appeared in my data and is analyzed below.

Participant's expressions of GENETIC INFORMATION IS LIGHT primarily portrayed genetic information as positive and therefore wanted. One participant discussed learning positive things from genetic information, such as athletic ability, as being a "light in the end of the tunnel" (PSS22, white male). This expression posits genetic information to be a positive or desirable thing: good news ("light") amidst less affirmative things in his life, represented by the presumably dark "tunnel." Themes of light and dark also came out strongly and repeatedly in a focus group. One participant spoke several times of not wanting to "live in the dark" as an argument for receiving genetic results from sequencing, or why "knowing is always good" (P03-01, African American male). Another participant in this same focus group used the same metaphor to explain why he *wouldn't* want to receive the results:

> I don't know if I wanna know any of that stuff. For myself, I mean... if it's good for science and you know for the world that, that's great. But me personally…I'd rather be in the dark I think. (P03-02, white male)

In contrast to positive portrayals of genetic information as light, I also identified examples of an opposing conceptual metaphor: GENETIC INFORMATION IS DARK(NESS), in which information is viewed as negative and undesirable. In this grouping I include references to clouds, or clouding over — that is, as genetic information blocking light rather than being a source of light. For example, one MUAA participant was “not very interested in knowing” about a genetic predisposition to “develop something…horrible in the future” (MUAA15, African American female). She said that to know she was at risk for something like early onset Alzheimer’s would be a “consistent cloud over my life” that might keep her from doing what she “would normally do” in the absence of that information. Here knowing about a genetic susceptibility to disease is like a cloud that shadows her life and therefore is not desirable.

Instances of GENETIC INFORMATION IS DARK(NESS) also occurred in focus groups. In these examples, the degree of clouding over participants anticipated was sometimes contingent on the uncertainty or actionability of results. One participant gave the following explanation of why she would not want to receive genetic information about something untreatable, such as Huntington’s:

> I don’t know if I want that knowledge and if I can't do something about it and for sure I don’t want the knowledge…I think it would be hanging over me… I don’t wanna know if I’m going to get in an accident in 10 years---[Right.] And not be able to walk. I don’t wanna know. (P09-05, white female)

Here the genetic information would hang over her, perhaps as a cloud or shadow obscuring light. In another focus group, participants also used language of clouding over. In the first reference, the participant speaks to the potentially uncertain nature of genetic information:

> I don't think I want to know all the potential possibilities I would want it only more if it was concrete information because I don't want all these false positives/ false negatives to cloud my thinking … if it were more concretely linked and this information was more to be true, that information would be helpful to me but I think that would be less likely to want to know chances and probabilities because it would just cloud my thinking as well you know, I don’t want to live in fear. It depends on how the information is processed back and what degree of certainty they provide with it. (P08-02, white female)

Here the clouding over is due to the probabilistic or uncertain nature of genetic information; she leaves open the possibility for wanting genetic results as long as they have an acceptable degree of certainty. Later on in this focus group, another participant speaks of clouded thinking not in reference to uncertainty but rather, as in the case of P09-05, in referring to actionability:

> I wouldn't want to know something that I’m actually not going to be able to cure or change yeah because it's just going to cloud my memory thinking, I would go walking around thinking I have this, I have this. I’m not going to be able to get rid of it. (P08-03, African American female)

Genetic information as goods in boxes

Participants also frequently likened genetic information to the contents of a box. Boxes have defined perimeters and edges and thus can be broken down into container and contents, the contents being genetic information in general, or perhaps specifically a whole exome or genome sequence. Participants' expressions of the conceptual metaphor GENETIC INFORMATION AS GOODS INSIDE A BOX involved two distinct types of boxes: a Pandora's box versus a conventional box used to contain or store things. Specifically, some participants likened WGS/ES to opening up a Pandora's box of information. For example, one interview participant stated when filling out his My46 preference grid:

> It's interesting. I'm going to want to [get] results on all of them. I'm curious like that. But I'm confident, not very confident. Kind of like <u>opening Pandora's box</u>, do you want to know what's <u>inside</u>? (PSS12, white male)

He contrasts his curiosity to know genetic results with a lack of confidence about what he might find out. Thus the desire to know is coupled with concern about what might (irrevocably) become known. The Pandora's box metaphor appears twice in another interview, in which the participant describes a hypothetical scenario of a young person who is planning to go to college but then learns about a genetic risk for mental illness. She finds the idea of learning this type of genetic information "worrisome" and "troubling:"

> …like a <u>Pandora's box</u>. You can just – going about your life and then you find out all these things and knowing those things could [cause] a lot of trouble. (PSS25, African American female)

Both of these passages underscore that critical to the act of "opening" is the threat of not being able to close the box, that genetic information cannot be unlearned. Once opened, the box cannot return to its closed state, and it loses the ability to contain.

Additional expressions of GENETIC INFORMATION IS A BOX included more conventional references to boxes, in contrast to the mythological references to Pandora's box. Instead of representing release, these boxes are means of storage and containment. In one focus group (P02), participants described storing genetic results in a "lock box" to which only they or a trusted person, such as their significant other, would have access. One participant referred to the anticipation of finding out results as being like a "Christmas present" (P02-01, white female). The lock box concept came up in another focus group as well, when participants described wanting to keep their own results rather than having their doctor manage them:

> I wanna bring my own <u>lock</u> to my bad stuff. So, I'll give you the <u>key</u> so when it need to be <u>opened</u>, you can <u>open it</u>. (P11-01, African American female)

This idea continued in the focus group, and shortly thereafter another participant said that if a medical problem arose, such as seizures, she would ask to "look in the little box over there" (P11-07, African American female).

Genetic information is a picture

The boundedness and containment of the box metaphors described above resonates with another conceptual metaphor that I identified: GENETIC INFORMATION IS A PICTURE. That is, pictures have perimeters or boundaries which mark off and in some sense contain their contents. However, the picture metaphor differs from the boxes above in that the focus is not on a binary of revealed versus unrevealed (e.g., an open or closed box), but rather on the amount or breadth of information that can be known. For example, one participant explained that she wanted to receive all her genetic information, both good and bad, "because it all makes the whole picture" (MUAA19, American Indian and African American female).

In the context of WGS/ES, the idea of a picture is particularly compelling. With single gene tests, only one small piece of the genome is rendered visible, like a narrow portion of a larger picture. Sequencing an entire exome or genome, however, enables a much wider and more comprehensive view of an individual's genetic profile, like a mural. Indeed, in one focus group a participant likened her whole genome report to a "mural" (P05-03, white female). The moderators picked up on this language and used it to help guide subsequent discussion of scope and type of sequencing results.

Genetic information as documents or reports

Several participants compared genetic information to formal reports or documents, including architectural plans, credit scores, and house inspection reports. In participants' expressions of the conceptual metaphor GENETIC INFORMATION IS A DOCUMENT, I discerned themes of ownership, modifiability, actionability, and interpretability. For example, in one focus group (P02) a conversation of what participants would want to receive if involved in a sequencing research study led to a comparison between genetic information and an architect's plans for a house. One participant said that it would be "kind of a bummer" not to have access to all the "really, really neat the information" (P02-02, Asian American female) the researchers generate. Another participant agreed:

> If there was an architect going through the neighborhood and they were drawing plans, I want a copy of the plans of my house… I'm not going to build a house, I just want it … I want to see it. Oh, that closet is four and half feet wide, I didn't know that. I didn't know, I don't know why (laughter). No, it's just, it's just 'cause, it's it's self-knowledge. (P02-03, white female)

Notably, throughout this analogy other participants murmur agreement. She wants a “copy of the plans” because the information is being produced and it is about her: her house, her genome — even if she does not foresee a specific use for it. Knowing the specific dimensions of a closet might be like knowing a specific genetic variant, for instance. It is good to know simply for the sake of “self-knowledge.”

Another type of document participants used to describe genetic information was a credit score report. Notably, this comparison came up independently in a focus group and an interview. A PSS interviewee used the metaphor when asked whether she could envision returning to the My46 website and changing or updating her results preferences over time:

> I think – you know how often people check their credit reports. I feel they do it once every three years…Only when they need to. I think that’d be how people use this site. Kind of an only when you need to or a general every couple years check in*.* (PSS25, African American female)

The stated tenor for this credit score report is the My46 website; however, this site is essentially an interface for receiving genetic sequencing results and therefore I considered the ultimate tenor to be genetic information. The idea of “checking in” on an exome or genome sequence report in the same way you would a credit score is in keeping with the moving target of genetic information. Specifically, sequencing may reveal genetic variants that are currently of unknown function or significance for disease. However, the import of these variants may be revealed by future research and thus become a more notable finding than they were at the time of sequencing. Furthermore, what is relevant to the individual may change as life circumstances and/or health status changes.

The focus group reference to genome sequences as credit reports highlights yet another feature: that credit scores can be modified or improved through the efforts of the individual. The metaphor starts with a clarifying question from the participant about what a genome report would actually look like:

> I’m not a scientist but, is this sort of like you get, like a credit score and [uh-hmm] you can find out ways to improve it? (P10-01, white female)

She goes on to say that especially if there were bad news, it would be particularly important how the information was provided:

> …it would be nice to know, I guess I’m thinking of credit score like, here’s your credit score and here’s how you can improve it. So here’s my score or whatever the result, here’s my can-and it sounds like subject to the, analyst’s interpretation. So you may get one person who says, here’s the information, they give you all the numbers, this is what it is. You get another person who says, you know what, we have your information, we have some broader information about yours in context to other people and here’s how they’ve been able to deal with. I’m just thinking of like how

> you communicate... I don't know. I think it can make a difference. That's all. (P10-01, white female)

This passage suggests that she thinks it is preferable to provide the information in context — what actions can be taken, how others have "been able to deal with it" — versus just getting "all the numbers" without an explanation of potential actions. This credit report metaphor relates to actionability of genetic information: can anything be done to mitigate the genetic risk? The comparison is quite keen and salient, likening potential actions available to improve one's credit score to potential actions available to improve (or maintain) health in the face of genetic susceptibility.

A last document under GENETIC INFORMATION IS A DOCUMENT is a home inspection report. The reference was made near the end of a focus group (P09), at which point there was general consensus that participants would want someone (e.g., a genetic counselor) to help them interpret their genetic sequencing results. Participants expressed that "it would be a lot" and they would want "some support" in going through it. One participant explained:

> Like when you're buying a home…You get your inspection report back and I remember getting it back and I was like 24 and I was like -- What is this? Uh--- and I didn't know what I was doing. I had no one else in my life that was like partnering with me in that, so I was like, "Dad!" [Laughter]. And so I wanted him to sit down with me and tell me, okay, this is significant, this you don't have to worry about--- This is gonna cause this amount of money, this is how you can prove this--- [Wow] So I feel like I would want that same thing, like I want the packet and then I want someone to sit down with me and say this means this. This you don't have to worry about. (P09-05, white female)

This comparison points to the potential complexity of genetic sequencing results and the aid that professionals or mentors can give to the individual interpreting the information. Similarly to the credit score metaphor, this participant also highlights the actions or consequences that might follow from the report: what might require money to fix, what negative aspects could be improved upon, for example. Both credit scores and home inspections can point to potential problems, but they also highlight avenues for improvement and change, making them both useful and potentially positive analogies for genetic information.

One participant's use of GENETIC INFORMATION IS A DOCUMENT highlighted issues of authorship, in addition to the ownership theme touched upon in the architectural plan comparison. Here she is concerned about the privacy and implications of participating in genetic research. She asks whether there would be “protection over the authorship of a person’s DNA” (P13-02). When asked if she would be willing to participate, or have a child participate, in a sequencing study, she repeats the concern:

> I would say pretty much but then there’s that intellectual property issue. That’s authorship, I’m willing to put myself on the line, but I would like really want to do that with my kids but I would really have to look at the legal ramification of doing that and the risk that would be attached with that by sharing my child’s genetic code. I would have to think a little bit harder but I would be willing to, you know, I’m vulnerable to it, but we would have to really talk about that and I would need to seek some legal advice. As long as I felt that the results of what they were finding is that my kid wouldn’t be victimized in any way, [then] I’d do it. (P13-02, African American female)

Disease as tenor

Next I present metaphors where disease is the tenor rather than genetic information: DISEASE IS A SLEEPING MONSTER and DISEASE IS AN ENEMY OF WAR. In expressions of DISEASE IS A SLEEPING MONSTER, participants portrayed diseases as hidden, dormant beings whose potential to resurface elicited a desire to be forewarned or “on the lookout.” For example, one interviewee explained how she would decide what health-related information she would want to receive by saying:

> …it depends on what diseases are out there and how many generations they could skip and each one would be different, but if I knew that someone somewhere had a genetic disease show up how many generations could that kinda be sleeping until it shows up again. (PSS18, white female)

She goes on to describe how genetic risk could be “under the surface for many generations” and how knowing about it could allow someone, including a parent on behalf of their child, to be “hopefully not overly cautious but at least um on the lookout.” Together these passages suggest that disease is a dormant being — perhaps a monster or underwater creature — that is hidden for generations until it emerges and manifests in a given person. An advantage of knowing risk information is being primed to be “on the lookout” for this surfacing or emergence.

Other interviewees similarly described disease as being dormant with the potential to resurface. One focus group parent explained that she would be interested in learning about things she might pass down to her children:

> Like, if there's something that is dormant inside of me but would show up in one of my children or my grandkids. (P11-07, African American female)

Another focus group participant talked about having two children with disabilities and two without. She described how with each child she had she was wondering if they would be affected like her firstborn:

> Because as a parent, when you have one kid that's disabled, you're always looking for it, you know, it's a <u>ghost</u>, it's <u>always riding you</u>. Also you live under a <u>witches ride</u>, waiting on it to <u>resurface</u> again. (P13-02, African American female)

Another example of DISEASE IS A SLEEPING MONSTER came from an MUAA interview participant. While going over her preferences settings, she considered out loud different diseases in the My46 categories: "Epilepsy I believe probably would've already <u>reared its ugly head</u> by now" (MUAA09, African American female). Soon after this statement she repeats the phrase when talking about receiving sickle cell anemia results for her young daughter: "at her age I would've thought it would've <u>reared its ugly head</u> by now." A head being reared is similar to the surfacing or waking up from dormancy in the previous group of quotes. Across all these metaphors, disease is at first hidden and then becomes seen or known. The "ugly head" part of the MUAA participant's language emphasizes the unpleasant, scary, and perhaps monster-like nature of the disease.

In expressions of DISEASE IS AN ENEMY OF WAR, participants personified disease as an outright attacker that needs to be fought off. One participant expressed feeling motivated to "take care" of herself to "reduce the risk of getting these diseases" (PSS27). She went on to say:

> I'm thinking that if I keep my weight down and eat the right foods, drink plenty of water I could perhaps maybe prevent that because in all my cells and acids in my body is saying wow we're all working together here. We're happy so we're gonna <u>kill off any disease</u> that try to <u>attack this body</u>… Now that I have conscious awareness I can pay more attention to what I intake in my body and also question myself is this what I wanna put in my body. Is it gonna help my good cells. Is it going to decrease my good cells or is it gonna increase my good cells or is there gonna be a <u>fight</u> going on in my body? (PSS27, African American female)

She paints a picture of the body as a battleground where disease is the attacker and the body's resources ("good cells") unite to fight off the enemy. Granted the metaphorical concept of "fighting off" disease is so pervasive that it is arguably a dormant metaphor. However, this participant's multiple references to fights and attacks seemed to sufficiently waken the metaphor enough to merit attention.

Life is a journey

Many participants expressed versions of and variations on the conceptual metaphor LIFE IS A JOURNEY. The context of focus groups and interviews naturally led to this topic, as genetic results often pertain to risk of developing certain diseases or conditions at some point in the future. Thus metaphors about life course have import for how people think about their future and thus how they might think about receiving future-oriented genetic information. For example, one participant asked, "Can a person's genome change through the course of their life?" (PSS12, white male). Another spoke of wanting to know his results so that he "could choose [his] life path a little bit better" (PSS22, white male). Similarly, an MUAA interviewee said that genetic information would help "get you started on your journey in figuring out what you're gonna do with your health as you get older" (MUAA09, African American female). Several participants used the phrase "down the road" (P09-01, P08-04, P12-05, PFG12-04, PFG13-07) or "down the line" (MUAA24, PFG12-05) when discussing their future. Notably, some of these uses were in the context of *not* wanting genetic information:

> If I'm going to be 80 when I get that I would really really rather wait until I'm 80 to know that's going to happen to me and spend those preceding however many decades blissfully unaware of that coming down the road later on. (P08-04, white female)

"Down the road" was also used to specifically describe the course of a life affected by disease, where the road is depicted as "long" and "tough" — i.e., an arduous journey. For instance, a woman talking about learning risk for diseases of the heart, blood, and lungs said, "it just seems like a long tough road that I don't think I'd wanna know about" (PSS25). She made a similar statement when discussing a friend whose child has neuroblastoma and thus is used to receiving upsetting test results: "she's already been down that hard road."

Discussion

The conceptual metaphors I identified have implications for enhancing understanding of and facilitating discussion around individuals' preferences and expectations for receiving sequencing results in both clinical and research settings. Using metaphor-led discourse analysis of focus groups and interviews with 109 unique participants, I identified metaphors likening genetic information to weapons and tools, to light and dark, to goods held in boxes, to pictures, and to formal documents or reports. In this chapter, I provide extended interpretations of these conceptual metaphors and consider superordinate or organizing themes that connect them. I then discuss the implications of my findings across multiple audiences, draw out strengths and limitations of my study, and suggest avenues for future research.

Locus of control: genetic information can either empower or overpower

An important theme across several conceptual metaphors was a contrast in who or what was controlling genetic information, which is likely to influence whether an individual wants to receive it. The contrast is most apparent in GENETIC INFORMATION IS A WEAPON. While participants' expressions of the metaphor share the same vehicle and tenor (i.e., GENETIC INFORMATION IS A WEAPON), they differ based on the locus of control: who is using the weapon and against what or whom? In some cases, the participants are the ones using the weapon (i.e., the genetic sequencing results). It is in their control and therefore serves to give them some control — over their future, over potential future disease risk, for example. They are the agents acting. However, in other instances of the same conceptual metaphor, individuals describe getting hit by, blindsided by, or bombarded with genetic information. The underlying conceptual metaphor remains the same (GENETIC INFORMATION IS A WEAPON), but the locus of control and origin of action is external to the individual. Locus of control was also important in the conceptual metaphors where disease was the tenor: DISEASE IS A SLEEPING MONSTER and DISEASE IS AN ENEMY OF WAR. In these metaphors, participants portrayed genetic information as a defense against being hit (i.e. by the disease) and thus as empowering the individual, again suggesting an internal locus of control.

Whether an individual wants to receive genetic information is likely to be influenced by who or what they think will control the information. As Lakoff and Johnson (1980) argue, metaphor can influence both thought and action so it is reasonable to consider how these metaphors may affect decisions about receiving sequencing results. If, on the one hand, the information is seen as a tool or weapon that *empowers* individuals, it may become a desirable thing or commodity to receive. Alternatively, if the information is seen as an object that will *overpower* — or potentially *disempower* — individuals, they are not likely to want to receive it. Getting genetic results may become something that happens to them rather than being something that they do, or can do something with. Notably, an additional interpretation is that these metaphors may reflect a particular world view rather than a decision about whether to receive and use health information. For example, persons not wanting genetic information may have a non-Western view of fate as a — potentially harsh — reality that should be accepted gracefully.

The dichotomy of internal versus external locus of control is also echoed in the duality of the light/dark metaphors (GENETIC INFORMATION IS LIGHT and GENETIC INFORMATION IS DARK), which again suggests different individual preferences for receiving results. When compared to light, genetic information becomes a positive and desirable thing, in the same way that a weapon or tool in one's control is positive and desirable. On the other hand, genetic information as darkness or obfuscation of light leads to negative perceptions about genetic information as undesirable, in line with metaphors where genetic information is a weapon used against individuals, overpowering them.

Boxes: genetic information can be contained or released

Another cross-cutting theme was that of genetic information being contained and, its opposite, genetic information being released. In the tools and weapons metaphors, participants spoke of a toolbox and an arsenal. As containers, the toolbox and arsenal both imply storage and management, which perhaps speak to the future-orientedness of genetic information. That is, genetic information is often obtained not for immediate action but rather for anticipated future use. Toolboxes and arsenals also suggest the presence of other tools and weapons, implying that genetic information is viewed as one of many useful pieces of information when seeking to control and optimize future health.

The themes of *containment* and the opposing notion of *release* were prominent in GENETIC INFORMATION AS GOODS IN A BOX. Thus in the same way GENETIC INFORMATION IS A WEAPON encompassed a dichotomy of internal versus external locus of control, the dualism of containment versus release occurs within the same conceptual metaphor. Box metaphors comprised two main types of boxes: Pandora's box and a lockbox. These two types of boxes differ in two key ways. First, a Pandora's box suggests release while a lockbox suggests containment. With Pandora's box, the contents are at first inside but then, through the individual's act of opening (i.e., obtaining genetic information), the contents get released or let loose in the world (see below for a detailed description). In contrast, participants described a lock box as one they would use to store genetic results for safekeeping. That is, the individual obtains genetic information and then chooses to contain it within a box. The second key difference between the two boxes is whether the individual gets to "see" the genetic information before or after it goes into the box. Genetic information in Pandora's box is initially hidden and thus the individual only sees the information after the box is opened. Alternatively, in the lock box scenario an individual has seen his or her results — or is at least aware of the existence of results — before deciding to gather them up and store them in a box.

Boxes may either contain or release genetic information and this again has implications for whether individuals want to receive sequencing results. With a Pandora's box, the desire to know is uncertain and there is little to no hope of containing the information once released. This scenario ties in yet again with locus of control in that individuals may feel unable to control genetic information (i.e. are *overpowered* by it) and thus may think it undesirable or risky. Alternatively, with a lock box, an individual's discomfort about deciding to receive information is lessened by the ability to securely contain the results, to call upon them only when necessary or desired. With the lock box metaphors, the individuals appear to be more in control.

Notably, the Pandora's box metaphor has appeared several times in discussions of genetic technologies (Henn, 1999; Liakopoulos, 2002; PBS, 2003; Stein, 2012), including more recent literature on genetic sequencing (Townsend et al., 2012). In the Greek myth, Pandora was given a box by the gods with the order that she should never open it. She disobeyed out of curiosity and unwittingly released "all the possibly misfortunes…which man did not already know" (Liakopoulos, 2002, p. 13). The vehicle of Pandora's box is apt for WGS/ES, which usually yields incidental or secondary findings: findings not directly relevant to the initial research question or clinical indication for sequencing (Presidential Commission for the Study of Bioethical Issues, 2013). There is often uncertainty and unpredictability about what variants may be detected. Furthermore, because research efforts are ongoing to understand gene functions and the impact of individual variants on those functions, there is often uncertainty about what incidental or secondary findings will actually mean for the health of the individual. In this study, however, I could not determine whether participants referred to Pandora's box because they had previously heard or seen it used in reference to genetic sequencing, as participants were not asked about the source of their metaphorical language.

Documents: genetic information has authors, owners, and interpreters

The GENETIC INFORMATION IS A DOCUMENT group of metaphors resembles the more well-known genetics metaphors of popular discourse: blueprint, book of life, and map (see Nerlich & Hellsten, 2004). However, the way participants used document metaphors to illustrate concerns about authorship, ownership, and interpretability marks a key point of divergence from the genetics metaphors of public discourse. Specifically, participants' usage of document metaphors illustrates a shift in thinking about genetics from the hypothetical to the tangible, suggesting that similar underlying metaphors may get expressed differently in public discourse versus individuals discussing return of results. To illustrate this, I will next revisit specific instances of the document metaphors in my data and draw out similarities and differences to document metaphors studied in public discourse about genetics.

The architect plan metaphor from one of the parent focus groups is similar to the well-known blueprint metaphor of the genome, yet differs by drawing attention to end products and individual ownership. Condit (1999b) has described the blueprint metaphor as focusing on the genome as a whole, rather than on individual genes. Condit also explains how the blueprint metaphor downplays genetic determinism and creates a role for environmental modification and influence. That is, a blueprint is a plan or template that requires both builders and building materials (elements of the environment) to become a reality. Similarly, the genome is relatively inert without the cellular machinery required to build and operate proteins. In the focus group discussion, however, the architect's plan is valued as a document, a fixed entity, and explicitly *not* for what it can be used to produce ("I'm not going to build a house, I just want it"). The document is something to own purely for the sake of "self-knowledge." Thus while the blueprint in public discourse is often discussed as a foundation, template, or starting point (e.g., for the biological machinery of the cell to do its work building the organism), the focus group's architect plan is a product, reference manual, and ending point. The participant wants to have or to own the architectural plan. It is understandable that historical uses of the blueprint metaphor in public discourse have not focused on individual ownership of genetic information, as it is only in the past few years that technological advancements have enabled more and more people to access whole exome or genome sequencing. This new spin on an old metaphor underscores that in the return of results context, individuals may view their genetic sequence as a document not in the abstract, such as the blueprint of *the* human genome, but as a physical reality that they have a right to own — the plans of *their* own house.

Other notable aspects of document metaphors in these data in comparison to public discourse are the importance of modifiability and interpretability, which are evident in the credit score and home inspection report metaphors. With these metaphors, participants described their genetic results as reports that can be changed or improved upon over time. The changes or improvements could come about by individuals making healthy lifestyle choices to mitigate any genetic risk learned about through the report. Similarly, audience studies of the blueprint metaphor in mass media have shown that many people interpret it to be non-deterministic, probabilistic, and suggestive of an individual's ability to make lifestyle changes that lessen genetic risk (Condit, 1999a). Thus malleability or modifiability of genetic risk via an individual's choices and actions is a consistent element of metaphors in both public discourse on genetics and in these data on individual return of results. A novel feature in this study, however, is the participant's emphasis on *how* genetic information should be presented to the individual. That is, the participant wanted the report to include the ways to improve upon one's genetic risk, the same way one could be given a credit score and then be told how to make it better. Including means for improvement when reporting back genetic results, which has previously not come out of public discourse studies of the documents metaphors, may provide concrete guidance to those researchers and clinicians trying to figure out the best way to return results. By comparing sequencing results to credit scores and home inspection reports, participants also expressed wanting help interpreting genetic information, another entailment of these metaphors that gives practical guidance to those navigating how to return results in both clinical and research settings.

Lastly, the notion of authorship in discussions of individual return of results in contrast to abstract public discourse about the genome has implications for participation in genetic research. The focus group parent who spoke of authorship of her or her child's DNA was concerned about victimization and exploitation of genetic material and showed general mistrust in research. Authorship of DNA links to the larger discourse metaphor of the genome as the BOOK OF LIFE (Hellsten, 2005). In the public arena, the book of life metaphor has been used to argue in favor of research in general and specifically as an argument for the HGP (Ceccarelli, 2013a). Francis Collins invoked the book of life metaphor in a 2000 White House speech celebrating the completed first draft of the human genome, arguing that the genome is “our own instruction book” and one that must be read (Collins in Ceccarelli, 2013a, p. 99). In this usage, the author of our instruction book is not stated, but it is implied to be of divine origin (2013a, p. 100). In contrast, the focus group participant expresses concern about a person’s authorship of their own DNA, not of some divine, external author. Thus document metaphors in this study demonstrate the importance of respecting research participants’ rights and ownership of their own genetic material, even after it has been donated to a research study (e.g., see Dressler, 2007 for debates on ownership and stewardship in biobank research).

“As genomic sequencing technology enters the realm of clinical care, its scale necessitates answers to key social and behavioral research questions about the complexities of understanding, communicating, and ultimately using sequence information to improve health.” (Facio et al., 2011)

Implications

The implications of the conceptual metaphors I identified and how they were used by participants are varied across clinical, research, and public domains. In clinical settings, health care professionals (HCPs) may discuss genetic information with patients both in deciding to order a genetic test (pre-test counseling) and pursuant to testing (post-test counseling). Such conversations are likely to touch on the nature of genetic information and its role in maintaining a patient’s health and/or treating disease. Metaphors may be used either intentionally or unintentionally by both the HCP and the patient during the course of these discussions. As I have shown with the conceptual metaphor GENETIC INFORMATION IS A WEAPON, different expressions of a metaphor may serve to make genetic information either more or less desirable to the patient. Thus there is a need for the HCP to make clear and conscious choices when using metaphor and to be attentive to metaphors used by the patient. Among genetic counselors in particular, it has long been common practice to use metaphors in explanations of genetic concepts such as Mendelian inheritance and the packaging of DNA into chromosomes (GCCCT, 2010; S. Jamal, MSc, LCGC, CCGC , personal communication, Dec. 8, 2013). While I do not argue the utility of such metaphors, I do suggest that caution and care is needed in metaphorical representations of genetic information, in particular as we move forward in the era of WGS/ES where decision making about return of results involves complex and nuanced ideas of uncertainty, actionability, and utility. One cannot assume metaphors have fixed or reliable meanings, as interpretations are likely to vary between persons, contexts, and cultures (Condit et al., 2002; Zinken et al., 2008).

Awareness of and attentiveness to metaphor is especially important in medical settings due to the wide-spread goal for clinical decision-making processes to be shared by patient and provider. In addition to the ethical arguments in favor of shared power in clinical decision-making (Elwyn et al., 2012), empirical studies provide evidence that the quality of communication between physician and patient influences health outcomes (Stewart, 1995). Shared clinical decision making involves finding a metaphorical “common ground” between patient and clinician, where each party actively participates in the decision making process (Guadagnoli & Ward, 1998). A prerequisite to the process is bi-directional “information sharing” between patient and provider. One can imagine in a decision about genetic testing that a provider might discuss clinical utility of a test while the patient might express personal preferences about receiving genetic results. While metaphors may help explain and illuminate, they may also bias or obscure. If noted and addressed, metaphors may help a patient and provider reach a shared understanding or at least a consensus on how to proceed. For example, a patient expressing concern over being “bombarded” by too much genetic information from a whole exome test can be counseled on how the information would be returned and interpreted, perhaps altering her perspective to see the information as empowering rather than overpowering. In the case where genetic testing offers clinical utility to the patient, a clinician who responds to the metaphorical “indicator” of bombardment by tailoring the information and education to recast the genetic test in a more positive, empowering light would indeed benefit the patient. However, selectively framing messages may diminish or deflect the patient’s original voice. Thus there is both potential harm and benefit of metaphor usage in clinical encounters.

In the context of genetic research, scientists may make both inadvertent and strategic use of metaphor both when discussing their work more broadly and in conversation/communication with individual study participants. In the former situation, researchers may use metaphors that promote their work to funders and to the public at large. As seen with the usage of the frontier metaphor by scientists in public discourse, metaphors that prima facie seem appealing can often have politically and ethically problematic entailments (Ceccarelli, 2013b). Also, Condit and colleagues (2002) have shown that different individuals can interact with and interpret metaphors in varied ways. Thus similarly to how genes and environment interact to produce a phenotype, metaphors interact with individual factors and the societal milieu to yield specific meanings and interpretations. My findings echo this, in that participants often expressed a given conceptual metaphor in contrasting ways. Thus the call for conscious use of metaphor by genetic researchers echoes my earlier recommendation for metaphor usage in the clinical setting.

In recent years, discussions and debates have emerged within the genetics community about returning individual genetic results to research participants (for an overview, see Fabsitz et al., 2010). Various research initiatives are aimed at addressing the practical and ethical issues in the return of results endeavor (e.g., Biesecker et al., 2009; CSER, 2014; Fullerton et al., 2012; Vassy et al., 2014).

Thus not unlike the clinical encounters described above, researchers are now involved in engaging participants about receiving genetic results. The same caveats apply: participant's own metaphorical framings of genetic information may either encourage or discourage their participation if results are likely to be returned. A researcher attuned to these metaphors may use them to tailor their communication with participants, perhaps to encourage participation. Conversely, a lack of attentiveness to metaphor may result in a missed opportunity to come to a shared understanding of the potential benefits and harms of participating in return of results research.

Overall, this examination of metaphor suggests that genetic professionals have clear and conscious choices to make in both using and staying attuned to metaphor in multiple settings: in clinical encounters with patients, in informed consent conversations with research participants, and when engaging with public audiences about developments in genomic sciences and genomic medicine. Multiple avenues exist for further research to better understand these choices and their implications, which are of particular importance as genetic information increasingly integrates into clinical care. First, this analysis was of participants considering hypothetical return of results. Thus a natural extension of this work would be to examine metaphorical language among individuals who have received results from WGS/ES, in either a research or clinical setting. Once could compare and contrast the metaphors seen in the discussions of hypothetical return of results reported here with those that arise after results have been returned. Do the tools and weapons metaphors persist? Do people actually feel hit or bombarded by genetic information? Are they able to fight off or at least be on the lookout for future disease?

Second, as scholars of genetics in public discourse have shown, metaphors shift in response to evolving understandings of science (Nerlich & Hellsten, 2004, 2009). Genomics is now in the company of numerous other high-throughput "-omics" sciences (Schneider & Orchard, 2011), including the study of the full complement of human proteins, RNA transcripts, metabolites, and epigenetic modifications. Thus future research could use a similar format (i.e., focus groups and interviews) to examine how individuals talk about receiving results from other "-omics" profiles, which in the future are likely to become more widely accessed types of personal and health information just as WGS/ES have become in recent years. To illustrate, following their study of metaphors in public discourse on the HGP, Nerlich and Hellsten analyzed newspaper coverage of the Human Microbiome Project and found a shift away from contained and deterministic genomics metaphors to metaphors representing humans as fluid, dynamic and integrated beings (Nerlich & Hellsten, 2009). With the present study, I have shown that analysis of metaphor in public discourse may have limited (or at least constrained) relevance for understanding how individuals use metaphor when discussing return of individual genetic results. Thus the work Nerlich and Hellsten have done to extend public discourse studies into newer "-omics" sciences could again be mirrored in the individual return of results context. For example, future study of conceptual metaphors used to discuss receiving and using personal epigenetic information would be particularly interesting. The epigenome is at once both fixed (inherited) and fluid (subject to environmental influences) and therefore may be difficult for individuals to place along the spectrum of determinism versus relativism (Parrott et al., 2004). The locus of control theme prominent in my study would therefore be intriguing to test in the context of individual epigenetic information. In summary, as science pushes towards more complex and multi-layered understandings of human health and disease, studying the metaphors individuals use to contemplate these emerging types of information may prove useful in guiding communication in research, clinical, and media settings.

Strengths and limitations

Language in general and metaphor in particular are but one part of the decision-making processes about obtaining genetic tests and genetic information. A wealth of literature exists on how individuals decide to get genetic information (for example, Charles, Gafni, & Whelan, 1997; Ensenauer, Michels, & Reinke, 2005; Kaphingst et al., 2010; Wolf, 2013), suggesting a deep complexity to decision-making. Thus, to speak metaphorically, I have isolated and probed but one variable from a very complicated equation. However, examining metaphor is particularly useful because language can be controlled and made intentional.

A potential pitfall of studying metaphor is over-interpretation. As organizational theorist Gareth Morgan has written, "Metaphor has an inherently dialectical quality that binds truth and falsehood into the same process, creating powerful insights that, if taken too literally, or too far, can become counter-productive" (1996, p. 232). While I have strived to avoid over-reaching interpretations of my participants' metaphors-in-use, I may be constrained by the amount of surrounding text and context that accompanies each metaphor. As Cameron has cautioned, discourse analysis of metaphor is often limited to identifying "metaphoric potential" rather than claiming to have identified cognitive metaphoric processing (2013, p. 348). Thus this work marks a starting point for additional follow-up studies in order to "build a robust argument for which aspects of the metaphor actually apply" (Hilligoss, 2014).

An additional limitation of this study is true in any discourse analysis: what Gee calls "the frame problem" (2010, pp. 67–8). To understand the situated meaning of any piece of text one must first understand the context in which it was spoken or written. But any aspect of context may affect meaning, making context "indefinitely large" (2010, p. 67). My datasets are de-identified transcripts from previously-conducted focus groups and interviews, thus I have limited knowledge of participants' background (i.e., beyond gender and self-identified race), including their socio-cultural upbringing, education level, and baseline familiarity with genetics and use of genetics metaphors. Nevertheless, while I was a few layers removed from the participants, throughout my study I had access to the researcher who designed both studies and two researchers who moderated these sessions, and in some cases I called upon them to help validate and corroborate my interpretation of metaphors.

My dataset is also a strength of my study, however, in that focus groups in particular are an ideal way to study language-in-use, in a social context. Group discussions "allow the types of thinking that circulate in society about the research object to be sampled" (Moloney & Walker, 2002, p. 305), as compared to the relatively pre-planned and often strategic language used in written texts. Cameron has also highlighted the benefits of using focus groups to study metaphor in particular, as the focus group setting allows for observing the shifts in metaphors as different participants pick up and respond to them (2013, p. 348).

Another significant strength of this study is the diversity of the participants: almost 60% were African American and other minority groups were also represented (see Table 1). Indeed, the primary research project under which these focus groups and interviews were conducted is aimed at understanding African Americans' perspectives on participating in sequencing studies and receiving results (Yu et al., 2013). As a secondary user of these data, the inclusion of different racial and ethnic viewpoints is critical in making my findings applicable beyond a single racial or cultural majority. That is, perspectives on genetic sequencing and the language used to express these perspectives are likely to vary between different cultural groups. While my analysis did not focus on these cultural differences in metaphorical language per se, it is an important question for future research.

Conclusion

In summary, I have conducted a discourse analysis of metaphorical language in 40 interviews and 13 focus groups in which participants were asked to discuss their preferences for and expectations about receiving genetic results from WGS/ES. The conceptual metaphors I identified contain dichotomies and tensions that have implications for communicating about and returning sequencing results, in both the clinical and research realms. My findings suggest increased awareness of and attentiveness to metaphorical language may serve to improve communication between stakeholders when discussing genetic information. Furthermore, my analysis reveals differences between how individuals use metaphors when talking about individual return of results and the more well-studied uses of metaphor in public discourse around genetics. Additional study is needed to instantiate and better characterize these differences. However, the implication is that metaphors are evolving as a reflection of — and perhaps in response to — the shift towards increasing access to and use of personal genetic information, particularly when accessed and used in pursuit of personalized, translational, genomic medicine. Overall, this examination of metaphor indicates that genetics professionals have clear and conscious choices to make when using metaphorical language to discuss genetic information, WGS/ES, and individual patient and participant preferences for return of results.

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Table 1. Demographics of interview and focus group participants

	PSS interviews (n=16)	MUAA interviews (n=24)	Parent focus groups (n=76*)
Sex			
Female	8	17	58
Male	7	7	18
Transgender	1	0	0
Self-identified race**			
African American	5	24	41
American Indian/Alaska Native	1	2	0
Asian American	3	1	3
White	5	0	31
Other	1	1	1
No response	1	0	0
Self-identified ethnicity			
Hispanic or Latino	1	1	4
Not Hispanic or Latino	8	21	70
No response	7	2	2
Age: mean (range)	40 (24-62)	42 (21-61)	43 (26-71)

* Seven focus group participants were also interviewed in either the PSS (3 overlapping) or MUAA (4 overlapping) study. Thus the sum of total unique participants across all interviews and focus groups is 109.

** Three MUAA participants who indicated more than one race are counted once in each race category with which they identified.

Table 2. Conceptual metaphors identified, with example quotes. For each of the conceptual metaphors presented in the results chapter, this table contains one to two example quotes from focus group and interview participants.

Conceptual metaphor	**Example quote(s)**
GENETIC INFORMATION IS A TOOL	[Getting genetic information] “might just be one additional piece of information to add to the toolbox” (P08-02)
GENETIC INFORMATION IS A WEAPON	[Receiving genetic results for a child] “could be a piece of information for them…to have in their arsenal for decisions that they’re going to make in their lives” (P02-01) “So you don’t want too much information and, and with, I think with this, it’s so much. Genetic, there’s so much out there, you don’t want to be bombarded either.” (MUAA24)
GENETIC INFORMATION IS LIGHT	[Receiving positive results, e.g., about athletic ability] “would be like hey there's a light in the end of the tunnel” (PSS22)
GENETIC INFORMATION IS DARKNESS	“To know that I would develop early onset Alzheimer’s or, or something like that, I think it would be a consistent cloud over my life” (MUAA15)
GENETIC INFORMATION AS GOODS INSIDE A BOX	“I’m going to want to [get] results on all of them. I’m curious like that. But I’m…not very confident. Kind of like opening Pandora’s box, do you want to know what’s inside?” (PSS12) [On choosing when to receive results] “I want to open that box that’s, that’s mine.” (MUAA20)
GENETIC INFORMATION IS A PICTURE	“I don’t think I’m closed out to anything. I, I like the good and the bad because it all makes the whole picture.” (MUAA19)
GENETIC INFORMATION IS A DOCUMENT	“If there was an architect going through the neighborhood and they were drawing plans, I want a copy of the plans of my house… I’m not going to build a house, I just want it.” (P02-03) “…it would be nice to know, I guess I’m thinking of credit score like, here’s your credit score and here’s how you can improve it.” (P10-01)
DISEASE IS A SLEEPING MONSTER	“…if I knew that someone somewhere had a genetic disease show up how many generations could that kinda be sleeping until it shows up again.” (PSS18) “Epilepsy I believe probably would’ve already reared its ugly head by now.” (MUAA09)
DISEASE IS AN ENEMY OF WAR	“We’re gonna kill off any disease that try to attack this body…” (PSS27)
LIFE IS A JOURNEY	“If I'm going to be 80 when I get that I would really really rather wait until I’m 80 to know that's going to happen to me and spend those preceding however many decades blissfully unaware of that coming down the road...” (P08-04)