A Visual Approach
to Improving the Experience of Health Information
for Vulnerable Individuals

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ABSTRACT

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Many individuals with low health literacy (LHL) and limited English proficiency (LEP) have poor experiences consuming health information: they find it unengaging, unappealing, difficult to understand, and un-motivating. These negative experiences may blunt, or even sabotage, the desired effect of communicating health information: to increase engagement and ability to manage health. It is imperative to find solutions to improve poor experiences of health information, because such experiences heighten vulnerability to poor health outcomes. We aimed to address a gap in the health literacy literature by studying the patient experience of health information and how visualization might be able to help. Our four studies involved patients presented with health information in various settings to improve understanding and management of their care. We used semi-structured interviews and observations to understand patient experiences of receiving personal health information in the hospital. We learned that the return of results is desired and has the potential to promote patient engagement with care. We developed a novel method to analyze LHL, LEP caregiver experience and information needs in the community setting. The novel method increased our understanding and ability to detect differences in experiences within the same ethnic group, based on language preference. Next, we interrogated the literature for a solution to easily communicate complicated health information to disinterested, LHL, LEP individuals. We found that visualizations can help increase interest, comprehension, support faster communication, and even help broach difficult topics. Finally, our
findings were used to develop a novel prototype to improve experiences of consuming genetic risk information for those having LHL and LEP. Unlike traditional approaches that focus on communicating risk numbers and probabilities, the novelty of our approach was that we focused on communicating risk as a feeling. We achieved this by leveraging vicarious learning via real patient experience materials (e.g., quotes, videos) and empathy with an emotive relational agent. We evaluated and compared the prototype to standard methods of communicating genetic risk information via a mixed methods approach that included surveys, questionnaires, interviews, observations, image analysis, and facial analysis. Main outcome variables were perceived ease of understanding, comprehension, emotional response, and motivation. We employed t-tests, ANOVAs, directed content analysis, correlation, regression, hierarchical clustering, and Chernoff faces to answer the research questions. All variables were significantly different for the prototype compared to the standard method, except for motivation as rated by 32 LHL, LEP community members. Findings revealed that LHL, LEP individuals have difficulty appropriately processing standard methods of communicating risk information, such as risk numbers supported by visual aids. Further, appealing visuals may inappropriately increase confidence in understanding of information. Visualizations affected emotions, which influenced perceived ease of understanding and motivation to take action on the information. Comprehension scores did not correlate with perceived ease of understanding, emotional response, or motivation. Findings suggest that providing access to comprehensible health information may not be enough to motivate patients to engage with their care; providing a good experience (taking into account the aesthetics and emotional response) of health information may be essential to optimize outcomes.
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Dedication

To all those who struggle understanding and communicating health information,

and to the nurse whose care inspired this effort.
Chapter 1
Introduction

“to affect thro’ the Eyes what we fail to convey to the public through their word-proof ears.”

- Florence Nightingale

Nightingale was one of the first to demonstrate the power of a novel visualization to penetrate “word-proof” ears and eyes to engage and support understanding of health information. In her wake, many have leveraged modern graphic technology to create visualizations to enhance communication. Consequently, visuals now abound, with little evidence elucidating which ones are effective. This is problematic. Visualizations are valuable tools that can be used to help vulnerable groups understand critical health information. However, to be effective they need to be carefully crafted for, and tested by, the intended audience. Otherwise, they can cause confusion or serious miscommunication, which in turn can have grave consequences. Preventing poor outcomes is an aim of biomedical informatics. Biomedical informatics is the science of making biomedical data meaningful. (1) Investigating the design and effects of visualizations for vulnerable individuals, therefore, is a significant biomedical informatics process, and the primary goal of this dissertation.

1.1 Background and Significance

Consequences can be severe when individuals with low health literacy (LHL) and limited English proficiency (LEP) do not understand critical health information. Health literacy is the capacity to
obtain, process, and understand health information to make health decisions.(2) Around 36% of the US adult population has limited health literacy, and 55% have basic or below-basic numeracy skills.(2) LEP has been defined as difficulty speaking, reading, and understanding instruction in the English language.”(3) According to the 2011 Census, nearly 21% of U.S. residents 5 years of age or older speak a language other than English at home.(4) LHL and LEP are associated with higher incidence of chronic disease, lower utilization of preventive health services, higher health care costs, lower health status, higher hospitalizations, lower medical regimen adherence, less shared decision-making (5), and higher likelihood of early death.(6) Recognizing the far-reaching consequences of ineffective communication, the Institute of Medicine's 2004 report on health literacy recommended making the creation of understandable health materials a national priority.(7) Equally, the American Medical Association recognizes that limited patient literacy is a barrier to effective medical care and encourages the allocation of federal and private funds for research on health literacy.(8)

1.2 Problem Statement

Comprehension and willingness to process health information is crucial for disease prevention and health maintenance. However, many patients report having poor experiences with health information, describing it as difficult to understand, unappealing, inadequate, impenetrable, unstimulating, and hard to relate to.(9–12) Individuals with LHL and LEP are particularly prone to having poor experiences because they have limited ability to understand abstract medical concepts and process text-based material, in which most health material comes. As follows, they have diminished desire to engage with and, in effect, act upon the information. If health professionals do not understand how to effectively communicate information to LHL and LEP patients, communication inequalities will deepen health disparities.
1.3 Purpose of this Study

The purpose of this study was to reduce the inequalities in communication by enhancing patient experiences of health information with the aid of appropriately designed visualizations. We aimed to do this by first investigating the patient experience of health information, then leveraging that understanding to develop a visual informatics solution that could furnish meaningful experiences of health information for individuals with limited ability to understand health information.

1.4 Theoretical Framework

*Why the focus on providing a good “experience” instead of the traditional informatics’ focus of meeting information needs?*

Much research has been dedicated to understanding information needs to inform the design and application of tools to meet those needs (e.g., is the tool usable? useful?). As technology, culture, and people have evolved, the bar has been raised from solely understanding how to address information needs to also investigating how to engage and enhance the experience of information. Studies indicate that people are less likely to engage with tools that do not provide a good experience.\(^{(13)}\) This may be less true for motivated patients, who may care less about how information is provided as long as access is provided. However, for patients having LHL and LEP, their experience of health information may strongly influence intentions to engage and act on the information.

*What do you mean by “experience”?*

We define and investigate “experience” using Pine and Gilmore’s \(^{(14)}\) experience framework.

The experience framework has been extensively tested and widely used in various fields to
represent theoretical understanding about staging optimal experiences. As we want to stage the optimal experience for patients with health information, we used this framework as a guide to explore the key elements that compose a great experience.

According to the experience framework, there are four types or “realms” of experiences: 1) educational: where one is able to understand and learn 2) escapist: where one knows what to do; 3) esthetic: where one is attracted to and feels comfortable to engage; and 4) entertainment: where one is engaged and entertained. While many experiences engage primarily one of the four realms, most experiences cross boundaries, combining elements from all four realms. But to provide the best experience, aspects from all four realms must be included. These center around the ‘sweet spot’ in the middle of the framework.(15) Figure 1.1 shows the different realms of experience along with the optimal ‘sweet spot’ that combines aspects from all realms.
This framework was especially useful to our studies as it allowed us to think through and explore how patients experience health information in different contexts. Specifically, we conducted four studies corresponding to different ‘realms,’ that explored patient experiences of health information: Study 1 (Chapter 3) investigated the patient experience of health information in the hospital; Study 2 (Chapter 4) investigated experience of information in the community setting; Study 3 (Chapter 5) interrogated the literature on how visualizations can help communicate complicated health information for future patients; Finally, in Study 4 (Chapter 6-10), we investigated and developed a solution to improve the patient experience of receiving genetic test results using the key lessons learned from each realm in Studies 1-3. Figure 1.2 illustrates the theoretical
constructs (“realms”), related studies, and lessons learned from each that inform Study 4. The text in blue show the methods used in each study.

<table>
<thead>
<tr>
<th>Realms</th>
<th>Studies 1-3</th>
<th>Lessons Learned</th>
<th>Realms</th>
<th>Study 4</th>
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</thead>
<tbody>
<tr>
<td>Educational Escapist</td>
<td>Inpatient experience with personal health information semi-structured interviews observations</td>
<td>Return of results desired &amp; has the potential to promote engagement with care</td>
<td>study 1</td>
<td>Develop Experiential-Report Collate Standard-Report on Genetic Test Results</td>
</tr>
<tr>
<td>Escapist</td>
<td>Latino Dementia Caregiver experience &amp; information needs college analysis</td>
<td>Method helped elicit lived experience of Latinos that words alone cannot &amp; new automated method to analyze images</td>
<td>study 2</td>
<td>literature review environmental scan hallway tests</td>
</tr>
<tr>
<td>Esthetic Educational</td>
<td>Information visualizations to help communicate Advance Directives literature review</td>
<td>Visualizations can help interest, comprehension, support faster communication, &amp; broach difficult topics</td>
<td>study 3</td>
<td>Evaluate Genetic Test Reportsobservations 1-on-1 interviews survey questionnaire image analysis facial analysis</td>
</tr>
</tbody>
</table>

**Figure 1.2** Guide to how concepts from the experience framework relate to each study, and how lessons learned from each study inform Study 4.

**Organization of Document**

This dissertation is comprised of four studies. The first three studies (Chapters 3-5) are presented as manuscripts (two are published and one is in revision), and the last study is comprised of multiple chapters: Background (Chapter 6), Prototype Development (Chapter 7), Methods (Chapter 8), Results (Chapter 9), and Discussion (Chapter 10).

**1.5 Specific Aims and Research Questions**

**Aim 1**: Assess patients’ and family experience with personal health information.

1. What is the inpatient experience with access to their medical information?
2. Do inpatients use the information and perceive it to be useful?
3. What are the information needs of inpatients?
**Aim 2**: Develop a novel method to analyze visual organization of vulnerable individuals’ experience and information needs

1. How can we develop a method to analyze visual organization of content?
2. What are the information needs and information organization patterns of Latino individuals?

**Aim 3**: Review literature on how visualizations can improve experience and communication of complicated health information.

1. What is the optimal format to present complex information to vulnerable patients to attract, explain, and engage?

**Aim 4**: Develop an experiential-report and collate standard-report.

1. What format and features should we use to design an “experiential” genetic report for LHL and LEP Latinos?”
2. What content should we include in the reports?

**Aim 5**: Evaluate the experiential-report compared to the standard-report through data triangulation.

1. How well do participants understand the standard-report vs. experiential-report?
2. What are the emotional responses to the standard-report vs. experiential-report?
3. How motivated do participants feel after viewing the standard-report vs. experiential-report?
1.6 Overview of Experiments and Methods Used

We conducted four studies to achieve the research aims, which use varying combinations of the following research methods:

1. Literature review
2. Semi-structured interviews
3. Observations
4. Visual image analysis
5. Hallway tests
6. Environmental scan
7. One-on-one interviews
8. Survey
9. Questionnaire
10. Facial behavior analysis

The four studies are described in detail across 7 chapters (3-9) of this dissertation.

Table 1.1 provides an overview of each research Aim, with its corresponding chapter, studies and research methods.

Table 1.1 Guide to studies with corresponding chapter, aim, and methods

<table>
<thead>
<tr>
<th>Aim</th>
<th>Chapter</th>
<th>Study</th>
<th>Description</th>
<th>Methods</th>
</tr>
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<td>3</td>
<td>1</td>
<td>Inpatients experience with personal health information</td>
<td>2, 3</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>2</td>
<td>Collage analysis of “underserved” caregiver experience and information needs</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>3</td>
<td>Integrative review of how visualizations help convey and improve experience of complex health information</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>7</td>
<td>4</td>
<td>Develop report prototype for vulnerable individuals and collate examples of a standard report</td>
<td>1, 5, 6</td>
</tr>
<tr>
<td>5</td>
<td>9</td>
<td>4</td>
<td>Evaluation of report prototype compared to standard report through data triangulation</td>
<td>3, 4, 7, 8, 9, 10</td>
</tr>
</tbody>
</table>
Chapter 2

Literature Review: Visualizations: How They Can Help LHL and LEP Individuals

Dangers of LHL and LEP

The need for effective communication about health risks is particularly acute, yet also tremendously complex, for reaching individuals with low health literacy (LHL) and limited English proficiency (LEP). Current efforts are insufficient to provide LHL and LEP individuals with relevant health information to empower them to make informed decisions about their best health care choices. (16) When the ability to understand health information is impeded by LHL and LEP, it leaves individuals vulnerable to numerous poor health outcomes. LHL and LEP are associated with increased hospitalizations, greater use of emergency care, decreased access to primary and preventive care (17,18), reduced ability to take medications correctly (19), increased disparities (20), and diminished ability to interpret health materials (21), decreased patient adherence (22), diminished patient satisfaction (23,24), increased costs (25), and higher likelihood of early death. (6) Clearly, health literacy and language proficiency are critical pieces to improving health outcomes and must be addressed.

Characteristics of Low Literacy that Contribute to Poor Comprehension

What are the deficiencies that lead to poor understanding in LHL individuals? The literature around low literacy and its relation to working memory provide some insight to this question. Low-literate individuals display smaller working memory capacity. (26) Working memory is limited and shared with the capacity for storage and processing information. (27) Working memory stores the results of word processing and combines them into sentence structure,
enabling readers to comprehend the overall text. Poor readers tend to have a smaller functional capacity for text comprehension because they must devote more resources to the process itself (e.g., reading at word level). Good readers tend to have greater vocabulary knowledge, which enables them to process word level reading much faster and more accurately. (29) As good readers' word reading process demands less working memory, more working memory can be distributed to the higher level (e.g., text comprehension) reading process. (28) Low-literate individuals devote more working memory at word-level reading and thus their limited working memory results in poor comprehension. (30) By comparison, relatively high-literate individuals devote less working memory at word-level reading, leaving more working memory for better comprehension. (31)

Additionally, researchers have found that low-literate individuals tend to process information based on single informational signals such as pictures. (30, 32, 33) Low-literate adults deal with written text by reading word for word, focusing on each word and accessory details rather than on key concepts; letting their eyes wander about page without finding the key points; and are unable to scan text, resulting in skipping many key information points. (34, 35) Low literate individuals engage in pictographic thinking, which is more than a dependence on pictures, extending to even viewing words as images rather than words to read. (31, 33, 36) Further, they tend to benefit from better memory for pictorial representations of brand information. (36) Thus, pictures appear to be effective and favorable in communicating with low literate individuals.

**Characteristics of Limited English Proficiency that Contribute to Poor Comprehension**

To gain insight into how LEP individuals process words corresponding to two languages, we consider the psycholinguistic model, the Revised Hierarchical Model, or RHM (37, 38), which
considers how bilingual individuals process words corresponding to two languages. This model suggests that conceptual or semantic processing is less likely to occur when a word is encountered in an individual’s second language than when it is presented in his first language. Thus, the RHM implies that memory for second-language messages will be inferior to memory for first-language messages. When relevant (or “congruent”) pictures accompany text, they have been found to facilitate conceptual processing of second-language messages, increasing memory for second-language messages processing, and thereby reducing the impact of language asymmetries on memory.\(^{(39)}\) Taken together, any considerable amount of English text presents a challenge for LHL and LEP individuals to accurately and easily interpret.

**The Shortcomings of Text for Communicating Health Information to LHL and LEP**

Text cannot compete with visuals’ velocity and ease of processing. The brain processes images 60,000 times faster than it does text.\(^{(40)}\) Through visuals an inordinate amount of information can be conveyed while requiring minimal cognitive effort and attention. The brain processes pictures all at once, but processes text in a linear fashion, meaning it takes much longer to obtain information from text.\(^{(41)}\) Studies indicate that text decreases interest in consumption\(^{(42)}\), increases anxiety\(^{(43)}\), and increases cognitive burden, particularly for those for whom English is a second language and those who have LHL.\(^{(37,44)}\) Unfortunately, most health information materials come in this low-bandwidth format. To deal with low-literate adults, most healthcare educators currently simplify the text language of educational materials. However, easy-to-read instructions alone only marginally improve low-literate patients’ understanding.\(^{(45,46)}\) Much of preventative health communication centers around trying to depict possible future disease experiences in order to promote healthy behavior. Text is a challenging format for
conveying such experiences efficiently and effectively. Text provides a limited experience of information relative to other formats, such as video. Use of text in health communication can cause patients, particularly those with LHL and LEP, to resist engaging with it. This is problematic. Researchers and clinicians must figure out how to not only communicate health information clearly and accurately, but to do so in a manner that patients will want to engage and process the information.

**How Visuals Help LHL and LEP Support Comprehension and Engagement**

Visualization is a broad term that is used in many fields (e.g., information visualization, scientific visualization, visual analytics, product visualization, visual communication, knowledge visualization), many of which overlap and have evolving definitions. For the purpose of this dissertation we will focus on and define visualizations as any technique for creating images, diagrams, animations, multimedia or augmented and virtual reality to communicate a message. Visuals are any graphic that is used to amplify cognition. Others have described visuals as data structures that support cognitive efficiency. Visuals make it possible for certain tasks to be done by using a few simple perceptual operations, which otherwise can be a laborious cognitive process. Because humans have only limited cognitive resources to process incoming information, unnecessary cognitive load is detrimental to understanding and should be avoided. The aim should be to free up cognitive resources to facilitate deeper understanding. Visualizations should be designed to manage this balancing act and to optimally support information processing. Visualization use can be an effective strategy against information overload, which is a major problem in information society.

Visuals alone support understanding, but they also have been shown to help readers perceive, understand, and remember text information. In such cases, visuals need to be related to
congruent with) the text. When they are not congruent, visuals impair understanding, which we discuss shortly. Visuals, being sub or pre-verbal, can ‘take over when words become ineffective.’

Our focus is to provide visual “gist” understanding, or the general meaning, rather than surface details such as exact quantities or percentages of health information. We are motivated by the work of behavior scientists, who explain that much of human behavior is not logical and not directed by numbers. For example, researchers suggest numbers (statistics) do not convince nor change perception, because perception is not based on numbers. Statistical information does not figure into the way people form their impression and opinions. People tend not to remember specific numbers, and instead have general gist semantic memories. This is based on Fuzzy-Trace Theory (FTT), a theory of cognition that predicts and explains cognitive phenomena, particularly in the memory and reasoning domains. According to this theory, health-care professionals should package, present, and explain information in more meaningful ways that facilitate forming an appropriate gist. Such strategies would include explaining quantities qualitatively, displaying information visually, and tailoring the format to trigger the appropriate gist and to cue the retrieval of health-related knowledge and values.

When designed properly, visuals can support trust and believability of health information. By enhancing the “processing fluency” or the subjective experience of ease with which people process information, visuals can influence whether people perceive information as more true or less true than information conveyed through less fluent formats. In a large review, Alter summarizes that processing fluency reliably influences people’s judgments and decision-making in a broad range of social dimensions. Thus, visuals are well suited to help increase trust and
believability of health information, as they excel, when designed correctly, at minimizing effort to process the information.

**Visuals are Engaging**

Engagement research has shown that the amount of attention directed to information can affect the weight assigned to that information in reaching a decision (60) as well as the final judgment itself. (61) Thus, any format that can grab attention and engage individuals will have more influence on how they process the information. Visuals tend to attract attention more than walls-of-text, as visuals tend to be more visually interesting, appealing and easier to consume, which we discuss further in Chapter 5.

Perhaps one of the reasons patients resist processing medical information is because the format in which it comes does not support fluent information processing and, compared to other formats, is unappealing. The concept of anything being unappealing is relative. During Gutenberg’s time, when text was a novel, rare, and costly technology, it is likely that patients may have viewed text as more engaging. However, today in our heavily visual society, the vivid formats make text pale in comparison. Industry reports indicate a shift in communication patterns calling visuals the new “universal language.” (62) While some may argue that visuals have always been a universal language, their usage has skyrocketed. For example, Facebook has, since June of 2014, played at least one billion videos every single day. And every day, people upload more than 350 million photos on average to Facebook. (62) Considering that the brain prefers what it is familiar with, and that more people are spending hours in front of a screen that is dominated by visuals, this would suggest that visuals are indeed the new universal language to use to communicate information and to engage individuals.
Visualizations Targeted to Improve Low Literacy

Numerous studies have attempted to improve the patient experience of health information specifically for LHL individuals through visuals. Low-literate adults have been shown to benefit from visuals added to text in comprehending medical risks (63,64), treatment risks (65), discharge instructions (66), websites (67), medication schedules (68) medication side effects (69) and health care brochures. (70)

Health information presented with visuals may benefit LHL individuals more than individuals with relatively higher literacy levels. Researchers also find that low-literate patients benefit significantly more than high literate patients when pictures (e.g., icon arrays) are added to support text. (65,66,68,70)

A popular engaging visual format targeted towards the Latino community is the fotonovela. Fotonovelas are a “form of Entertainment–Education” (71) that are formatted as pamphlets similar to comic books, with photographs instead of illustrations, combined with small dialogue bubbles. They have been demonstrated to effectively communicate information to the Latino community. (72–74) They typically depict a simple story enveloped in a dramatic plot that contains a health message. (73)

Multimedia, Videos, Augmented Reality

Multimedia is the use of more than one medium of communication. An advantage of multimedia is flexibility. It can assist in overcoming linguistic, cultural, and physical barriers; in addressing different learning levels; in providing for the unique experiences of patients and health care professionals; in presenting materials in different formats and from different perspectives; in providing feedback and decision-making resources; and in tailoring and customizing information to the needs of individual patients and providers. (75–77)
The literature has conflicting results regarding video’s efficacy relative to other types of media for LHL and LEP. Studies show that video and print interventions can at times promote recall of health-related information, but have not always proven to be effective. (75, 78–80) Numerous successful examples have come from Volandes team. (47, 81, 82) They use videos to enrich understanding to boost confidence in decision-making in LHL and LEP individuals. For example, Volandes et al (47) and his team studied Hispanics with LHL who expressed more uncertainty about their preferences for end-of-life care than did subjects with adequate literacy. Video decision aids improved decision-making by decreasing uncertainty regarding subjects’ preferences, especially for those with limited literacy. Researchers conclude that videos may serve an important role in enriching the understanding of the condition and allowing one to imagine a future health state.

**Visualizations are Tricky**

While visualizations have proven effective at supporting comprehension and engagement with health information. They need to be carefully designed and tested with and by their intended audience. When improperly applied, visuals can be misinterpreted, detract from wanting to view the information, and increase confusion and dislike. (12, 30, 83, 84) Some visuals appear to provide no benefit to populations with low health literacy (85), and some appear to incite potential harm. (86) Further, visuals that have been tested with one group can repel another. For example,
researchers Goldman et al (12) report that the commonly used crowd chart (see Figure 2.1) which tends to be used to provide accurate interpretations of quantities, was disliked by all participants. They report that patients perceived this graphic as: “busy,” “your mind starts to lose the comprehension of the dots,” “it doesn’t have any oomph,” and that it took a lot of thought to understand. The researchers also investigated responses to a bar chart. Participants perceived it as lacking impact, “too dry,” “too statistical,” geared toward “scientific medical-types,” and removed from personal experience.(12) This demonstrates that to encourage processing and engagement with health information, researchers need to not only test for accuracy of interpretation, but also how to promote appealing visuals.

Irrelevant visuals presented next to text that do not support the intended message can diminish information processing abilities and distract low literate individuals. Harber (87) details that when low-ability readers encounter illustrations that are irrelevant to the text, the pictures may interfere with their reading performance (word recognition and reading comprehension) because of the effects of selective attention. Low literate individuals are deficient in selective attention; therefore, they are more susceptible to interference, such as through irrelevant illustrations, because their attention is concentrated on the visual dimensions of the reading task. Individuals with lower literacy levels will perform better with text-only messages versus incongruent picture-text messages because of selective attention, and this effect is greater for individuals with lower levels of literacy relative to consumers with higher levels of literacy.
Below are visuals taken from Google’s Knowledge Panel that are incongruent with the main text (see Figures 2.2 and 2.3). These are examples of how people apply visuals to add interest and appeal to text. However, these visuals do not support the ‘gist’ message of high cholesterol. In Figure 2.2, the focus is “About” high cholesterol but displays people in diagnostic waiting room. One would expect a visual that supports understanding of what high cholesterol is. In the next visual, Figure 2.3, the focus is on “Symptoms” of high cholesterol, but the visual displays a man eating a salad with medication close by. In the bottom corner is a drawing of what high cholesterol could look like in the blood vessel.

**Figure 2.2** Example of visual that is incongruent with text: caption reads “High amounts of cholesterol in the blood” but the image depicts a waiting room.
Figure 2.3 Example of visual that does not support gist understanding of topic. The images do not depict symptoms of high cholesterol.

Although at first appealing, these visuals do not support the purpose of the message and miss the opportunity to help viewers gain a deeper meaning and significance of the health condition.

How Culture Influences Interpretation of Visualizations

Culture plays a significant role in influencing how the brain processes information. For example, Peng and Nisbett (88) found that when asked to interpret what the fish on the right (see Figure 4) was feeling in the graphic below, Americans and Chinese responded differently. Americans viewed the fish as angry, while the Chinese thought it must be feeling sad.
Figure 2.4 Example of how culture influences interpretation of visuals. Americans interpret this graphic differently than Chinese.

Implicit and unconscious influences of culture are known to affect visual attention. Researchers have demonstrated how Japanese, more than Westerners, incorporate information from social context. Researchers had participants view cartoons depicting a happy, sad, angry, or neutral person surrounded by other people expressing the same emotion as the central person or a different one. The surrounding people's emotions influenced Japanese but not Westerners' perceptions of the central person. Researchers conclude that the differences in results reflect differences in attention, as indicated by eye-tracking data. Further, researchers investigated the influence of Russian culture on interpretation of visuals. Russians spent significantly more time looking at negative than positive pictures, whereas Americans did not show this tendency. The researchers suggest that this may be due to the Russian culture, which they described as brooding and melancholy.

In a cross-cultural study, Garcia-Retamero and Galesic found that icon arrays may be especially helpful for US participants compared to Germans when interpreting treatment risk. The study examined how low literate Americans and Germans interpreted numerical treatment risk. Understanding medical information presented numerically was more difficult for US
participants (66% provided inaccurate estimates) than for German participants (40% provided inaccurate estimates). When icon arrays were added to the numerical information, however, these percentages were similar in the 2 countries (31% and 36%, respectively).

Culture provides a context and a framework for people to understand concepts and interact with information. (91) Cultures all have certain expectations of what constitutes an acceptable display of information in a given context, which can influence trust of the information. (92)

In sum, variability in visual interpretations may be partly attributed to cultural factors. As such, cultural influences should be incorporated in studies aimed at developing tools for those with a different cultural orientation.

Summary

Navigating the ever increasing complex health care system is fraught with peril for those with literacy and language deficiencies. Their unique characteristics make comprehension of health information challenging. Much of the health information LHL and LEP individuals need to comprehend comes in a format that hinders understanding and engagement with the information. Using visualizations to overcome barriers to understanding and engagement is promising, but they are tricky to use appropriately. Research is needed to confirm the effectiveness of previous findings and explore yet untested interventions. Such interventions might include interventions to increase motivation to process risk information (Study 4, Chapters 6-10). Despite research advances to mitigate the effects of LHL and LEP, there remains much to be done to improve the experience of health information for patients having LHL and LEP.

Through the Specific Aims and exploration of the research questions described in Chapter 1, we attempted to fill knowledge gaps framed by the experience framework, in order to improve the experience of health information for vulnerable individuals.
Chapter 3

**Aim 1:** Assess patients’ and family experiences with personal health information

Study 1 aimed to assess the patient experience of health information *in the Hospital*. Specifically, we conducted a qualitative study on the experience of hospitalized patients’ experiences with their personal medical information provided through an inpatient personal health record. This manuscript was published in Applied Clinical Informatics in 2016.(93)

**Patient Experiences Using an Inpatient Personal Health Record**

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**Keywords**
Patient engagement, inpatient, technology, personal health records

**Summary**

**Objective:** To investigate patients’ experience using an inpatient personal health record (PHR) on a tablet computer to increase engagement in their hospital care.

**Methods:** We performed observations and conducted semi-structured interviews with 14 post-operative cardiac surgical patients and their family members who received an inpatient PHR. Themes were identified using an inductive coding scheme.

**Results:** All participants responded favorably to having access to view their clinical information. A majority (85.7%) of participants used the application following an initial training session. Patients reported high satisfaction with being able to view their hospital
medications and access educational materials related to their medical conditions. Patients reported a desire to view daily progress reports about their hospital stay and have access to educational information about their post-acute recovery. In addition, patients expressed a common desire to view their diagnoses, laboratory test results, radiology reports, and procedure notes in language that is patient-friendly.

**Conclusion:** Patients have unmet information needs in the hospital setting. Our findings suggest that for some inpatients and their family members, providing personalized health information through a tablet computer may improve satisfaction, decrease anxiety, increase understanding of their health conditions, and improve safety and quality of care.

1. Background

Being a patient in the hospital is an anxiety-inducing experience. Poor communication and lack of access to information can have detrimental effects on a patient’s psychological wellbeing and coping abilities (94–98). Policymakers (99,100) and patient advocates (101,102) are increasingly focusing on this problem. This study investigates how an inpatient personal health record (PHR) may help address the information needs of patients and improve their engagement and experience in the hospital.

Provision of medical information and education about care can allay a patient’s uncertainty and stress (103–108). Further, sharing information has been shown to reduce patient requests for clinicians’ time, foster a sense of control and empowerment while promoting self-efficacy and ownership of illness (109–111), and lead to increased participation as an informed partner in making health decisions (112–115). Previous research suggests that patients want to use PHRs and believe that they will be valuable (116). Moreover, patients believe that their adherence to treatment regimens will improve if they have the opportunity to read and understand their health information (117,118). However, patients are not typically given the opportunity to review their health information in the hospital. For example, in a survey of hospitalized patients conducted by Cumbler and colleagues, 90% of respondents said they
wanted to review their hospital medication list for accuracy, but only 28% said they were given the opportunity to do so (119). Without access to a documented care plan, patients are uncertain as to the care they have received and what to expect. For example, studies show that patients remember less than half of what physicians explain to them in the hospital (120,121). These findings suggest that there is potential to expand data-sharing practices with hospitalized patients in order to improve patient experience.

In previous work, we conducted a small pilot study where we provided a prototype of an inpatient PHR to five hospitalized patients in a supervised manner to assess their initial impressions and interest (122). Using tablet computers, patients viewed photos of their care teams, medications they received, and their reconciled home medications and allergies. The response of patients and healthcare providers was positive (122,123), demonstrating that the inpatient PHR could be a useful platform for addressing patients’ information needs in the hospital. Based on the feedback we received from this earlier study, we enhanced the inpatient PHR system to address a number of limitations. The present study describes a larger deployment of the system and assesses patients’ perceptions and information needs after having access to the technology without supervision for at least 24 hours during the hospital stay.

2. Objectives

The three aims of our study were to assess (1) the factors surrounding patients’ use of an inpatient PHR, (2) patients’ experience with the application, and (3) patients’ information needs that might be partially met using an inpatient PHR.
3. Methods

3.1. Setting and Technology

In 2009, NewYork-Presbyterian Hospital (NYP) / Columbia University Medical Center (CUMC), a large urban academic medical center in New York City, implemented an outpatient portal called myNYP.org. In addition to functions such as the ability to search for NYP physicians, schedule appointments, and pay bills, the system allowed patients to access their laboratory test results, radiology reports, operative notes, and discharge summaries after leaving the hospital. In 2011, we developed a version of myNYP specifically for hospitalized patients. The initial inpatient PHR allowed patients and their families to view their care team (names, photos, and biographies), confirm allergies and home medications, and track hospital medications.

Based on the feedback from an earlier pilot study, we enhanced the inpatient PHR to increase usability and provide feature enhancements. These enhancements included user interface and navigation improvements, electronic self-reporting of pain level, and a feature to record notes, comments and questions for health providers that were made available to the care team within the hospital’s electronic health record. Additionally, we made available links to medication information on MedlinePlus.gov, as well as links to curated educational content on myNYP.org, such as educational videos and explanations of medical conditions. A sample screen of the patient comment interface is shown in Figure 3.1.
3.2. Study Design

Patients and their family members from a post-operative cardiac surgery unit at NewYork-Presbyterian/Columbia University Medical Center were invited to participate in the study from August to December 2012. English-speaking participants were recruited based on consultation with the attending physician managing post-operative patients on the floor. Exclusion criteria included patients with severe mental illness, substance abuse, language barriers or severe physical discomfort. This study was approved by the Columbia University Medical Center Institutional Review Board.

After providing informed consent, participants were given an Apple iPad tablet computer with access to the inpatient PHR application. Initial use of the application was observed for 15 minutes to assess usability, answer questions, provide guidance on navigation of application, and
collect initial impressions. The following day, participants participated in a semi-structured interview that took on average 20–30 minutes. The interview questions consisted of 23 questions based on core concepts from the Technology Acceptance Model (124). To ensure accuracy of interpretations of interview data, we reflected back to participants our understanding of what we heard them reporting during the interviews (125). Questions covered patients’ demographics, technological adeptness, health information seeking behavior, knowledge of medical conditions, previous use of PHRs, information needs while in the hospital, and experience and use of the inpatient PHR application (see Appendix A). Interviews were audio-recorded and transcribed by members of the research team, who met weekly to review general findings and themes of collected data. Participant recruitment continued until we reached thematic data saturation, i.e., when no new general themes were observed (126).

3.3 Data Analysis

Using a qualitative content analysis approach, two members of the research team (JW and AS) independently reviewed all the data, and through the process of consensus building generated the coding scheme. They independently coded the data, and discussed to clarify meaning and boundary of codes to finalize themes (127). Participant demographics and self-reported usage of application were analyzed using descriptive statistics.

4. Results

Twenty-four patients were approached, twenty patients consented to participate in the study, and fourteen completed the semi-structured interviews (Table 3.1). The mean age of the participants was 59.0 (SD=16.0), with an equal split between male and female. The majority of participants (57.1%) had at least some college education. Almost all participants (92.9%) reported
using the Internet on a daily basis and 21.4% had previous experience using a tablet computer.

Three of the fourteen patients (21.4%) used the inpatient PHR along with a family member.

**Table 3.1** Participant Demographics and Technology Experience (n=14).

<table>
<thead>
<tr>
<th></th>
<th>Overall (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7 (50%)</td>
</tr>
<tr>
<td><strong>Ages</strong></td>
<td></td>
</tr>
<tr>
<td>26 – 79</td>
<td>Mean = 59</td>
</tr>
<tr>
<td></td>
<td>SD = 16</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>Some college</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>College graduate</td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td><strong>Prior Computer Experience</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13 (92.9%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td><strong>Prior Tablet Experience</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>No</td>
<td>11 (78.6%)</td>
</tr>
<tr>
<td><strong>Average Daily Internet Use</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>1–30 min/day</td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>31–90 min/day</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>&gt;90 min/day</td>
<td>6 (43.9%)</td>
</tr>
</tbody>
</table>

Half of the participants (50.0%) stated that they kept a physical file of their medical records at home. Nearly three-quarters of participants (71.4%) reported searching online for health information from consumer health websites. Two of the fourteen patients (14.3%) reported having access to their personal health information via a portal maintained by their
provider. One patient reported having a digital copy of his records provided by his physician on a USB drive.

4.1 Application Usage

Most participants (85.7%) reported using the application during the period after the initial observation session (Table 3.2). The majority of participants (57.1%) reported not using the tablet computer for other purposes (e.g., checking email, social media, browsing the Internet), even though they were invited to do so. The main factor patients reported that influenced their use of the application was their well-being. Patients reported feeling less inclined to use the application if they were experiencing pain or nausea, or had general malaise. In addition, patients who underwent multiple tests and/or procedures reported less use. In several cases where the patient was too ill or otherwise disinclined to participate, a family member reported using the application (with the patient’s permission).

Table 3.2 Participant Use of Inpatient PHR (n=14)

<table>
<thead>
<tr>
<th>Reported Inpatient PHR Use</th>
<th>Overall (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not use after observation period</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>0–15 mins</td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>16–30 mins</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>1–2 hrs</td>
<td>2 (14.3%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reported Tablet Use for Other Purposes</th>
<th>Overall (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td>Yes</td>
<td>6 (43.9%)</td>
</tr>
</tbody>
</table>
In the small sample of participants, there were no apparent socio-demographic variables that impacted tablet usage. For example, there was no significant difference in application usage between female and male patients, and neither education level nor age play a role. However, we observed that patients who owned and used a tablet device previously had an easier time using the tablet and navigating through the application. Although most patients reported that the application was easy-to-use, during initial observations, it was noted that about half had difficulty operating the tablet computer. After about 15 minutes of instruction, each of these participants reported feeling comfortable navigating the application.

4.2 Patients’ Experience with the Inpatient PHR

Ten themes emerged from analysis of interviews: 1) desire to understand and engage, 2) desire for status report, 3) report test results, 4) ownership of data, 5) desire for guidance, 6) inpatient PHR serves as information and memory aid, 7) improves safety, 8) well-being affects use, 9) messaging providers: mixed response, 10) self-reporting pain: mostly unfavorable.

Definitions of these themes and example quotes are further detailed in Table 3.3.

Table 3.3  Themes Related to Patients’ Experience with the Inpatient PHR

<table>
<thead>
<tr>
<th>Themes</th>
<th>Description</th>
<th>Examples Quotes from Patients and Family Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desire to Understand and Engage</td>
<td>An inpatient PHR can help patients and their families learn about and engage with their care.</td>
<td>“I looked up the medicines to see what it does. I would have never known what [the medicine] was.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I can’t believe I am taking all these medications.”</td>
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<tr>
<td></td>
<td></td>
<td>“They started all kinds of new medications, and it was very easy for me to go on the medication [page] and see the side effects. Instead of thinking there is something else wrong with me I was able to say, ‘Gee, well maybe it’s a side effect from this.’”</td>
</tr>
</tbody>
</table>
“I read about the whole procedure that I had, the cardiac bypass surgery, and it’s amazing exactly what happened and what they were able to do. And I didn’t really realize that because they use all these big terms, and when you break it down to someone who is not medical, it’s very interesting.”

“Access to their medical information gives patients and their caregivers perspective and insight into their hospital care and empowers them with knowledge about [what is going on], which reduces anxiety.”

<table>
<thead>
<tr>
<th>Desire for Status Report</th>
<th>Inpatients want information concerning their health status and recovery progress.</th>
<th>“When am I getting out of here?...What progress am I making?”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>“Like right now, [I would like my care team to tell me] what's my plan? ‘All x-rays are good. We are now waiting for your INRs to reach the level of 3. It is now at a level of 2.5. So hopefully we can increase the heparin dosage and by tomorrow it should reach it, and you should be discharged.””</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“If [the clinician] is performing a procedure on me, I don’t know what the hell it is called.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“He’s had x-rays and blood draws and I would like to see the results.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I know they were giving him phosphorous, so I would like to see what the levels were.”</td>
</tr>
<tr>
<td>Ownership of data</td>
<td>Inpatients consider their medical record as something they have a right to own.</td>
<td>“I think if it pertains to them, they should have anything that they want. It’s your record.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Everything.”</td>
</tr>
<tr>
<td>Desire for Guidance</td>
<td>Inpatients want instructions about what to do and expect in and out of the hospital.</td>
<td>“I just had open heart surgery, something saying…the feelings you might experience, how long the feelings may be there for…things you have to do, how long you have to do it. The road to recovery.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“You want to go home knowledgeable. If I could have a tablet…where I could see..., Dad had this, this, and this.”</td>
</tr>
<tr>
<td>Inpatient PHR Serves as Information and Memory Aid</td>
<td>Inpatients’ questions can go unattended for long periods and can be missed or forgotten. An inpatient PHR could serve as an informative agent covering the time between provider visits.</td>
<td>This is what you should be looking for. That would be ideal. That's what I want.”</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Improves Safety</td>
<td>Patients and family members can use the application to prevent errors.</td>
<td>“It's great cause I can look up all my questions and I won't forget anything.”</td>
</tr>
<tr>
<td>Well-being Affects Use</td>
<td>Patients’ lack of well-being affects use and interest in the application.</td>
<td>“I always am under the impression that doctors are busy people; they can't just stop and come to see me and explain things to me.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“A lot of times doctors come in and tell you 20 things and out of the 20 things you’ll only remember like 1 or 2. So you’re like, ‘What the hell did he say? I forgot what he said.’”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I had problems naming doctors because so many of them come to my room.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“[The inpatient PHR is an] awesome idea because if you are sitting in bed and you have a question often times you forget it by the next day.”</td>
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<tr>
<td></td>
<td></td>
<td>“I like it because I discovered yesterday a medication he's getting that he is taking at home, and they're actually giving him half the dose he's getting at home.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(A family member recognized a dosing error while using the application. She alerted a nurse and the medication was changed to the appropriate dose.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“When you first come in you might be too damn sick to really care about it or read the formalities. You have to be feeling better.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I was very nauseous and not feeling well so I really wasn’t up to using it. Started this morning, trying to look at it a little bit because I was feeling better… if you’re not feeling well you’re not going to really be using it because you’re not up to it… you don’t have the energy.”</td>
</tr>
</tbody>
</table>
| Messaging Providers: Mixed Response | Inpatient-provider communication via electronic messaging may be beneficial for some and ignored by others. | “Me personally, I don’t need to see you. I just want to text you.”

“I think it’s a good thing—if they answer, some of them aren’t online to answer. I think we should be able to email our doctors all the time. I don’t care where they at. They always got computers, iPhones, whatever.”

 “[Doctors] are not going to be available sitting down at the desk the whole entire day. They’re going back and forth, so...they’re just not going to have time to [answer questions].”

“It would be nice to have the communication face-to-face, but for some questions like about meds [it] might be quicker to text the doctor.”

“I don’t think it’s a good idea. The doctor is supposed to see the patient, sometimes feel them.”

“I just think it’d be nice if I [sent a message] and then they said, ‘I’ll be with you in ten minutes,’ or something.” |

| Self-Reporting Pain: Mostly unfavorable | Although some participants thought entering pain scores in the application could replace or supplement clinician pain assessments, most participants did not think self-reporting pain scores would be advantageous. | “If I say I need pain medication and I enter it and tell you—and enter it as a 6 or a 7—then I guess the nurse can determine how quick she has to get to me. So maybe it’s a good thing.”

“I don’t know the benefit that would do. Because if you’re in pain all you do is ask the nurse, I’m in pain and they’ll ask you 1 to 5, it’s a 4, and they’ll assign you some medication. It’s very simple.”

“No. You know why? Because I want to see [that] the nurse knows.” |
4.3 Hospitalized Patients’ Information Needs

Thirteen of fourteen patients in the study (92.9%) wanted more information about their hospital care, and the same number stated that the tablet-based inpatient PHR was helpful in addressing their information needs and valuable in increasing their understanding of their hospital stay. Some patients said they believed they should be given access to review any part of their medical record during their hospital stay, even if they cannot fully understand it. Though most participants pushed for greater access, 28.6% expressed hesitation about seeing sensitive material (e.g., a terminal prognosis) before their doctor could share it with them at an appropriate time. They felt safeguards should be put in place for sensitive information. Nearly half of participants (42.8%) believed that in some instances, the application could replace face-to-face conversations with their providers.

4.3.1 Information patients found most useful in the inpatient PHR

Of the information provided in the inpatient PHR, the information reported as most useful was the list of hospital medications administered and links to educational materials. Specifically, 85.7% of patients found the medication names and links to MedlinePlus.gov helpful for participating in and understanding their hospital care. For example, a potential medical error was prevented when a family member recognized a dosing error while using the application and notified the provider. Most participants also indicated that they liked seeing photos and short bios of their care team members as well.

4.3.2 Additional information patients wanted

In addition to what was accessible in the inpatient PHR, participants expressed interest in seeing their progress notes (85.7%), operative reports (71.4%), documented medical conditions
(50%), laboratory test results (35.7%), and radiology reports (35.7%). Participants were particularly interested in test results that were noted by their physicians to be important for discharge. Most participants desired more tailored information in the inpatient PHR, such as the following: a personalized care plan, a daily progress report, intended discharge date, key items providers needed to approve discharge, and a daily schedule (e.g., tests, procedures, and therapy sessions). Patients reported that this would help give them a sense of control over their day and help them plan when their guests should visit. Most participants requested educational information about their medical conditions and surgical procedure, along with self-care instructions and what to expect after discharge. In addition, a few patients wanted to be able to view information about their hospital bill and follow-up doctors appointments.

All participants reported wanting access to their records upon leaving the hospital. Some participants requested the ability to email their information to themselves or to their primary care provider. Several patients requested that information not typically part of a medical record be accessible outside the hospital or during their next hospital stay, such as viewing previous care team members. One patient wanted the ability to review ratings and provide reviews of exemplary staff members.

5. Discussion

This study explored hospital patients’ usage, experience, and information needs using an inpatient PHR during their post-operative hospital stay. Participants uniformly responded favorably to having access to their clinical data and believed that the inpatient PHR was useful. The results of our study suggest that an inpatient PHR can be helpful to improve understanding, engagement, and safety for some patients in the hospital. These findings are consistent with the
results of previous research investigating the effects of sharing medical information with patients through PHRs and patient portals in the outpatient setting (110,112,128–133). Many patients want to play an active role in their care (101,110,128,134), but patients cannot express informed preferences unless they are given sufficient and appropriate information about their medical care.

Our study adds to the limited research that has examined the benefits of providing hospitalized patients with access to their medical information and educational information (135–142). There is still only a rudimentary understanding of how PHRs can contribute to improving inpatient experience and increasing patient engagement in the hospital setting (143).

5.1 Implications

5.1.1 Challenges

Fulfilling patients’ desires for personalized information about their hospital stay presents numerous challenges. Some of these challenges include determining what information is most beneficial to present to patients and choosing the format and context in which such information should be presented. Although patients wanted access to “everything,” presenting the whole medical record (or even the many items requested by the study participants), may overwhelm rather than empower and truly inform. To avoid “information overload,” considerable effort will be required to identify the most informative pieces of medical data that are meaningful to patients with various conditions and across various health services.

In order to fully explore the potential of inpatient participation and real-time sharing of medical records with inpatients, additional research is needed to determine how best to present medical record information to diverse patients. This is not a small challenge, as there are many factors that may influence patient interest and engagement with their health information and
care (144). For example, Weed proselytized the importance of format to profoundly help or hinder error discovery in and understanding of the medical record (145). Key to maximizing understanding and engagement will be designing effective user interfaces (146). Presenting medical record information to inpatients creates numerous new challenges: accommodating a patient’s native language, health literacy level (147–149), information disclosure preferences (150–153), lack of familiarity with new technology, feelings of isolation and compromised constitution.

Providing daily “patient-friendly” progress reports as requested by participants may increase demands on clinicians to create and keep these reports up-to-date (154). While clinicians typically write daily progress notes of patients for other clinicians, the content of these notes tends to be highly technical, is often in short form and is thick with abbreviations, reducing its informative value to patients. It is possible that existing technologies, such as natural language processing, could be leveraged to help interpret these notes to make them more accessible to patients and their families (155,156).

Ensuring privacy is a significant challenge for an inpatient PHR. To protect electronic health information, security measures must be instituted to prevent access to unauthorized persons. However, such measures (e.g., passwords) may hinder accessibility and convenience and, thus, use of an inpatient PHR. Passwords are easily forgotten, especially by impaired hospital patients. Additionally, patients have expressed a desire to have granular control over of their medical record (113). New policies, logistics and technical challenges must be resolved in order to meet such desires without hampering usability, data sharing, or accessibility.

5.1.2 Benefits
From the interviews, we discovered how an inpatient PHR can bring value to hospitalized patients in five ways:

1) *Facilitating data ownership:* Patients view medical data as their property. Regardless of whether it is actionable or understandable, patients expressed it was their right to own and have ready access to their medical record. An inpatient PHR facilitates patients’ feelings of ownership of their data.

2) *Reducing uncertainty and anxiety:* Study participants reported that receiving information about their care helped alleviate their uncertainty and stress by providing a sense of control.

3) *Providing understandable information:* Study participants appreciated the application’s patient-friendly language, crediting it for helping them understand and take greater interest in their medical conditions. Additional work is needed to address issues of health literacy and numeracy, including providing information in a patient’s preferred language (157).

4) *Improving accuracy of data in the health record:* Medical records can be inaccurate, incomplete, and biased (158). With increased patient demand for access to medical records (101) and increased incentives to provide that access in recent federal legislation (100), more patients may review their medical records and help correct mistakes they discover (159). Furthermore, this practice may motivate clinicians to improve data collection and documentation. Improving data quality and accuracy could in turn improve reuse of the data for secondary purposes such as quality improvement activities (160).

5) *Improving patient safety:* Providing patients with their medical information is beneficial for safety, as exemplified by a study participant in our study who intercepted a medication dosing error. An inpatient PHR may enable patients and family members help reduce
medical errors, which have been identified as among America’s leading causes of death (161).

5.2 Suggestions for Future Research

There remains a critical gap in the rigorous evaluation of inpatient PHRs to enhance patient engagement. Encouragingly, more health systems and an electronic medical records vendor have recently spearheaded studies of inpatient PHRs (140–142, 162, 163). Further research is needed to clarify the appropriate design and implementation of these systems. Though usage in our study of the application was relatively high (86% of patients), it was a very high-touch intervention, with a research assistant spending considerable time educating patients about the technology and addressing concerns. Future research should help clarify what usage might be in a typical hospital ward.

The right balance must be struck between sharing all of a patient’s record versus sharing information that is deemed useful, to avoid overwhelming patients with large volumes of data. Consideration must be given to policies of sharing sensitive test results or diagnoses before physicians can have conversations with their patients. Progress must also be made on creating user-interfaces and device ergonomics that take into consideration that “a hospital patient should be treated as a situationally-impaired user (164),” and their physical and mental state is likely to fluctuate over the course of a hospital stay. As part of this process, family members should also be considered as users, particularly for frail and elderly patients, and attention should be given to appropriate security and privacy controls when granting them access (128, 165).

Future research should quantify the benefits and negative consequences of patient-facing technologies at the bedside. Specifically, a "dose-response" paradigm could be employed to determine whether the level of technology use is associated with changes in patient outcomes.
such as satisfaction, activation, health system utilization, readmission rates, and mortality.

Randomized clinical trials should be conducted on a large and diverse inpatient population spanning a variety of healthcare settings (e.g., community hospital, long-term acute care, and academic medical center) to ensure results are widely applicable.

Finally, in pursuing precision medicine’s goal to take into account individuals’ differences, future studies could characterize patient demographic traits associated with inpatient PHR usage patterns. Variability exists in patients’ ability to handle the uncertainties and stress of a hospitalization. Accordingly, we anticipate an intervention like ours will be less compelling to patients who are relatively comfortable with uncertainty and have fewer information needs. Notwithstanding, family members may benefit, even if patients themselves do not wish to use the PHR system.

5.3 Limitations

This study had several limitations. First, it was a small qualitative study conducted in a single setting at a large academic medical center. All of the participants were post-operative cardiac surgical patients in the post-ICU step-down unit. These patients may not be representative of all hospitalized patients. Second, there is the potential for volunteer bias, as our study was a convenience sample of English-speaking patients who were mentally and physically stable. Twenty-four patients were approached, and fourteen patients completed interviews. This could lead us to overestimate the number of patients or family members that would use an inpatient PHR. Third, there is the potential for response bias since the study was not blinded and participants may have chosen to answer questions in a way they thought was favorable to the researchers. A subset of answers, such as to questions about participants’ daily Internet use and
the time participants spent interacting with the application, could have been subject to recall bias.

The impact of taking part in a formal study on inpatient PHRs may have had an effect on the amount that the tablet and inpatient PHR were used, as mentioned previously. With 14 patients, we did not have sufficient power to detect differences in usage based on sociodemographic variables. In addition, interviewer bias could have resulted in a more positive interpretation of participant responses than was shown in the data. We attempted to mitigate this last issue, by conducting two independent content analyses of the transcribed interviews and comparing results. Finally, inpatient PHRs may vary in content, usability, and function and thus the experience of participants in this study with the application may not generalize to experience with other inpatient PHR applications.

6. Conclusion

This study uncovered a high desire by inpatients to have access to information about their hospital care. Providing hospital patients access to an inpatient PHR may potentially help improve patient satisfaction, understanding of care, and safety. Our results highlight the need for further investigation of the optimal ways to share medical information with inpatients and the efficacy of inpatient PHRs in improving patient experience and health outcomes.

Clinical Relevance Statement

Patients have unmet information needs in the hospital setting. Providing hospitalized patients with personalized health information through a tablet computer may yield considerable benefits--improved data quality and patient safety, increased patient understanding of health
conditions and hospital care processes, increased patient awareness of the recovery process, decreased patient stress, and increased patient satisfaction.

Conflicts of Interest

The authors have no competing interests to declare.

Acknowledgments

This project was supported by grants from the National Library of Medicine (T15 LM00707) and the Agency for Healthcare Research and Quality (R01HS21816).

Human Subject Research Approval

This study was approved by the Columbia University Medical Center Institutional Review Board.

How Lessons Learned from Study 1 Informed Study 4

Findings from Study 1 provided evidence that patients want return of medical test results and access to health information. Helpful information is actionable information that patients can easily consume and use. As follows, in Study 4, we aimed to return actionable easily consumable medical results.
Chapter 4

**Aim 2**: Develop a novel method to analyze visual organization of vulnerable individuals’ experience and information needs

In Study 2, we aimed to understand the patient experience of health information *in the community setting*. Many vulnerable individuals speak a language other than English. Because of this, it can be challenging to assess their experience and information needs. To overcome language barriers, we developed a method that did not require understanding of a foreign language, specifically Spanish; By leveraging image analysis software we built upon the standard approach to interpret collages, which was the method used to collect information needs and experiences from participants in Study 2. This manuscript is under revision and will be submitted to an appropriate journal.

**A Semi-Automated Approach to Analyzing Complex Visual Representations of Individuals’ Experience and Needs for the Development of a Family Health Information Management System**

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Abstract

Culturally- and linguistically-tailored health communication is needed for vulnerable populations to manage their health and the health of their families. This presents a significant design challenge. The use of collages is an increasingly popular technique with the flexibility to capture the needs and experiences of individuals with various cultural and language preferences. Collage analysis has typically remained qualitative in nature. We introduce a novel, objective, semi-automated approach that enhances collage analysis to elucidate pattern differences not detectable by natural perception. We present a case scenario based on the expressed experience and self-management needs of Hispanic dementia caregiver’s (n=24) through collage analysis. We demonstrate how our innovative approach may reveal cultural differences between language groups that would have otherwise been missed using traditional techniques.

Introduction

Effective health information and communication is critically needed to address health disparities among vulnerable populations. Immigrant populations are among the most vulnerable members of society and suffer disproportionately from significantly higher levels of morbidity and mortality than the general population.(166) Many are challenged by intercultural and linguistic communication barriers, which impede them from understanding important health information.(167,168) Individuals’ culture can influence their understanding and perception of health information. Thus, it is important to identify and examine relevant cultural factors that can influence an individuals’ response to health communication.(169) Understanding the influence of these key cultural factors can help inform the design of information and communication technologies to effectively transmit health-related content.(166,170,171)
Popular research methods such as interviews and focus groups may not be optimal for detecting the nuances of cultural influences. Specifically, immigrants may feel subordinate to researchers and may not feel comfortable or empowered to share deep details of their needs and experience. Consequently, data collected by such means may paint an incomplete picture of the needs and experiences of participants and may be tainted by social desirability bias, in which participants are partial to pleasing the investigator.\(^{172}\)

Collage assembly is a promising approach to explore the nuances of the needs and experiences of diverse users of technology. A collage is a non-linear, intuitive arrangement of image fragments that conveys personal experiences through linguistic and non-linguistic representations. Tacit ideas and conscious and unconscious connections are made explicit by the participants’ selection and arrangement of images.\(^{173}\) The images may be selected freely from any media source or a specific set may be provided to participants to construct a collage. Marginalized voices may overcome various social inhibitors, revealing attitudes, feelings and perceptions, which they themselves might be unaware of or unable to verbalize directly.\(^{10}\) Further, visual presentation of certain sensitive issues can stimulate respondents to include aspects of their reality that they otherwise would find difficult to verbalize. The increased transparency of the participants and their ability to express themselves through collage may lead to a deeper understanding of participants’ needs and experience.\(^{174}\) As such, collage assembly is well suited to ascertain experiences from individuals with diverse cultural and linguistic backgrounds.

Collage analysis is traditionally qualitative and subjective in nature. It focuses on eliciting personal meaning by relying on participants’ own interpretations. Researchers review transcribed interviews and videos of participants explaining the meaning of the collage, while noting non-verbal cues such as speech cadence, intonation and emotion.\(^{175–177}\)
Because collages can exhibit rich information about participants’ experiences, we set out to develop a method of extracting the underlying patterns of participants’ experiences based on their intentional arrangement and grouping of images and textual phrases. We introduce an approach that directly evaluates the collages themselves as a supplement to analyzing participants’ interpretations of their collages. This new semi-automated approach detects pattern differences in collages that most likely would have been missed by manual human assessment. We demonstrate our approach to analyzing collages to generate preliminary insights for designing a Family Health Information Management (FHIMS) for Hispanic dementia caregivers. The purpose of this paper is to describe (i) the innovative method and (ii) summarize the application of the method to characterize collage content and shape features to inform the design of the FHIMS.

**Research Context**

This research is part of a multi-stage project known as NHirP: New York City Hispanic Dementia Caregiver Research Program. The overall goal of NHirP is to help meet Hispanic dementia caregiver needs through participatory design of a FHIMS. Study 1 explored the experience of caregiving using a combination of focus groups and interviews, while Study 2 involved documenting experience through use of collage assembly and reflective interview. Here we report a critical analysis of the collages, highlighting the most important advantages and disadvantages of using collage assembly as a part of a multi-method informatics project.

**Methods**
Data Collection

With approval by the Columbia University Medical Center Institutional Review Board, we obtained 24 photographs of collages (see Figure 4.1) assembled by Hispanic English-speaking (n=10) and Spanish-speaking (n=14) de-identified study participants (mean age = 59.7 ± SD = 7.67, 79.2% female, 58.2% had less than or some high school and 41.7% had a degree beyond high school). All participants received the same linguistically-appropriate instructions to create a collage about their experience managing their health and the health of their family member with dementia. All participants received the same resources (images and phrases) to construct their collages. Study participants created collages independently for 30 minutes and were seated strategically apart to minimize mimicry influence from neighbors. Collages were composed on a large white Post-it board (63.5 x 76.3 cm) with linguistically-appropriate (Spanish or English) phrases and images reflecting dementia concepts elicited from prior focus groups studies. Photographs of collages were taken using an iPhone and adjusted in an image editor (Photoshop) to standardize dimensions and angle.

Data Analysis

We uploaded the photographs to NVivo® 10 software (QSR International) and coded each item (phrase and image) in the collages for content, spatial, and cluster analysis (using Jaccard’s coefficient as the similarity metric). Results were exported to Microsoft Excel® (Redmond, WA, USA), in which data was normalized for detailed count and content comparison. Data was broken into four groups: 1) images used in Spanish-speaking group, 2) images used in English-speaking group,
3) *phrases* in *Spanish*-speaking group, and 4) *phrases* in *English*-speaking group. Each group included metadata of the collage identifier and number of times each item in the collage was used. Data was arranged in descending order according to number of times the item was used and color coded to reflect usage (darker shade = more usage; lighter shade = less usage), which provided for easy visual comparison. After several passes of reviewing each group separately and then all together, we inductively grouped items into categories to identify key themes.

For automatic computational pattern analysis, we used ImageJ, an open source image processing application (http://imagej.nih.gov/ij/), to calculate and measure visual features (*e.g.*, perimeter, diameter, angle) of collages and used the ImagePlot macro to visualize the collection of collage images with respect to select features. The macro positions a mini-image of a collage according to any two specified features (*e.g.*, perimeter and collage) in a 2-D scatter plot (*i.e.*, a 2-D visual representation that uses Cartesian coordinates to display two sets of numerical values) enabling descriptive visual inspection and analysis. For example, one could compare pattern analysis of collage size (*x* axis) with respect to participant language preference (*y* axis). We compared participant demographics (age, education level, gender) and language preference (*Spanish* or *English*) with respect to collage features (*e.g.*, perimeter, diameter, angle).

**Results**

The results to inform the *content* of the FHIMS are shown in Table 4.1. Characteristics of collages (*n*=24) related to content include the most used phrases and images in *Spanish*- and *English*-speaking groups, key themes, frequency of item at a specific location in collage, content similarity between collages, and collages with the most items. Themes were consistent in both language groups. Few images or phrases were consistently located in the same quadrant in collages. Eleven collage pairs shared a Jaccard coefficient (measure of similarity) above 0.5. A value of 0 indicates
there is no similarity, whereas a value of 1 indicates strong similarity. Collages with the highest similarity score were the collages with the most items (phrases and images).

**Table 4.1.** Collage content characteristics and results.

<table>
<thead>
<tr>
<th>Characteristics of Collages (n=24)</th>
<th>Results Related to Content of Collages</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Total items coded = 1,610 items (675 phrases, 935 images)</td>
<td></td>
</tr>
<tr>
<td>• Each phrase (n=54) or image (n=82) was used by at least one participant</td>
<td></td>
</tr>
<tr>
<td><strong>Most Used Phrases</strong> (% used)</td>
<td><strong>Spanish-Speaking Hispanic Participants</strong></td>
</tr>
<tr>
<td>• Información sobre el uso previsto de la medicación y los efectos secundarios (Information on medication intended use and side effects) (80%)</td>
<td>• Schedule and view appointments (80%)</td>
</tr>
<tr>
<td>• Consejos de meditación y relajación (Meditation and relaxation tips) (80%)</td>
<td>• Calendar for family member’s appointments (80%)</td>
</tr>
<tr>
<td>• Enviar mensaje a la farmacia local (Message local pharmacy) (70%)</td>
<td>• Appointment reminders sent by email or text messaging (80%)</td>
</tr>
<tr>
<td>• Recordatorios de pago de facturas médicas enviadas por correo electrónico o mensajes de texto (Appointment reminders sent by email or text messaging) (70%)</td>
<td>• Message local pharmacy (80%)</td>
</tr>
</tbody>
</table>
### Most Used Images

<table>
<thead>
<tr>
<th>Image 1</th>
<th>Image 2</th>
<th>Image 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image 1" /></td>
<td><img src="image2.png" alt="Image 2" /></td>
<td><img src="image3.png" alt="Image 3" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>% used</th>
<th>% used</th>
<th>% used</th>
</tr>
</thead>
<tbody>
<tr>
<td>70%</td>
<td>70%</td>
<td>80%</td>
</tr>
</tbody>
</table>

### Themes

Confusion, Self-Care, Medication Information, Scheduling Reminders, Communication

### Frequency of Item at a Specific Location in Collage

7 of the 20 times this image was used, it was located in the **top left quadrant** of collages.

Other items appeared in random locations throughout the collages.

### Cluster Analysis

<table>
<thead>
<tr>
<th>Collage</th>
<th>Jaccard Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish 13 - English 01</td>
<td>0.702128</td>
</tr>
<tr>
<td>Spanish 09 - English 06</td>
<td>0.642857</td>
</tr>
<tr>
<td>Spanish 13 - English 06</td>
<td>0.629371</td>
</tr>
<tr>
<td>Spanish 13 - English 07</td>
<td>0.628571</td>
</tr>
<tr>
<td>English 06 - English 01</td>
<td>0.618705</td>
</tr>
<tr>
<td>English 07 - English 01</td>
<td>0.617647</td>
</tr>
<tr>
<td>Spanish 13 - Spanish 09</td>
<td>0.597122</td>
</tr>
<tr>
<td>English 07 - English 06</td>
<td>0.589552</td>
</tr>
<tr>
<td>Spanish 09 - English 01</td>
<td>0.585185</td>
</tr>
<tr>
<td>Spanish 05 - English 01</td>
<td>0.531746</td>
</tr>
</tbody>
</table>
The results to inform the design of the FHIMS are shown in Table 4.2. Collage shape features that were measured include perimeter, diameter, and angle. Results of feature distribution (x axis) by participants’ language preference (y axis) are displayed in a graphical plot. Collages assembled by Spanish-speaking Hispanic participants lie above the horizontal line, while collages assembled by English-speaking Hispanic participants lie below the horizontal line. In all three graphs, the collages from the Spanish-speaking cohort vary more and are less uniform compared to collages from the English-speaking cohort. We compared participants’ sex, age, and education level to collage shape features, but observed no notable pattern.

<table>
<thead>
<tr>
<th>Top 5 Collages with Most Items</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Spanish</td>
<td>128 items used</td>
<td></td>
</tr>
<tr>
<td>2. English</td>
<td>120 items used</td>
<td></td>
</tr>
<tr>
<td>3. English</td>
<td>113 items used</td>
<td></td>
</tr>
<tr>
<td>4. English</td>
<td>108 items used</td>
<td></td>
</tr>
<tr>
<td>5. Spanish</td>
<td>101 items used</td>
<td></td>
</tr>
</tbody>
</table>

out of 136 possible items (phrases and images)
Table 4.2 Collage shape features and results of feature distribution by language preference.

<table>
<thead>
<tr>
<th>Measured Collage Shape Features</th>
<th>Results of Feature Distribution by Language Preference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perimeter</strong></td>
<td></td>
</tr>
<tr>
<td>Continuous line forming the outermost boundary of collage</td>
<td></td>
</tr>
</tbody>
</table>

The **Y axis** represent the Spanish- and English-speaking participants. The **X axis** represents the **length of the perimeter** around each participant’s collage. The red line demarcates the Spanish-speakers from the English-Speakers. The rectangles are images of the participants’ collages.

The collages **above the red line** (Spanish-speaking) have longer, **more varied** perimeters than the collages below the red line (English-speaking).
**Diameter**

Longest transverse distance passing from side to side through the center of collage

The **Y axis** represent the Spanish- and English-speaking **participants**. The **X axis** represents the **diameter** of each participant’s collage. The red line demarcates the Spanish-speakers from the English-Speakers. The rectangles are images of the participants’ collages.

The collages **above the red line** (Spanish-speaking) have **longer, more varied diameters** than the collages below the red line (English-speaking).

---

**Angle**

Measure (in degrees) between collage diameter intersecting the x axis

The **Y axis** represent the Spanish- and English-speaking **participants**. The **X axis** represents the **angle** of each participant’s collage. The red line demarcates the Spanish-speakers from the English-Speakers. The rectangles are images of the participants’ collages.

The collages’ angles **above the red line** (Spanish-speaking) **have more variation** than the collages below the red line (English-speaking).
**Discussion**

We have described a semi-automated approach for image-based analysis of collages. This approach is suited for studying cohorts with diverse cultural orientation and language preferences. Understanding cultural orientation, the “totality of socially transmitted pattern[s] of thoughts, values, meanings, and beliefs”(179), is an essential component to health communication, as it impacts an individual’s worldview and decision-making process.(179) Our case study explored needs and experiences of ethnically similar participants with different language preferences indicating possible diverging cultural orientations. Results will be used to inform the design of the FHIMS for Hispanic dementia caregivers.

*Insights to Inform FHIMS Content*

Overall, there was no remarkable difference in content needs by language preference. Collages generally did not cluster together. In other words, Hispanic dementia caregivers share similar needs but their depiction of their experiences are unique. Items related to self-care (e.g., image of fruits and veggies, phrase related to meditations tips) were used slightly more often in the Spanish-speaking cohort, while items related to managing information (e.g., image of safety box, phrases related to a calendar and appointment reminders) emerged slightly more often in the English-speaking cohort. There was no one image of confusion (i.e., images picturing salient question marks) that ranked among the most frequently used images, but collectively, the various confusion images constituted one of the top themes. Supporting the confusion theme is the finding of the most frequent item at a specific location: the picture of the older gentleman with a crown of question marks often was placed in the most important, attention-grabbing quadrant in collages.
Insights to Inform the FHIMS Design

Through descriptive visual-analysis of collage feature distribution, we were able to detect an unexpected difference in collage design based on participants’ language preference (i.e., Spanish or English). Since all the participants identified as Hispanic adults, we did not anticipate their language preference would result in noticeable differences in how they constructed their collages. We surmise that Spanish language preference connotes a lower acculturation level to the United States and may serve as a measure of native cultural orientation. Literature describes Hispanic culture as free-flowing and flexible with schedules. Though a generalization, this may give insight why collages made by participants with a Spanish language preference—many of which flowed out of the designated work-space—are less uniform. Participants whose language preference was English created more uniform collages that stayed within the boundaries of the workspace.

Spanish-speakers made larger, non-uniform collages but did not use more items than English-speakers. Since the items that participants placed on the collages included phrases in the participants’ chosen language, we thought the larger size of Spanish collages might be caused by longer wording in Spanish phrases. However, participants (particularly the Spanish-speaking cohort) often overlapped and layered items in their collages, while leaving empty space in other parts of their collages. Thus, the size of collages was likely not affected by longer Spanish phrases.

Design and graphical characteristics such as use of images and colors have been shown to impact audience trust of technology. Trust is generally accepted to be an important precondition for technology adoption. Thus understanding and tailoring design to cultural preferences may be key for engagement and usage. The larger, more creative designs by the Spanish-speaking cohort may suggest that to engage them in FHIMS or other tool use, designs should be
less formal, boxy, and “bureaucratic.” Instead, perhaps designs should be more stylistic and leave room for “white space,” which has been linked to increased usability.(186) Future collage studies could investigate use of color, as it conveys different information in different cultures.(187) Though it would have been easy to algorithmically measure color, brightness and other aesthetic features of collages, we refrained from doing so because no images were offered to participants to put in their collages for mere stylistic effect; most images represented functional concepts literally (e.g., picture of a pill box).

Benefits of this Analytic Approach

We suspect we were unable to detect consistent patterns between collages by manual review because the human brain is imprecise and limited in its ability to detect slight differences between images, a phenomenon known as “change blindness.”(188) By leveraging computational methods we were able to enhance our ability to detect patterns in the collages and were able to analyze many collages quickly, more precisely, and with reproducible results.

Another advantage of this method is that it allows the researcher performing the analysis to not be proficient in the participants’ language (e.g., Spanish). Language comprehension is only needed to code phrases in NVivo software; all other analysis can be performed without proficiency in participants’ language.

In informatics, computational methods have been wielded to process scores of data (e.g., electronic medical record data (189) and drug-gene networks (190)) to augment human understanding and reasoning. Likewise, this semi-automated approach leverages computers to do what they excel at—process data—and saves the task that humans do best—relating processed data to human experience—to humans.(191)
**Future Studies**

Future studies could expand cohorts from different cultural backgrounds to investigate if cultural and linguistic differences are reflected in collage characteristics. This method can be reproduced and extended through use of any of the multiple image-analysis software packages and libraries available in R, Matlab and openCV, to name a few, that offer more measurement options. For example, we initially conducted our analysis using an R spatial-analysis package and arrived at similar results. We used and report results using ImageJ software because readers may find it easier to use and may find its visually-appealing graphs more engaging. Further, as previously noted, this method could easily be adapted to investigate further aesthetic features such as colors and shapes that may give further insight into cultural underpinnings. (177)

**Limitations**

A limitation of our method is that it does not reflect personal meaning of collages. However, this approach is not meant to take the place of traditional methods, but merely to deepen and expand them. Results using this method may be triangulated with interview data to enrich and improve accuracy of interpretations. Regarding limitations to the study, though we did not detect any demographic variables other than language preference affecting collage design, our sample was not large enough to make any strong inferences about other demographic variables. Findings may not be generalizable to other Hispanic cohorts as participants are from a single region in New York and many are of Dominican Republic descent.
Conclusion

We demonstrate a novel approach to analyzing collages that is systematic and repeatable with similar results. A semi-automated approach aids in rich, quick characterizations of collages during the early stages of a research program designed to investigate diverse individuals’ needs and experiences. This method facilitates detection of patterns in collages that are hard to detect by the human eye. Moreover, this method shows promise to support easy detection in differences of information-organization arrangements between different groups, which may in turn inform the design of information tools. As our study sheds new light on possible cultural differences within the same ethnic group based on language-preference, we suspect this method may help detect differences in collages among other cohorts. We hope the method described here may aid future studies in detecting cultural or demographic differences, in order to tailor communication tools for those most vulnerable to health disparities.

Acknowledgements

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How Lessons Learned from Study 2 Informed Study 4

Our work with individuals having LHL and LEP in Study 2 opened our eyes to assessing if there might be differences in experience and information needs between individuals within the same ethnic group by language preference in Study 4. Also, we used the method to analyze the collage images in Study 2 to also analyze graphical charts in Study 4.
Aim 3: Review literature on how visualizations can improve experience and communication of complicated health information

In Study 3, we aimed to interrogate the literature for an informatics solution to improve the experience of communicating complicated health information, specifically, advance directives. This manuscript was published in the Journal of Gerontological Nursing in 2016.(192)

ENGAGING PATIENTS WITH ADVANCE DIRECTIVES USING AN INFORMATION VISUALIZATION APPROACH

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ABSTRACT

Despite the benefits of advance directives (AD) to both patients and care providers, they are often not completed due to lack of patient awareness. The purpose of this paper is to advocate for creation and use of an innovative information visualization (infovisual) as a health communication tool aimed at improving AD dissemination and engagement. The infovisual would promote AD awareness by engaging patients to learn about their options and inspire contemplation and conversation regarding patients’ end-of-life (EOL) journey. An infovisual may be able to communicate insights that are often communicated in words, but are much more powerfully communicated by example. Furthermore, an infovisual could facilitate vivid understanding of options and inspire the beginning of often-difficult conversations between care providers, patients and loved ones. It may also save clinicians’ time, as care providers may
be able to spend less time explaining details of EOL care options. Use of an infovisual could assist in ensuring a well-planned EOL.

**INTRODUCTION**

An advance directive (AD) is beneficial to patients and care providers in guiding end-of-life (EOL) care; however, ADs are often not completed, largely due to patients’ lack of awareness.\(^{(193)}\) A recent survey found that around 75% of participants did not have an AD, with the top reason for not having one being “I don’t know what advance directives are”.\(^{(193)}\) This paper summarizes reasons for this lack of awareness and explores the literature for pivotal ways information visualizations can improve understanding, dissemination, and engagement of ADs.

**WHY ADVANCE DIRECTIVES ARE DESIRABLE**

Completion of an AD has been associated with greater use of palliative care, decreased stress during EOL, shortened length of stay,\(^{(194)}\) improved communication between providers and healthcare surrogates, and a significant decrease in costs.\(^{(195)}\) Failure to discuss, understand and complete an AD can result in confusion, distress, and guilt in family members, as well as increased patient suffering and unwanted procedures \(^{(196)}\) that proffer questionable value.\(^{(197)}\) Moreover, the absence of an AD often causes clinicians to face moral distress and conflict with their own medical judgment and with family members.\(^{(198)}\) Furthermore, relying on family members or clinicians to guess patients’ EOL preferences has proven unreliable. Studies reveal that neither families nor clinicians accurately predict patients’ EOL preferences.\(^{(199,200)}\)

**BARRIERS TO ADVANCE DIRECTIVES AWARENESS**
Healthcare providers operate under great pressure in a system that does not provide incentives or adequate training to discuss EOL options with patients and their families. Discussing EOL care is generally difficult for physicians. (201) Most are reluctant to discuss ADs because they lack the necessary training to do so, think that ADs are not urgent for those not terminally ill, fear that it will induce anxiety, or do not get paid for, nor have the time to spend, discussing the topic. (202) Patients often wait for their healthcare providers to bring up the subject, while many healthcare providers assume patients will bring up the subject. (203)

**The advance directives form**

Patients must be able to read and understand AD forms before signing them. However, AD documents often fail to provide detailed, practical guidance, and are therefore misinterpreted. (204) Moreover, research indicates that ADs are usually written in language above the average patient reading level. (205) The increased ethnic and cultural diversity of the population and varying levels of health literacy present additional barriers to the understanding of ADs by patients and their surrogates. Moreover, there are strong indications that many people increasingly resist reading documents that are of medium length or longer, (206) which is the primary format in which ADs are presented to patients. Despite clinician efforts to explain AD to patients, researchers discovered that the majority of patients complete ADs without understanding them. (207) This is troubling for a number of reasons, in part because patients rated clear communication of EOL options as one of the highest concerns of EOL care. (208) Furthermore, some EOL experts question whether patients would consent to certain EOL treatment if they truly understood what the words in ADs actually represented. As one physician puts it: certain forms of EOL care are close to torturing a patient. (209)
QUESTION

While there are a number of issues plaguing AD procurement and understanding, here we focus on the vehicle in which AD information is primarily organized, presented and disseminated: words. Can healthcare providers effectively convey the grave details of their EOL treatment to patients using words alone? Evidence would suggest otherwise.(203) In order to help patients and families discern pertinent EOL information, entry points into the text must be provided so that they do not unknowingly consent to spend the last moments of life undergoing interventions that even a vast majority of clinicians would electively forgo.(210) Perhaps a more complete and comprehensible image of EOL options can be provided using an innovative infovisual to enhance interest, understanding, recall, contemplation and sharing.

PROPOSITIONS FOR HOW INFOVISUALS CAN FACILITATE LEARNING OF ADVANCE DIRECTIVES

In the following paragraphs, the authors draw on evidence across a range of academic fields and real-world examples to illustrate how infovisuals can improve AD awareness, dissemination, comprehension and engagement.

Infovisuals enhance insight, comprehension and learning

Infovisuals have been defined as the use of computers to interactively amplify cognition, using visual representation.(27) The primary goal of an infovisual is to provide insight. Insight as an experience that is complex, deep, qualitative, unexpected, and relevant.(27) Infovisuals for ADs should aim to impart this type of insight to patients and their families or other healthcare surrogates in order to facilitate true informed EOL planning.
While there are various categories and types of infovisuals, most, if not all, infovisuals aim to provide insight through visually-enabled reasoning of phenomena that are not obvious or observable. An applicable infovisual for an AD could arrange, organize and present various informative elements (e.g., text, pictures, images, videos) to effectively elucidate EOL interventions. An example of such an infovisual may be inferred by the interactive infovisual about President John F. Kennedy (found here: http://nvcdn.nbcnews.com/_util/jfk50/#).

Figure 5.1 is a screenshot of the interactive infovisual that houses short video clips and network diagrams displaying connections between interviewees.

**Figure 5.1** Example of interactive infovisual

A mixed-media infovisual such as this would furnish many potential tools to aid comprehension and serve as an enhanced communication application. Studies have found that the addition of visualization to instructions improves patient comprehension, recall, and interest and causes deeper and more accurate understanding of medical information in the elderly and in individuals with low health literacy. This effect tends to be larger among patients who are female,
nonwhite, or have no more than a high school education. This cohort is also the target population for AD education and procurement, as they are the least likely to have completed an AD.(193)

ADs have been found to be difficult to comprehend for those with low health literacy.(212) Addressing the literacy gap of ADs is of ethical interest, as studies indicate that due to the misinterpretation and incomprehension of ADs, patients are naively consenting to EOL treatment that may be different from their true wishes and values.(207) Visual representations of EOL options can ameliorate this problem by serving as a visual universal language. Images of EOL care appeal to the more-objective faculty of vision rather than to incomplete or biased interpretations of EOL care described in texts. For example, a video/visual capture of what EOL treatment is like may be more informative than a textual description particularly to those with low health literacy or limited English proficiency. Infovisuals, in effect, support more equitable medical care. Visualizations increase accessibility of information in high risk populations, while fostering the interest of patients at all levels of reading ability.

**Infovisuals communicate information quickly and effectively**

The human brain processes images faster than it does written text.(213) When it comes to quick, clear communication aimed at a heterogeneous audience, the airline industry is very experienced. Airlines use visuals, instead of textual explanations, on their emergency information pamphlets because visuals facilitate rapid communication and comprehension of information with little cognitive effort compared with texts.(214) Lessons from the airline industry may be applicable to support EOL decision making. Many individuals find themselves having to make EOL decisions in the heat of the moment. They stress a need for better tools to access and
understand care options. An infovisual could quickly and effectively convey pertinent information to patients and family members, while helping time constrained clinicians who face numerous challenges in communicating EOL options.

**Infovisuals help dissemination, communication and collaboration**

Embedding AD information in an infovisual has great potential to increase awareness and knowledge. Information contextualized and encapsulated in an infovisual makes it appealing, easily disseminated and accessible to anyone with an Internet connection. It can serve as a shared interface and point of reference about EOL options, promoting clear informed communication between patients, families and healthcare providers. Researchers have demonstrated that shared interactive visualizations are effective in communicating and developing insights, supporting awareness, and establishing common ground between collaborators.

If knowledge of ADs increases, it may spur individuals to broach the subject with their healthcare providers, or at least be knowledgeable about AD if healthcare providers broach the subject with them. Furthermore, because an infovisual typically includes the entire context needed within the visualization, an infovisual could help focus and circumscribe patients’ attention on, and interaction with, vetted information provided in the visualization. This could save time and facilitate improved communication, as patients are known to spend time browsing online for medical information, without knowing if the sources they find are trustworthy.

Every individual has various experiences, ideas and wishes for their EOL that are hard to predict. These unique, diverse preferences cannot be well accommodated by static, fixed text describing EOL options. However, a mixed media, interactive infovisual can accommodate such preferences; it is flexible, yielding, and versatile, offering multiple facets and nuances of EOL.
information that accommodate the subtlety of individual understanding and preferences. It is this ambiguity and open-endedness, which offers the greatest possibilities for conveying information and providing an engaging experience for critical AD decision making.

An AD infovisual could facilitate collaborative knowledge creation by serving as an anchor on which patients and family members could gather (asynchronously or synchronously) to discuss each person’s understanding of EOL options. An AD infovisual could facilitate communication between the clinician (the expert in EOL care options) and the patient (the expert in what constitutes a “good death”), to collaboratively devise a plan for the patient’s finale. This may be particularly important in situations in which the clinician and patient differ in cultural background or other aspects of common ground.

Infovisuals are made to be shared. Infovisuals are usually networked, often public, and by their digital nature can be quickly, economically and automatically distributed across a network. While AD text can also be made digital and shared over the Internet, AD text lacks the engaging aesthetic and artistic appeal that infovisuals wield.

**How aesthetics of infovisuals promote interest and engagement**

Talking about EOL wishes with loved ones and healthcare providers has been identified as key to ensuring EOL will be followed. However, as discussed previously, people often find broaching the topic awkward and challenging. The design and aesthetics of an infovisual may provide an entry for people to discuss the difficult topic.
The aesthetics of an AD infovisual could induce emotional responses to pique interest, curiosity, and engagement. For example, Burmester, Mast, Tille and Weber (217) found that good aesthetic design was the major factor inspiring curiosity and interest in their study’s visualizations. Aesthetics persuades the user to unconsciously choose to become involved.(218) Aesthetics can reduce perceptions of response effort and increase arousal and interest.(219) Proper construction of aesthetic elements can entice the senses to arouse intellect, intuition and personal experience, in concert with new information, to provide an experience that is deep and engaging.(220)

An AD infovisual with good aesthetic design could foster a desire to return to view, remember, or share the visual and possibly spark a conversation about EOL care. This would be desirable for ADs, as studies show EOL preferences can change over time.(221) Good aesthetic design may positively affect user experience, memory and interest in AD infovisual. AD documents are currently pushed onto patients and their families; an aesthetically well-designed AD infovisual has the potential to pull patients and families in.

**HOW INFOVISUALS COULD HELP NURSES**

The medical community is currently focused on precision medicine — “prevention and treatment strategies that take individual variability into account.”(222) Though this initiative has primarily focused on caring for the unique genetic and physical nature of an individual, one might argue that precision medicine as it pertains to EOL treatment should take into account the unique psychology and emotional nature of an individual. While researchers may eventually find that these elements are closely related,(223) healthcare providers must act now to address what
patients have expressed – that along with more information, the largest unmet needs in EOL care are emotional, psychological and spiritual.(224)

Nurses play a crucial role in providing support that addresses these specific needs, but they are challenged by time and communication constraints.(225) Perhaps an AD infovisual accessible online could help free-up time and improve a nurse’s ability to support patient-valued needs. Communicating EOL options to patients or family members who have various emotional and psychological needs may be improved through use of adaptable, immersive visuals,(226) which better speak to the emotional psychology of an individual than words alone.(227)

In addition to the roles of supporter and advocate, numerous studies report that nurses also play a central role in EOL decision making as information broker to physicians, patients and family members.(224) While providing physicians with updates on patient clinical, emotional, psychological status, and expressed wishes, nurses, in tandem, educate, update, clarify, and interpret medical information to patients and family members.(228) Nurses mediate and serve as an important source of information to aid physicians and family members in EOL decision making.(229) A time-constrained information broker may benefit from an AD infovisual to enhance his or her ability to disseminate and facilitate understanding of EOL options to patients and family members.

**CONCLUSION**

Better communication tools are needed to promote reflective insight into EOL care options and to increase awareness of ADs. Patients and families lack access to information on what to expect, what to look for, and what their options and rights are at the EOL.(230) They know the
principles, but they need ready access to pertinent information presented in a way that facilitates a deeper understanding of the specifics.

Leveraging infovisuals to visually articulate and support textual ADs could improve understanding, help broach often-difficult conversations, increase dissemination, and better engage patients with EOL care options. Ultimately, AD infovisuals could help true patient preferences be respected, and in doing so help patients live the end of their life on their own terms.

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**HOW LESSONS LEARNED FROM STUDY 3 INFORMED STUDY 4**

In Study 3, we learned that visualizations can help increase interest, increase comprehension, and support faster communication of complicated health information even to individuals having LHL and LEP. Further, visualizations may even help broach difficult topics with family members. Thus, we leveraged these aspects of visualizations to communicate complicated sensitive information to individuals having LHL and LEP in Study 4.
Chapter 6

Aims 4 & 5: Background and Significance

Study 4

See What I Mean:
Experiential Visual Genetic Report for Vulnerable Individuals

Problem

Individuals diagnosed with a genetic predisposition to a disease condition must understand relevant health information in order to minimize symptoms and manage their health; however, genetic health information can be challenging to comprehend for individuals with low health literacy (LHL) and limited English proficiency (LEP). LHL has been defined as the lack of personal, cognitive, and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health.”(231) In this paper, “LHL” will also represent low numeracy. Low numeracy is having limited “ability to access, use, interpret, and communicate mathematical information and ideas, to engage in and manage mathematical demands of a range of situations in adult life.”(232) LEP individuals are those who are not able to speak, read, write, or understand the English language at a level that permits them to interact effectively with health care providers.(233) Populations that have LHL and LEP are also those who tend to be most in need of disease prevention and health maintenance efforts because of their disparities in morbidity and mortality.(42) Due to their disproportionate morbidity and mortality from common chronic diseases (234), Latinos are an important audience for developing genetic information related to chronic disease.
Latinos and Familial Hypercholesterolemia

A common cause of chronic disease in the Latino population is hypercholesterolemia, which may originate from a highly prevalent genetic disorder known as familial hypercholesterolemia (FH). FH causes markedly increased plasma cholesterol levels from birth onwards. Left untreated, it increases the overall risk of cardiovascular disease eightfold.\(^{(235)}\) Although FH can be easily diagnosed and treated, FH is underdiagnosed (only around 20% of at-risk people have been diagnosed) and undertreated worldwide.\(^{(236)}\) Because of its long asymptomatic prodrome and its potentially devastating consequences and genetic origin, it is worthwhile to test for the condition. Such testing may allow the condition’s harmful effects to be prevented or minimized. Although FH is a common genetic disorder that substantially shortens life expectancy, public awareness is low compared with other inherited disorders, including conditions such as breast cancer and colon cancer.\(^{(237)}\) At-risk individuals can be identified through cascade screening the relatives of diagnosed people. Cascade screening is a mechanism for identifying people at risk for a genetic condition by a process of systematic family tracing.\(^{(238)}\) Cascade screening strategies can depend on diagnosed people informing relatives of their increased risk and advising them to volunteer for testing.\(^{(239)}\) However, poor health literacy both impedes the ability and reduces the likelihood of diagnosed people to approach and adequately explain the risk of familial hypercholesterolemia to relatives. Further, relatives may misunderstand the significance of their messages or not see them as personally relevant.\(^{(240)}\) Thus, solutions are needed for LHL individuals to convey disease significance in an engaging format to reduce the burden of understanding and explaining relatively complex information.
Despite being the largest growing minority group (241), little attention has been directed to developing genetic information for LHL and LEP Latinos. Thompson et al aimed to develop LHL genetic reports for African-Americans using participatory design to enhance and tailor existing genetic information packets. They and other literature (243–246) recommend that when developing genetic information materials for LHL, concepts must be simplified to the most basic level needed to prevent and manage disease. Only essential information should be communicated. Further, cultural and spiritual beliefs are a primary source of support and coping for Latinos (247) and influence perception of information. (248) Considerable cross-cultural work suggests that collectivist (e.g., Latino culture) and individualist cultures are associated with different modes of cognitive processing involving holistic and analytic thinking styles. (187,249–252) As such, these must also be considered when tailoring genetic reports for Latinos by including their feedback. Available evidence suggests that genetic information, regardless of how it is communicated, is beyond the conceptual knowledge, print literacy, and oral literacy skills of many individuals. (253) The limited existing literature in this area suggests that health literacy will affect the understanding of and engagement with genomic information in ways that may diminish its potential to motivate health behavior change. Thus, there is a need to develop genetic reports that are understandable and engaging to vulnerable groups.

**Problems of Current Genetic Test Reports for Vulnerable Individuals and Preliminary Introduction to the Theoretical Framework**

Genetic risk information is typically communicated through text-heavy reports, numbers, and graphics that require use of the brain’s “analytic system” (AS) to process. The AS is relatively slow, requires conscious effort, and is cognitively taxing. This is particularly true for individuals with LHL because of the challenges they face processing text. Individuals with LHL process
written text by reading word for word, focusing on each word and accessory details rather than on key concepts; they let their eyes wander about the page without finding the key points, and they are unable to scan text, missing many key information points.\(^{(35,254)}\)

To address LHL, healthcare professionals often simplify the text of health materials. However, easy-to-read information alone only marginally improves low health literacy patients’ understanding.\(^{(45,46)}\)

Further, even if numbers are presented in such a way that innumerate individuals can understand the quantity or proportion, Peters et al. demonstrate that it may not be of much value. Whereas numerate individuals are more likely to use the AS to pay attention to numbers in making health care decisions, innumerate individuals rely less on numbers and more on emotion and trust or distrust of the clinician or medical system.\(^{(23)}\)

Innumerate individuals employ what theorists call the “experiential system” to process disease risk. Theories suggest that brains, in general, favor a parallel system to the AS to process risk information: the “**experiential system**” (ES). The ES is a primal survival mechanism, and it continues to be the prevailing, natural way people react to risk.\(^{(4)}\)

The ES is intuitive, fast, mostly automatic and unconscious. It uses emotions to process risk information. Few studies have focused on developing methods to communicate risk that employ the favored ES.

### Research Efforts to Communicate Risk Information and Theories of Emotion & Decision Making

Research in risk communication has largely focused on strategies that communicate probability using tables and graphics such as bar charts and icon arrays.\(^{(255–263)}\)

The improved visual salience of tables and pictographs may be helpful in promoting understanding of probability and numbers among those with poor language and numerical skills. However, even these strategies may require the brain’s AS instead of the ES to understand risk. The AS uses algorithms and
rules, such as probability and formal logic, to process risk information. According to Kahneman and Tversky, “people do not follow the principles of probability theory in judging the likelihood of uncertain events... as laws of chance are neither intuitively apparent, nor easy to apply.”(264)

The problem is that the majority of risk information is presented in formats that aim to convey probabilities, which people generally do not rely on to make decisions, particularly individuals with low numeracy. Kahneman and Tversky affirm that people replace the laws of chance by heuristics. More specifically, Slovic et al.(265) assert that people favor the affective heuristic (a mental shortcut in which emotional response, or "affect" in psychological terms, plays a lead role in making decisions). This is consistent with several recent theories of decision-making formulated by Loewenstein, Damasio and others.(266,267) While traditional guidelines to communicate risk warn to, “Be aware that factual risk information is often distorted by emotions”(268), Peters, Lipkus and Diefenbach instead argue that affect serves four important functions in the context of health communications: affect is information, a spotlight, a motivator, and a common currency for comparing disparate outcomes.(269) Barrett’s Theory of Constructed Emotions asserts that “emotions are meaning” and are “prescriptions for behavior.”(270,271) Moreover, Ferrer et al. provide a useful theoretical foundation for understanding how emotions influence health-related decisions by extending the Appraisal-Tendency Framework to health care decision making.(272) Taken together, contrary to the popular view that emotions generally contaminate rational decision-making, converging evidence indicates that they actually can improve decisions.(265–267,273) Heath and Heath urge to: “Focus on emotions. Knowing something isn’t enough to cause change. Make people feel something.”(274)

The Gap (or Opportunity) and Challenge
Making people feel their risk in test reports is a relatively unexplored area and is no easy task. The cognitive scientist and design expert, Don Norman, champions the value and power of emotional design; however, “how to do it is the weakest part” because “it’s still an art and intuition.”(275) Designing products that will deliver in the person the appropriate emotion is challenging. However, as numerous researchers have stressed, it is imperative to attempt if we desire to help individuals with poor literacy, numeracy, and language ability to adequately process risk information.

**How Visualizations Can Help**

Cognitive science and neuroscience show that people remember and respond most effectively to what they see and experience.(276) Visualizations excel at furnishing “experiences.” Compared to other mediums such as text and numbers, visuals, especially videos, have been shown to quickly immerse people into empathetic states where they feel experiences that are not their own. Thus, it is the optimal medium to deliver desired affective-information or emotions. Moreover, visualizations are the preferred format for learning for people with LHL.(42) When designed appropriately, they can help reduce the cognitive burden to process information while also promoting engagement with complicated health information.(192,248,277,278) Due to the continuous and rapid development of computer graphics technology, computer-based communication channels can more easily be enriched with various visualization formats. Visuals (e.g., graphics, photos, emoticons, videos) are now relatively easy to create, edit and share. As detailed in the Chapter 2, different visual formats can strongly affect behavior and interpretation and judgment of information.(279–282) Thus, in order to avoid misinterpretation that could lead to serious negative consequences (283), systematic user-based research is needed to evaluate the effectiveness and impact of such media to convey information as intended.
How Vicarious Learning and Emotions Can Help

As mentioned, approaches to communicate risk information have mostly focused on making what is uncertain more certain by conveying numbers and probability. The assumption is that if people cognitively understand, they will be motivated to change. But studies investigating the effect of receiving genetic risk information through these approaches have shown little impact on motivation to adopt preventative behavior.(284) Findings in neuroscience and psychology may shed light on why: The human brain does not value all information equally.(264) Humans evolved to assign high value to affective-information, especially fear.(270,285–287) The brain must feel at risk, not just know how much it is at risk, in order to feel motivated to take preventative action.(288)

A promising approach to help the brain feel at risk and understand what is at risk, without having to personally experience potential harm is through social learning (289) and vicarious learning.(290) That is, by observing the emotions and consequences of others' actions, humans may acquire knowledge of the emotional significance of situations.(289) According to Bandura: “People gain understanding of causal relationships and expand their knowledge by learning from the wealth of information derived from vicarious experiences. People generate solutions to problems, evaluate their likely outcomes, and pick suitable options without having to go through a laborious behavioral search.”(290) Even “the behavior of observers can be substantially modified as a function of witnessing other people’s behavior and its consequences for them.”(291)

Vicarious learning can occur not only by direct observation, but also by viewing visualizations such as videos and pictures depicting painful experiences. For example, Olsson et al (292) demonstrated that an individual can acquire fear of stimuli by watching a video of others’ faces showing distress due to the stimuli. In fact, the researchers show that fear acquired indirectly
through social observation, with no personal experience of the aversive event, engages similar neural mechanisms as fear conditioning based on personal experience. Their work suggests that indirectly attained fears may be as powerful as fears originating from direct experiences.

Moreover, their work shows that an individual can experience others’ emotions simply by observing their facial expressions. According to Preston and Hofelich (293), this mirroring of experience through facial expressions is spontaneously and effortlessly processed at a semantic level. The decoding of others’ affect is automatic and can happen even without motivation.

This suggests we may be able to help individuals easily and quickly feel and understand genetic risk by showing them visuals depicting individuals experiencing the harmful impact of a genetic risk condition.

The Challenge of Measuring Experience of LHL Latinos and How Assessing Emotions Can Help

Measuring experience of individuals with LHL and LEP can be challenging. Certain artifacts threaten the validity of self-report measures such as sociological power differences, language nuances, and cultural customs.(32) For example, researchers have found high bias in responses to personally relevant items in nations that are high on family collectivism, such as in Latin cultures.(295) Compounding this issue is that surveys affected by response bias still often have high reliability, which can lure researchers into a false sense of security about the conclusions they draw.(296) Nevertheless, traditional subjective tools, like surveys and interviews, can provide useful insights into individuals’ conscious state of mind and their response to stimuli. Thus, a mixed methods approach may help provide a fuller understanding of LHL and LEP participants’ experience with health information. Evidence from neuroscience suggests that we can route
around self-report bias by assessing emotions.(297) Emotions help elucidate underlying assumptions and perceptions. For example, if the individual reports feeling neutral or good during the entire time while consuming a report, it would suggest she did not “experience” the risk information because “risk information is never received dispassionately. Risks create feelings.”(298)

In summary, lack of understanding of FH genetic test result information may substantially limit the benefits of communicating results, and may adversely influence individuals’ interest and understanding of the results. Consequently, individuals may not seek nor receive treatment and their at-risk family members may not get screened nor receive treatment, and as a result may suffer preventable poor health outcomes, even early death. However, little guidance is available on how best to present genetic test results in an understandable format for Latino individuals with low health literacy and low English proficiency.

**Objective**

The goal of our study was to develop a culturally-relevant, “experiential” genetic report of FH for LHL and LEP Latinos community members to more easily process health information. We had two aims: one focused on development of an experiential-report (Chapter 7, Aim 4), and the second, examining responses to the experiential-report compared to a “standard-report” (real-world examples of genetic test reports), using qualitative and quantitative measures (Chapter 9, Aim 5).

In Chapter 7 (Aim 4), we describe the development of the experiential-report. We leveraged our previous research (Chapter 2-5) and lessons learned from collaborating with Latino community
members 1) to develop engaging infographics to support comprehension of health information (278) and 2) to develop an information management system. (Chapter 4, Study 2)

In Chapter 9 (Aim 5), we report the evaluation of the experiential-report and the standard-report. We examined participants’ perceptions and emotional reactions to visualizations (e.g., video and graphic illustrations) designed to convey risk information about the genetic variant for FH (inherited high cholesterol).

The study builds upon the research infrastructure already in place for the Washington Heights/Inwood Informatics Infrastructure for Community-Centered Comparative Effectiveness Research (WICER)(299), such that those participants will serve as the primary sampling frame for the proposed research.

**Research Questions for Aim 4** (Develop an experiential-report and collate standard-report):

1. What **format and features** should we use to design an “experiential” genetic report for LHL and LEP Latinos?
2. What **content** should we include in the reports?

**Research Questions for Aim 5** (Evaluate the experiential-report compared to the standard-report through data triangulations):

1. How well do participants understand the standard-report vs. experiential-report?
2. What are the **emotional responses** to the standard-report vs. experiential-report?
3. How **motivated** do participants feel after viewing the standard-report vs. experiential-report?
Chapter 7

Aim 4: Develop an experiential-report and collate standard-report

Development of the Experiential-Report

Aim 4 of this dissertation research was to provide the materials for Aim 5. The goals were to 1) develop and preliminary evaluate an experiential genetic test report (experiential-report) for a low health literate (LHL), limited English proficient (LEP) Latino audience, and 2) collate “real-world” examples of genetic reports (standard-report) from industry, research, and health care domains to serve as practice and comparison reports for the evaluation.

In this chapter, we first present our efforts to develop a set of desired design features and content for the experiential-report and its preliminary evaluation. Next, we describe our process to assemble “real-world” examples of genetic reports and information designed for patients. Finally, we discuss how we aimed to make the two reports similar in length, order, and medium (e.g., graphics, text, video).

Research Questions:

- What format and features should we use to design an “experiential” genetic report for LHL and LEP Latinos?

- What content should we include in the reports?

Method to Develop an Experiential-Report

Figure 7.1 displays the design process to develop the experiential-report.
Figure 7.1 Design process

We reviewed the findings of our previous studies described in Chapter 2 -5 (Literature Review and Studies 1-3), performed an environmental scan, and reviewed the literature and theories to look for suggested design features, and content for an experiential-report. We tabulated what we perceived to be the most appropriate design features and content and cited the rationale (Table 7.1 – Table 7.2). The rationale provided for each design feature includes findings from our previous work and others’ work in the literature.

Table 7.1 Design features and their rationale for the Experiential-Report

<table>
<thead>
<tr>
<th>DESIGN FEATURE</th>
<th>RATIONALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relational Agent (RA)</td>
<td>RAs are computer agents designed to form long-term, social-emotional relationships with their users. We used an RA in our report because RAs have been shown to be helpful in explaining health information to individuals with low health literacy (300,301) and increase motivation to pay attention.(302,303)</td>
</tr>
<tr>
<td>Animated RA</td>
<td>We animated our RA because studies indicate that people prefer and trust animated RAs over static ones.(304)</td>
</tr>
</tbody>
</table>
Display and Manipulate only RA’s Face and Eyes

Unlike other RAs that show the upper torso and body, we focus solely on displaying the face as it is the primary object people tend to orient towards to obtain situational cues (what is important to look at?) (305) and discern affective-information. (306) People automatically and rapidly evaluate faces on multiple trait dimensions using the “experiential system.” (307–309) People focus specifically on the eyes and mouth regions. (310) Eyes particularly are influential: people tend to look where another person’s eyes are looking; Even seeing a disembodied image of a pair of eyes can influence people’s behavior, such as increasing donations (311) and reducing the probability of littering. (312) This is known as the “watching eyes effect.”

By manipulating where the RA’s eyes look, we aim to guide the participant’s attention to where to focus and to provide value-judgements on the information. For example, if the RA looks concerned and moves his eyes to a specific line of text, one might feel compelled to also focus attention on that specific line of text.

To reduce any gender-based judgements made on the RA that might influence how participants relate to the RA, we designed the RA with no hair and with gender-neutral facial features. According to McCloud (313), the less specific-features (e.g., hair style) added to a character, the more the viewer is able to relate to the character as the viewer is not distracted by any specific-features that might cause the viewer to dislike the character.
Use RA’s facial expressions (based on FACS) to transmit emotions (affective information).

Research has demonstrated that most human communication is non-verbal. Individuals with LHL and LEP especially rely heavily on nonverbal communication, particularly that which emanates from the face. Non-verbal communication is a significant channel of information Latinos use. It is not only significant to the heritage but to development interpersonal relationships.\(^{(314,315)}\)

Patients report disregarding verbal information and making judgement on clinicians based on their nonverbal behavior.\(^{(316–318)}\)

Researchers have demonstrated that individuals can mirror the emotions of others by looking at emotive images of human faces.\(^{(292)}\) This phenomena is known as empathy (see (293) for review).

We aim to induce emotions in participants (to communicate affective information) by having them look at faces showcasing specific emotions.

We designed the emotional faces of the RA in accordance with the Facial Action Coding System (FACS).\(^{(319)}\) FACS is an internationally recognized, research tool that precisely measures the entire spectrum of human facial expressions. FACS has elucidated the physiological presence of emotion with very high levels of reliability.
Rather than using photos and videos of human faces to depict the emotional expressions, we used cartoons as they allow us to take advantage of the “caricature effect:” caricatures of human faces are often faster, easier, and more accurate to identify than normal (un-caricatured) faces. Thus, to encourage speed of recognition and identification of the correct emotion depicted on a face, we used cartoon faces. (Exaggerating emotional expressions on a cartoon face is normal, but on a human face it may be unconvincing.)

Fotonovellas have been shown to be a culturally-sensitive, effective method to communicate health messages to Latinos.

Chapter 3 and other literature inform us that videos are one of the most effective mediums to convey emotion and immersive experiences regardless of learning style.
Chapters 2 & 5 detailed numerous reasons visualizations such as photos and images are optimal mediums to convey experiential information. Here is a short summary:

Photos are effective at increasing belief and trust in the information. “Seeing is believing.”(323)

Images convey large amounts of information quickly through the brain’s high-bandwidth visual information channel.(324)

Images are easier to consume (lower cognitive load) than long words and numbers.

People prefer viewing and sharing photos compared to text, to communicate feelings and experiences.(325)

Images are easier to encode into memory and have high “retrieval fluency”: the ease with which information can be retrieved from memory (326), compared to text and numbers. Having high retrieval fluency is favorable because we can leverage availability bias (being swayed by more easily retrievable information when evaluating or making decisions) to influence behavior.(327)

Photos tend to be more immersive than text; they are able to swiftly activate empathy and imagination of experiences.(328)

Risk information is about uncertain events in the future. Due to fatalistic cultural influences, Latinos may not be concerned about information concerning uncertain future events. Moreover, humans, in general, have difficulty feeling motivated to change behavior for uncertain future events. To get people to care about uncertain future events, the literature suggests to display the future event *vividly*. (329) Vivid images can shrink the perceived (time) distance of a future event, which in turn tends to increase concern for the event. The more vivid something appears, the closer and more relevant it feels. Photos and images are excellent mediums to portray potential vivid scenarios.
Collage

We created collages inspired by those made by the Latino participants (who shared their caregiving experiences through collages) in Study 2 (Chapter 4) to portray patient experiences of familial hypercholesterolemia. Similar to the collages made in Study 2, we designed the collages for the Spanish speakers less uniform and the collages for the English speakers more uniform. The content for the collages consisted of quotes from actual patient experiences found in the literature. We also included images that reflected the content of the quotes.

Color

Color has been shown to influence perceptions and behavior.\(^{(330,331)}\) To determine a culturally appropriate color scheme and to leverage colors to help induce desired affective interpretations, we:

1) Performed an environmental scan of the colors our participants’ neighborhood stores exhibit by entering WICER zip codes into Google Street View.

2) Collected the first 2 pages of images from Google Images with search term: “Dominican Republic Art” and “Dominican Republic Culture.”

3) Analyzed use of color-affect combinations in films and animations.

4) Reviewed color theory\(^{(187,331,332)}\) and recent literature about different color properties (lightness, chroma and hue) shown to contribute to affective interpretations in information visualizations.\(^{(333)}\)
Vicarious Learning (Social Learning)

By observing the consequences of others' actions, individuals may acquire knowledge of the significance of situations. (289, 290)

We included real patient experience content (see Patient Experiences in Table 7.2) to showcase the possible consequences of not getting treatment for the genetic condition.

### Table 7.2 Content and Rationale of Experiential-Report

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>RATIONALE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Essential message of the report</td>
<td>A senior geneticist provided the essential information to convey in the report. The comprehension questions tested how well participants understood the essential message.</td>
</tr>
<tr>
<td>Patient Experiences:</td>
<td>Study 1 (Chapter 3) and literature (334) indicate that patients want information on how disease will affect their lives.</td>
</tr>
<tr>
<td>Show what patients risk losing</td>
<td>To provide information on the impact of familial hypercholesterolemia on patients’ lives, we reviewed the literature for patient experience studies related to the condition. We extracted the quotes from these studies and grouped them by their reported themes. We selected representative quotes from each theme-group and included them in our report, along with images and videos of patient experiences.</td>
</tr>
</tbody>
</table>

The following screenshots are from a 1-minute video depicting patient experiences:

![Patient Experience Image 1](image1.png)

![Patient Experience Image 2](image2.png)
Continued…

The following screenshots are from a 1-minute video depicting patient experiences:
Continued…

The following screenshots are from a 1-minute video depicting patient experiences:
Collage of real patient quotes from patient experience studies with pictures supporting the quotes:

<table>
<thead>
<tr>
<th>Emphasize family</th>
<th>Latino culture is high in collectivism and values family. (335) We included images and text emphasizing the impact the genetic condition could have on family.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide rapport</td>
<td>Unlike America’s direct, efficient culture, Latino culture prefers to “establish trust, support, warmth, and caring before dealing with difficult issues.” (335) So we buffered the beginning of the report with a few pages where the participant is able to establish rapport with the RA.</td>
</tr>
</tbody>
</table>
### Convey what it feels like to experience the disease

Study 2 (Chapter 4) provided insight into the emotional strain disease incurs on the patient and family. This affective-information is often not communicated in health prevention information. However, it is valuable to convey. For example, pain and fear play crucial roles in teaching the brain what to feel motivated to avoid and take action to prevent. These emotions can be experienced vicariously through immersive visuals. Without pushing on these emotional levers, there is low probability an individual will care about, remember, and take action to prevent the disease. (266, 272)

To convey affective-information, we included emotion-provoking images & video, designed emotional facial expressions on the RA, included patient quotes, and manipulated the colors (e.g., black to support feelings of fear and red to support arousal & attention), and provided contextual cues (e.g., falling rain in the background).

### Arousing information

Arousal is a level of activation varying along a continuum from calm to agitated. (336, 337) Arousal seems to affect how information is processed; emotionally arousing stimuli are attended to selectively, processed preferentially, and retained over long time periods relative to neutral stimuli. Plus, negative emotional arousal appears to enhance gist memory for emotional stimuli, to enhance memory for verbatim details that are central to those stimuli, and to interfere with or leave unaffected verbatim memory for peripheral details. (338–340) For example, Adolphs and colleagues showed that arousing, negative emotion enhanced memory for the “gist” of presented information (e.g., scenes of a car accident), but reduced memory for neutral details. (341, 342)

Studies report that people share arousing news. (343) This suggests that if information is not arousing it is unlikely to be shared. As previously discussed in Chapter 6, familial hypercholesterolemia care providers rely on cascade screening strategies to identify other individuals who might have the condition. If patients do not find their genetic test results arousing, the likelihood of them sharing the results with relatives may be low.

To encourage the sharing of genetic test information, we included arousing visuals (e.g., man collapsing from a heart attack) and words (e.g., “damaging”).

### Fear

Fear focuses attention and triggers high anticipated effort towards risk-avoidant behavior (344), which is one of our desired outcomes (tempered by understanding). We ideated and tested various fear inducing visuals.

(next three image are examples of visuals used to convey fear)
Example of a brainstorm-mockup:
(heart was animated)

Final version:
(heart was animated)
Surprise

Getting healthy individuals to focus their attention on health information can be challenging, but is a critical first-step to helping them care about and understand it. The literature suggests that making people feel surprised will help focus their attention on the surprising event (345), and may even promote learning and memory. Essentially, adding an element of surprise creates an opportunity to learn. The brain is constantly predicting what is going to happen next in order to keep us safe. When it confronts a surprising event it quickly focuses its attention on the unexpected event to gain new information (to learn) so it can make better predictions and won’t be surprised in the future. Inducing surprise may help increase attention to health information an individual may have not otherwise paid attention to.

Surprise seems to promote learning and memory of words. Researchers demonstrated that pairing words with novel images helped improve memory of words compared to pairing words with familiar images. (346,347)

Surprise seems to be an indication of changed beliefs, according to Itti and Baldi. They claim that, “only data observations which substantially affect the observer’s beliefs yield surprise.” (345)

“Surprise measures how data affects an observer, in terms of differences between posterior and prior beliefs about the world.”

We want to “substantially affect the observer’s beliefs” about high cholesterol if they do not have the correct prior understanding and beliefs of its dangers. Thus, we designed the report with a “surprising” scene in a video.
Hope and belief in the ability to reduce the impact of future illness

Latinos tend to promote “fatalismo,” the belief that the individual can do little to alter fate. (335) As a result, Latino patients may be less motivated to seek preventive screenings and may delay visiting a western doctor until symptoms become severe. They may also avoid effective therapies for diseases. (348) Thus, we aimed to instill hope and belief that the participant can effectively prevent or reduce the impact of the genetic condition. Literature on affect and behavior map “hope” to feeling motivated to take action. Thus, we ended the report with positive colors, positive images, and a hopeful message:
According to fuzzy trace theory, most decisions are based upon “fuzzy” memory traces (gist representations) as opposed to more detailed, quantitative memory (verbatim representations). (344) Gist-based processing yields a categorical evaluation of a stimulus as good/bad or an ordinal evaluation as better/worse. This evaluation drives judgment and decision making. (349)

Valence appears to affect what information is encoded (e.g., people encode the fundamental gist that an event was emotionally positive or negative). (350) The valence (good/bad or better/worse) of a stimulus can make other information about the stimulus irrelevant in judgment and decision making. For example, researchers showed that judgments were relatively insensitive to significant changes in probability for stimuli in which valence was more salient compared to judgments about stimuli with less salient valence. (351)

We designed for gist representations (excluding lots of detailed information and numbers) to support individuals with LHL and LEP to identify quickly and automatically unfavorable affective information that could inform health decisions.


We conducted hallway tests from May 2017 - June 2017 with Latino community members (n=13), where we randomly approached individuals in the neighborhood to view iterations of the preliminary experiential-report. Through verbal feedback, we assessed aesthetic agreeableness, ease of understanding, emotional impact (e.g., Too intense? Too boring?), motivation to act on
the information, and solicited suggestions for improvement. We iteratively made improvements to the report according to the feedback we received. We also measured and iteratively adjusted the length of time it took to consume the report, to determine a comfortable viewing speed for the formal evaluation in Aim 2. Table 7.3 shows examples of the experiential-report’s iterations.

**Table 7.3** Sample Iterations of the Experiential-Report.

<table>
<thead>
<tr>
<th>Before</th>
<th>After (Final Version)</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td><img src="image2.png" alt="Image" /></td>
</tr>
</tbody>
</table>

**Development Method and Preliminary Evaluation of Standard-Report**

We performed an environmental scan from November 2016 - February 2017 in the literature and gray literature for examples of patient-facing genetic test reports and information. We used
combinations of the following key words: “patient,” “genetic test report,” “genetic report”
“research genetic report.” “Familial Hypercholesterolemia,” “Inherited Heart Disease,”
“Inherited High Cholesterol” “Infographic” In PubMed, CINAHL, Google Scholar, Google
Video, and Google. We found numerous examples of text-based genetic reports and information
for patients, which we determined too difficult to understand for our low health literate and
limited English audience. We decided to use examples from 23andMe, American Heart
Association, Familial Hypocholesteremia Foundation, FH Journeys based upon the quality of the
media materials, aesthetics, clarity of presentation, and appropriate information. Appropriate
information was determined by a senior geneticist. We measured and iteratively adjusted the
length of time it took to consume the report with three low literate individuals, in order to
determine a comfortable viewing speed for the formal evaluation in Aim 5.

Similarities and Differences of the Reports

We aimed to design the reports to be comparable in length (~ five minutes), with similar formats
(both use graphics with text, both furnish 1 video of similar length), and in the similar
presentation order of information: results, effects of condition, treatment information. The
reports differ primarily in content (e.g., the experiential-report has no numbers), affective-
information, graphics, and colors. Table 7.4. shows our efforts to arrange the reports similar
enough to be comparable.
Table 7.4 Samples of the Experiential-Report and Comparable Samples of the Standard-Report.
Results

The findings of Aim 4 provided us with examples of real-world genetic test reports and comparable prototypes (the experiential-report and the standard-report) to serve as practice and comparison reports for the evaluation in Aim 5.
Chapter 8

Aim 5: Methods

In Chapter 8, we describe the methods used to evaluate the experiential-report compared to the standard-report (Aim 5).

Methods

Study Design

The study design was a two-group mixed methods experimental design in which participants were randomized to view a standard or experiential report about familial hypercholesterolemia. Quantitative methods included survey, questionnaire, and facial behavior analysis. Qualitative methods were interviews and observations.

Sample

Participants were recruited from the WICER Survey Cohort.(299) Eligibility criteria include:1) signed WICER consent form indicates willingness to be contacted for future research, 2) self-identified Hispanic, 3) ability to comprehend English or Spanish.
### Measures & Instruments

#### Table 8.1 Overview of Research Questions, Measures, Methods, Instruments, and Variables.

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Measures</th>
<th>Method/Instrument</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UNDERSTANDING</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How well do participants understand the Standard- vs. Experiential-report?</td>
<td>Ease of Understanding</td>
<td>Survey</td>
<td>5-point scale</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Observed behavior</td>
<td># of times asked to review report to answer question</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview</td>
<td>Open-responses</td>
</tr>
<tr>
<td>Comprehension</td>
<td>Gist &amp; verbatim comprehension questionnaire</td>
<td></td>
<td>Multiple choice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview</td>
<td>Open-responses</td>
</tr>
<tr>
<td><strong>EMOTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are the emotional responses to the Standard- vs. Experiential-reports?</td>
<td>Valence (negative - positive)</td>
<td>SAM survey</td>
<td>5-point scale</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Arousal</td>
<td>Line graph</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Open-responses</td>
</tr>
<tr>
<td><strong>MOTIVATION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How motivated do participants feel after viewing the Standard- vs. Experiential-reports?</td>
<td>Motivation</td>
<td>Survey</td>
<td>5-point scale</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview</td>
<td>Open-responses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Observed behavior</td>
<td>Observations</td>
</tr>
<tr>
<td><strong>CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are the individual characteristics of the study sample?</td>
<td>Preferred Language</td>
<td>Self-reported</td>
<td>Spanish or English</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health Literacy</td>
<td>Adequate or Limited literacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>≤8th or &gt; 8th grade</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Education Level</td>
<td>Years</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Male or Female</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sex</td>
<td></td>
</tr>
</tbody>
</table>
1. Understanding

1.1 **Ease of Understanding**

1.1.1 **Survey:** Perceptions on how easy the report was to understand were assessed using two 5-point Likert scale questions related to ease to understanding and ease of explaining the information to a family member (Box 1) (Cronbach alpha = 0.77). We combined responses to both questions into 1 variable by averaging the responses as they showed little variance.

1.1.2 **Observed Behavior:** We tallied the number of times participants asked to look back at the report to answer a comprehension questions.

1.2 **Comprehension**

1.2.1 **Gist Comprehension:** Gist comprehension refers to the participant’s ability to understand the bottom-line implications of the text, images, or numbers for health. Five multiple-choice questions were designed to measure gist comprehension. For example, participants were asked “If you have familial hypercholesterolemia, you are likely to have ________: 1) Foot sore, 2) Stomach ache, or 3) High cholesterol.” The same gist comprehension questions were asked in both standard and experiential groups. Gist comprehension was measured as the total number of correct responses (0-5). These scores were used to compare comprehension between groups.

1.2.2 **Verbatim Comprehension:** Verbatim comprehension refers to the participant’s ability to understand the literal facts or “surface form” of information, preserving information about precise numeric values. Verbatim questions were different
for the two groups. Verbatim questions in the standard group focused more on numbers as compared to the questions for the experiential group which focused on text. (The experiential-report did not have any numbers.) Seven multiple-choice items measured verbatim understanding. Examples include: (Standard-report) “How much at risk is an individual with this condition for early heart attack?: 1) 10x at risk, 2) 20x at risk, 3) 80X at risk.”; (Experiential-report) “What do patients say about this condition?: 1) They cannot work, 2) They lost independence, 3) All of the above.” total verbatim score was based on the number of correct answers (0–7). These scores were combined with the gist scores to compare comprehension within groups in subgroup analyses.

1.2.3 Open-Responses: Verbal comments related to content comprehension were noted and audio recorded.

2) Emotion

2.1 Subjective Emotions

2.1.1 Survey: Subjective affective (emotional) responses to visual stimuli were assessed through a standard self-report survey, the Self-Assessment Manikin (SAM). SAM is a pictorial 5-point scale (Box 1) (other variants exist such as 7- and 9-points scales) broadly employed in emotion research for the collection of subjective affective ratings. It is among the most popular best-established self- reporting tools. The paper (352) that introduced the SAM scale has collected over 4428 citations since its publication.
There are a number of scales that assess emotion, but most are text-based requiring the participant to read. As a portion of our target audience has trouble reading, we chose to use the SAM scale because of its nonverbal design and its proven usage record. It is considered to be usable regardless of the age, educational or cultural background of the participants. SAM is a scale that measures the dimensions of valence (negative-positive), arousal and dominance using a series of graphic abstract characters horizontally arranged according to a 5-points scale. Valence ranges from a frowning to a smiling figure, and arousal spans from a sleepy to a widely awake figure showing an incremental explosion at the center. We used the valence and arousal measures for this study (the dominance scale is often not used because it is not always easily understood by participants or not applicable to the study.) The coefficient alpha for valence was .97, whereas the coefficient alpha for arousal was .94.(352)

2.1.2 Open-Responses: Verbal response and observations made by participants related to participant affect were noted and audio-recorded.
2.2 Objective Emotions

2.1.3 Facial Behavior: We used facial analysis software developed by MIT called, Affectiva www.affectiva.com/, to scientifically measure emotional responses objectively and unobtrusively. Through machine learning techniques it identifies and categorizes facial muscle movements to appropriate emotions (e.g., anger, surprise). 2-alternative forced choice (2AFC) is a standard two-alternative forced choice method for measuring detection or discrimination thresholds.(353) Affectiva reported an overall 2AFC score of 88.2% on detection accuracy of asymmetric expressions.(354) Moreover, Affectiva demonstrated highly significant pearson correlation ($r = 0.74$) between the data from a standard emotion-assessment instrument and its facial expression data.(355) Affectiva categorizes facial expressions based on the Facial Action Coding System (FACS), developed by Paul Ekman.(319) FACS is also the framework on which the facial expressions made by the relational agent in the experiential-report were designed.

3) Motivation

3.1 Survey: A senior geneticist and resources from the National Society of Genetic Counselors (356) determined the outcome measure of participants’ motivation to take action on the health information. Specifically, two 5-point Likert scale questions assessed motivation to go to the doctor and to tell family members to get tested for the health condition (Box 1). We combined these two items into 1 motivation variable by averaging the responses as they showed good internal consistency (Cronbach alpha = 0.97). A senior geneticist and resources from the National Society of Genetic Counselors determined these outcome measures.(356)
3.2 Open-Responses: Verbal response made by participants related to motivation were noted and audio-recorded.

4) Individual characteristics

Socio-demographic data were collected including age, gender, language preference, education. In addition, numeracy and general literacy were measured using the Newest Vital Sign (NVS) which includes 6 questions to test reading, interpretation, and numeracy skills based on a nutritional label from an ice cream container. A point is given for each correct answer, and the total points are categorized into three health literacy levels: high likelihood of limited literacy, possibility of limited literacy and adequate literacy. It is reliable (Cronbach alpha > 0.76 in English and 0.69 in Spanish) and correlates with the TOFHLA ($r = 0.59$, $p < .001$ in English and $r = 0.49$, $p < .001$ in Spanish). Area under the ROC curve is 0.88 for English and 0.72 for Spanish versions. (357)

Procedures

Study procedures were approved by the Columbia University Medical Center Institutional Review Board (IRB). A bilingual research coordinator called WICER participants who met study eligibility criteria and assessed their interest in the study. Data were conducted between July 18 and August 23, 2017 at Columbia’s School of Nursing and at the Community Partnership for Health, a storefront health-focused community engagement center located in Washington Heights run by the Irving Institute for Clinical and Translational Research. Participants were compensated for their time with $50 grocery coupons. Half of the participants were randomized to view a novel “experiential” report and half of the participants were randomized to view a
standard report. Each group had a randomly assigned equal number of Spanish and English speakers.

One-on-one interviews were conducted by members of the research team using the same interview guide. After informed consent was obtained, participants were briefed about the experimental procedures. Participants were told 1) we needed their help to judge whether the example images were good or bad ways to present health information to individuals with LHL and LEP, and 2) we would be assessing their opinions and reactions to a series of images on the computer screen. Each participant was given a response booklet containing measurement instruments (e.g., 5-point Likert scales, multiple-choice questions). The reports were presented on a 15” laptop approximately 23” away from the seated participant in a private room.

A 15-min practice session was conducted during which participants viewed two text-based genetic reports designed for patients (1st report: 1 page panel of diseases such as diabetes, cancer, heart disease; 2nd report: 5 pages on Reyes Syndrome). The practice reports were real-life examples of patient-friendly genetic reports found in the literature with simulated data. After perusing a report, participants 1) rated the report on ease of understanding and how much it made them feel motivated to address the health issue on a 5-point scale (Box 1), 2) answered a multiple-choice gist (essential) or verbatim (actual) comprehension question (Box 1), and 3) rated how the report made them feel (valence and arousal) on a 5-point scale (Instrument shown in Box 2). Participants were allowed to view the report while providing their feedback. A brief break followed; Participants were asked to close their eyes to clear their mind and take five slow, deep breadths. This concluded the practice session.

The formal study began with participants viewing a multi-page report (experiential or standard) for 5 minutes. After viewing the report, like in the practice session, participants provided their opinion on ease of understanding and their motivation to address the health issue (Box 1). Next,
the participant viewed each image in the report one-by-one for 6 seconds (timing was based on previous emotion assessment studies (358)) with a washout period between each image during which a blank screen displayed on the computer screen. During the washout period, participants rated how viewing the image made them feel and answered a multiple-choice gist (essential) or verbatim (actual) comprehensions question (sample questions in Box 1). If needed, participants could view the image again in 6-second increments to answer the comprehension question. We tallied the number of times a participant asked to look back at the image.

Box 1: Sample Questions

**Opinion**
- Please rate the presentation on how easy it was to understand.
  (anchors 1= extremely hard to understand, 5 = extremely easy to understand)
- Please rate how easy it would be to explain the health condition described in the presentation to a family member.
  (anchors: 1= extremely hard to understand, 5 = extremely easy to understand)
- Please rate the presentation on how effective it was at making you feel motivated to go to the doctor.
  (anchors: 1= extremely does not make me feel motivated, 5 = extremely makes me feel motivated)
- Please rate the presentation on how effective it was at making you feel motivated to tell your family to get tested for the health condition.
  (anchors: 1= extremely does not make me feel motivated, 5 = extremely makes me feel motivated)

**Gist Comprehension**
If you have this condition, does it mean someone in your family likely has this condition too?
- a) Yes, this condition is often inherited
- b) No
- c) I’m not sure

**Verbatim Comprehension**
Is a child too young to get tested?
- a) Yes
- b) No
- c) I don’t know
Objective emotional responses by participants were unobtrusively recorded through the computer camera during the 5-min presentation using facial expression analysis software. We noted empirical observations and verbal comments on paper. Immediately after the interviews research team members debriefed about findings. The interviews were also digitally recorded, transcribed, and translated by members of the research team. The audio recordings of the interviews were transcribed verbatim. The Spanish recordings were translated into English prior to data analysis. Information provided in the sample stimuli was based upon simulated data, not actual participant data.
# Statistical Analysis

**Table 8.2  Overview of Research Questions and Analysis Methods**

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Bivariate Method</th>
<th>Multivariate Method</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UNDERSTANDING</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How well do participants understand the Standard- vs. Experiential-report?</td>
<td>( t )-test</td>
<td>Two-factor ANOVA – Factors (with 2 levels)</td>
</tr>
<tr>
<td></td>
<td>Directed content analysis</td>
<td>Correlation - with ease of understanding, comprehension, end-valence, motivation, age</td>
</tr>
<tr>
<td><strong>EMOTION</strong></td>
<td>( t )-test</td>
<td></td>
</tr>
<tr>
<td>What are the emotional responses to the Standard- vs. Experiential-reports?</td>
<td>Directed content analysis</td>
<td>Linear regression – with ease of understanding, end-valence, motivation.</td>
</tr>
<tr>
<td></td>
<td>Image analysis &amp; visualization</td>
<td></td>
</tr>
<tr>
<td><strong>MOTIVATION</strong></td>
<td>( t )-test</td>
<td>Hierarchical Clustering – with ease of understanding, comprehension, change in emotion (valance range), motivation.</td>
</tr>
<tr>
<td>How motivated do participants feel after viewing the Standard- vs. Experiential-reports?</td>
<td>Directed content analysis</td>
<td></td>
</tr>
<tr>
<td><strong>CHARACTERISTICS</strong></td>
<td>( t )-test</td>
<td></td>
</tr>
<tr>
<td>What are the individual characteristics of the study sample?</td>
<td>Chi square</td>
<td></td>
</tr>
<tr>
<td></td>
<td>( t )-test</td>
<td></td>
</tr>
</tbody>
</table>
Statistical analyses were performed using R. All tests of significance were two-sided, and the level of significance for testing of each model was set to an alpha of 0.05. Initially univariate analysis was used to examine the distribution of study variables calculating mean and standard deviation, range, and percentage as appropriate.

$t$-tests and two-factor analysis of variance (ANOVA) tests were used to examine differences between standard group and experiential group participants. A $t$-test was used to examine differences in continuous variables (e.g., age). Based on the results of Study 3, we anticipated there may be differences between participants by language preference. To explore this possibility and other outcome differences between socio-demographic variables, we performed subset analyses for each outcome variable by performing two-factor ANOVA tests. We compared the main effects of categorical variables (type of report: experiential vs standard) and the interaction effects between subgroup categorical variables (language preference, health literacy level, and education level) on dependent continuous outcome variables (e.g., comprehension scores).

To assess the relationship between continuous variables of ease of understanding, comprehension scores, emotion, motivation and age, we also calculated the Pearson correlations between variables of the same type for each experimental condition. Factors determined to be significant by correlations analyses were entered into a multiple regression model to identify predictors of ease of understanding and motivation. Data are expressed as percentages, range, and mean ± SD. Significance was accepted as $p<0.05$ for single comparisons.

Facial behavior data was analyzed using an adapted technique from Study 3. We performed image analysis using ImageJ an open source image processing application (http://imagej.nih.gov/ij/) on the color graphs produced by facial expression analysis software, Affectiva. Group differences were determined by comparing total amount of “emotion” or facial
behavior between groups by comparing the total area under the curve of each graph. It is common to analyze facial expression results based on valance (positive vs negative) rather than specific emotion categories (e.g., anger, surprise). Accordingly, we separated and analyzed the graphs by their positive and negative colors (e.g., positive: white = smiling; negative: red = anger) to determine which group made more positive and negative facial expressions. Results were analyzed through visual inspection of graphical techniques.

Cluster analysis is an explorative analysis that tries to identify and group structures within the data using distance measures between variables of interest. To identify homogenous groups of participants with similar outcome variables and who are distinctively different from other participants in our data set, we performed hierarchical cluster analysis. We used hierarchical clustering instead of its counterpart, flat clustering, because it outputs a hierarchy, a structure that is more informative than the unstructured set of clusters returned by flat clustering. Plus, we did not know the potential end number of clusters, and hierarchical clustering does not require us to pre-specify the number of clusters, unlike flat clustering. The advantages of hierarchical clustering come at the cost of lower efficiency. As our data set was not large, the longer processing time hierarchical clustering requires, compared to flat clustering, was not a concern. We clustered the continuous variables of ease of understanding, comprehension, emotion, and motivation using Euclidian distances as our metric. In hierarchical clustering, the dendogram is the main graphical tool for getting insight, as it unveils the structure in the data. We chose to use a circular dendogram because it is visually similar to a pie chart. Pie charts, though weak in precision, excel at communicating a sense of proportionality within a group (when there <=5 groups), which was our goal.
We used Chernoff faces to summarize the main characteristics of continuous variables (e.g., ease of understanding, motivation) and categorical variables (e.g., education level). Chernoff faces is a visualization technique used to display data by mapping it to human facial features, such as the width of the nose or the height of the face. This technique has been shown to enable faster, more accurate classification of objects. However, it has limited uses as it can lead to distortions and variations in interpretations as it uses a nonlinear perceptual space. However, for this study it is a perceptually efficient visualization technique to summarize and convey key variables (e.g., emotion of participants, motivation).

**Qualitative Analysis**

Directed content analysis was used to analyze verbal feedback. We used the outcome variables of interest (e.g., understanding, emotion, motivation) as the predetermined codes. Data that could not be coded were identified and analyzed to determine if they represent a new category or a subcategory of an existing code. A senior member of the research team (S.B.) with expertise in qualitative analysis reviewed the coding and made suggestions for refinements.

**Data Triangulation**

We performed within-method triangulation with qualitative and quantitative data collected through multiple approaches of obtrusive and unobtrusive methods. For example, to analyze how well participants understood the information in the report, we cross-checked each result with other measures related to understanding to see if they converged. Specifically, we cross-checked these 5 measures: 1) survey results on perceived ease of understanding, 2) performance on comprehension questionnaire, 3) behavior observations (total number of times participant needed to look back at the report to answer a question), and 4) open-responses.
In this case, we weighted the data in the following order from highest to lowest: unobtrusive quantitative behavioral observations (the number of times a participant needed to look back at the report to answer comprehension questions), open-responses, comprehension questions, and opinion survey data. We weighted the open-responses higher than the comprehension questions because some of the participants were not familiar with the multiple-choice format, and said they were just guessing when they circled an answer. We evaluated open-responses in two ways: by the number of participants who voluntarily verbalized what they learned in the report, and what they actually said. Survey data is recognized for being prone to social desirability bias so we weighted it lowest.

Qualitative measures of open-responses contextualized quantitative measures such as survey responses. For example, if a participant indicated on the survey that the report was easy to understand, however, performed poorly on the comprehension questionnaire, looked back at the report numerous times to answer the comprehension questions, and verbally shared being unable to see the report because he doesn’t have his glasses, then these results may suggest that self-perception of understanding was higher than actual understanding.

We also cross-checked with theories to help interpret our findings. For example, if the participant indicated having high motivation on the survey, but reported feeling neutral and no arousal on the SAM emotion instrument, and had scant facial movement with the exception of yawning twice (see Figure 8.1), then according to behavior theories, the participant may not actually have been motivated because the emotions and behavior do not align with typical motivated behavior.
Figure 8.1 Example of Data Triangulation to Assess Motivation

Chernoff faces facilitated visual sense-making of multiple measures as one “face.” For example, in the above example, a Chernoff face could support easy detection of conflicting measures of motivation by showing data through different facial and hair features. That is, a Chernoff face could show low emotional arousal (e.g., constricted eyes and slight frown) but high self-report motivation data (e.g., big hair). As human being tend to excel at reading faces, these opposing motivation results would be relatively quick and easy to spot.

Of note, we weighted emotional data reported on the SAM instrument in combination with open-responses the highest because the experiment was designed to minimize bias for data collection using this instrument. That is, participants were instructed to “judge the report on whether it was a good or bad way to present genetic test results for low literate individuals with limited English proficiency.” If the participant indicated feeling somewhat positive on the SAM scale and verbalized: “It’s clear, I feel good,” then the participant was following directions; however, if the participant indicated strong negative emotion on the SAM instrument and verbalized: “Scared,” then she was experiencing the affective-information in the report and going
off task. The task was to be a “critic” not an “audience” member. Given that strong emotions such as fear are prioritized in the brain, we anticipated that if the participant was truly feeling a strong emotion, that emotion would “hijack” the participant’s attention off the task of being a critic, and it would be the emotion reported on the SAM scale.
Aim 5: Evaluate the experiential-report compared to the standard-report through data triangulation

Participant Demographics

A total of 37 eligible participants were called to participate in the study, of whom 35 (94.6%) agreed to be interviewed. The most common reason given for not participating was lack of time. Three of the 35 participants recruited, failed to attend their scheduled research session resulting in a sample size of 32 participants.

Table 9.1 describes the characteristics of the survey sample. Of the 32 participants, 81% were female and 22% had an eighth-grade education or less. The majority had LHL. The average age of the sample was 53 years. Participants preferring to perform study procedures in Spanish over English constituted 50% of the study population by design. Half of each study group had Spanish data collection.
Table 9.1  Demographics by Report Format

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Standard n=16</th>
<th>Experiential n=16</th>
<th>All n=32</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>13 (81)</td>
<td>13 (81)</td>
<td>26 (81)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;=8th grade</td>
<td>3 (19)</td>
<td>4 (25)</td>
<td>7 (22)</td>
</tr>
<tr>
<td>&gt; 8th grade</td>
<td>13 (81)</td>
<td>12 (75)</td>
<td>25 (78)</td>
</tr>
<tr>
<td>Health Literacy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited Literacy</td>
<td>10 (63)</td>
<td>12 (75)</td>
<td>22 (69)</td>
</tr>
<tr>
<td>Adequate Literacy</td>
<td>6 (38)</td>
<td>4 (25)</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-55</td>
<td>7 (44)</td>
<td>8 (50)</td>
<td>15 (47)</td>
</tr>
<tr>
<td>56+</td>
<td>9 (56)</td>
<td>8 (50)</td>
<td>17 (53)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>M (SD)</th>
<th>M (SD)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>52 (15.7)</td>
<td>54 (11.5)</td>
<td>53 (13.5)</td>
</tr>
</tbody>
</table>

Post-Hoc Power Analysis

Because we were not testing hypotheses given the exploratory nature of the study, we did not do a power analysis prior to data collection. Instead, we performed a post-hoc analysis. Post-hoc analysis of "observed power" is conducted after a study has been completed, and typically uses the obtained sample size and effect size to determine what the power was in the study, assuming the effect size in the sample is equal to the effect size in the population. "Power" is the ability of an experiment to detect a difference between two groups. If a study has inadequate power, it may not be able to detect a difference even though a difference truly exists. This false conclusion is called a type II error.(364) Post-hoc power analysis has been criticized as a means of interpreting negative study results.(365) Because post-hoc analyses are typically only calculated on negative results (p \( \geq 0.05 \)), such an analysis will produce a low post-hoc power result, which
may be misinterpreted as the study having inadequate power. As an alternative to post-hoc power, analysis of the width and magnitude of the 95% confidence interval (95% CI) may be a more appropriate method of determining statistical power. Acknowledging the concerns of post-hoc power calculations, we performed post-hoc power analysis as a formality to roughly determine the probability that our statistical analyses detected statistically significant relationships and differences. Table 9.2 presents the power for the primary statistical tests conducted in our study. Using $\alpha = 0.5$, means and standard deviations from study results, and the number of participants in each group, the power is at least 80 for three of the five statistical tests. Power was inadequate for comprehension and motivation.

Table 9.2 Power of Select Statistical Tests

<table>
<thead>
<tr>
<th>Variables</th>
<th>Standard $n = 16$</th>
<th>Experiential $n = 16$</th>
<th>power</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ ($SD$)</td>
<td>$M$ ($SD$)</td>
<td></td>
</tr>
<tr>
<td><strong>Ease of Understanding</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>t-test</td>
<td>3.8 (1.1)</td>
<td>4.6 (0.6)</td>
<td>80%</td>
</tr>
<tr>
<td><strong>Gist Comprehension Score</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>t-test</td>
<td>0.88 (0.2)</td>
<td>0.98 (0.1)</td>
<td>60%</td>
</tr>
<tr>
<td><strong>Range in Emotion</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Valence) t-test</td>
<td>1.7 (0.8)</td>
<td>3.6 (0.6)</td>
<td>100%</td>
</tr>
<tr>
<td>(Arousal) t-test</td>
<td>1.8 (0.9)</td>
<td>3.7 (0.7)</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>t-test</td>
<td>3.8 (1.5)</td>
<td>4.5 (0.7)</td>
<td>42%</td>
</tr>
</tbody>
</table>

Note: $\alpha = 0.5$

**Analysis**

The analysis begins with the research questions then is divided into four main sections based on research questions and an exploratory summary analysis at the end. Each of the first three sections is further divided based on measurement instrument, closing with an exploratory analysis.
conducted with subgroups of the study sample. The fourth section integrates and summarizes certain results from across the first three sections in an exploratory analysis.

Research Questions

1. How well do participants understand the standard-report vs. experiential-report?
2. What are the emotional responses to the standard-report vs. experiential-report?
3. How motivated do participants feel after viewing the standard-report vs. experiential-report?

Understanding Results

Table 9.3 compares the effect of standard-vs experiential-reports on participants’ perceived ease understanding and gist comprehension. Both ease of understanding and gist comprehension were significantly greater among participants who received information using the experiential-report as compared to the standard-report. Only participants who preferred to speak Spanish asked to look back at the report to answer comprehension questions while viewing the experiential-report. In contrast, for the standard-report, both English and Spanish speakers requested to look back at the report to answer comprehension questions. One participant’s data was excluded from this analysis due to participant’s lack of attention during this section of the study.

Multiple regression models identified one main factor predictive of perceived ease of understanding. The predictor of perceived ease of understanding was the last emotion participants felt at the end of viewing the report (standard $p = 0.010$; experiential $p = 0.004$). For example, if the participant felt neutral at the end of viewing the report, the participant tended to answer that the report was moderately easy to understand. If the participant felt very positive at the end of viewing the report, the participant tended to answer that the report was very easy to understand.
Table 9.3 Effect of Report Format on Ease of Understanding, Gist Comprehension, and Open-Responses.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td><strong>Ease of Understanding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1= hard, 5=easy</td>
<td>3.8 (1.1)</td>
<td>4.6 (0.6)</td>
</tr>
<tr>
<td># of times needed to look</td>
<td>31 (total count)</td>
<td>4 (total count)</td>
</tr>
<tr>
<td>back at report to answer question</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gist Comprehension Score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shared questions</strong></td>
<td>0.88 (0.2)</td>
<td>8 (0.1)</td>
</tr>
<tr>
<td>Standard questions</td>
<td>0.61 (0.2)</td>
<td>0.9</td>
</tr>
<tr>
<td>Experiential questions</td>
<td>3 (0.1)</td>
<td></td>
</tr>
</tbody>
</table>

*Note: All p-values are two-tailed
**“Shared questions” are the questions that both intervention groups received, which tested on the essential message of the report, as determined by a senior geneticist. Standard questions are the questions that relate only to the information in the standard-report. Experiential questions are the questions that only relate to the information in the experiential-report.

ANOVA (Tables 9.4 – 9.9) showed a main effect of intervention group, language, and education, but not health literacy on ease of understanding. Perceived ease of understanding was higher in the experiential group. Spanish speakers reported higher perceived ease of understanding (p =0.040) than the English speakers. Participants having an education higher than eighth-grade comprehended the reports better (p=0.002) than those having an eighth-grade education or less. There were no significant interaction effects. For comprehension, the only main effects were intervention group and education level (p=0.002) in the same direction as perceived understanding.
Table 9.4 Effect of Language and Report Format on Ease of Understanding

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>15</td>
<td>4.50 (0.60)</td>
</tr>
<tr>
<td>English</td>
<td>16</td>
<td>3.88 (1.18)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.63 (0.58)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.75 (1.10)</td>
</tr>
<tr>
<td>Spanish X Experiential</td>
<td>7</td>
<td>4.79 (0.39)</td>
</tr>
<tr>
<td>Spanish X Standard</td>
<td>8</td>
<td>4.50 (0.65)</td>
</tr>
<tr>
<td>English X Experiential</td>
<td>8</td>
<td>4.50 (0.71)</td>
</tr>
<tr>
<td>English X Standard</td>
<td>8</td>
<td>3.25 (1.25)</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Source</th>
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<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>3.02</td>
<td>4.43</td>
<td>1</td>
<td>0.04</td>
<td>0.115</td>
</tr>
<tr>
<td>Report Format</td>
<td>6.34</td>
<td>9.28</td>
<td>1</td>
<td>0.01</td>
<td>0.220</td>
</tr>
<tr>
<td>Language X Report Format</td>
<td>0.99</td>
<td>1.44</td>
<td>1</td>
<td>0.24</td>
<td>0.034</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.68</td>
<td></td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Table 9.5: Effect of Literacy Level and Report Format on Ease of Understanding

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>$M$ (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Literacy</td>
<td>22</td>
<td>4.31 (0.81)</td>
</tr>
<tr>
<td>Adequate Literacy</td>
<td>10</td>
<td>3.9 (1.26)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.63 (0.58)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.75 (1.10)</td>
</tr>
<tr>
<td>Limited X Experiential</td>
<td>11</td>
<td>4.64 (0.64)</td>
</tr>
<tr>
<td>Limited X Standard</td>
<td>10</td>
<td>3.95 (0.86)</td>
</tr>
<tr>
<td>Adequate X Experiential</td>
<td>4</td>
<td>4.63 (0.48)</td>
</tr>
<tr>
<td>Adequate X Standard</td>
<td>6</td>
<td>3.42 (1.43)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>$p$</th>
<th>eta$^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy Level</td>
<td>1.136</td>
<td>1.416</td>
<td>1</td>
<td>0.245</td>
<td>0.021</td>
</tr>
<tr>
<td>Report Format</td>
<td>5.523</td>
<td>6.883</td>
<td>1</td>
<td>0.014</td>
<td>0.192</td>
</tr>
<tr>
<td>Literacy X Report Format</td>
<td>0.448</td>
<td>0.559</td>
<td>1</td>
<td>0.461</td>
<td>0.016</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.802</td>
<td></td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 9.6  Effect of Education and Report Format on Ease of Understanding

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 8th grade</td>
<td>6</td>
<td>4.33 (0.75)</td>
</tr>
<tr>
<td>&gt; 8th grade</td>
<td>25</td>
<td>4.14 (1.04)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.63 (0.58)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.75 (1.10)</td>
</tr>
<tr>
<td>≤ 8th grade X Experiential</td>
<td>2</td>
<td>4.75 (0.35)</td>
</tr>
<tr>
<td>≤ 8th grade X Standard</td>
<td>4</td>
<td>4.12 (0.85)</td>
</tr>
<tr>
<td>&gt; 8th grade X Experiential</td>
<td>13</td>
<td>4.61 (0.62)</td>
</tr>
<tr>
<td>&gt; 8th grade X Standard</td>
<td>12</td>
<td>3.62 (1.17)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
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<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Level</td>
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<td>0.222</td>
<td>1</td>
<td>0.641</td>
<td>0.022</td>
</tr>
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<td>Report Format</td>
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<td>7.988</td>
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<td>0.009</td>
<td>0.226</td>
</tr>
<tr>
<td>Education X Report Format</td>
<td>0.147</td>
<td>0.180</td>
<td>1</td>
<td>0.674</td>
<td>0.005</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.813</td>
<td></td>
<td>27</td>
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Table 9.7 Effect of Language and Report Format on Comprehension

<table>
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<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>16</td>
<td>0.89 (0.17)</td>
</tr>
<tr>
<td>English</td>
<td>16</td>
<td>0.96 (0.08)</td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>0.98 (0.10)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>0.88 (0.15)</td>
</tr>
<tr>
<td>Spanish X Experiential</td>
<td>8</td>
<td>0.95 (0.14)</td>
</tr>
<tr>
<td>Spanish X Standard</td>
<td>8</td>
<td>0.83 (0.19)</td>
</tr>
<tr>
<td>English X Experiential</td>
<td>8</td>
<td>1 (0)</td>
</tr>
<tr>
<td>English X Standard</td>
<td>8</td>
<td>0.91 (0.10)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
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<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>0.038</td>
<td>2.28</td>
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<td>0.142</td>
<td>0.064</td>
</tr>
<tr>
<td>Report Format</td>
<td>0.090</td>
<td>5.45</td>
<td>1</td>
<td>0.027</td>
<td>0.152</td>
</tr>
<tr>
<td>Language X Report Format</td>
<td>0.003</td>
<td>0.17</td>
<td>1</td>
<td>0.683</td>
<td>0.005</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.017</td>
<td></td>
<td>28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 9.8 Effect of Literacy Level and Report Format on Comprehension

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Literacy</td>
<td>22</td>
<td>0.92 (0.14)</td>
</tr>
<tr>
<td>Adequate Literacy</td>
<td>10</td>
<td>0.92 (0.14)</td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>0.98 (0.10)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>0.88 (0.15)</td>
</tr>
<tr>
<td>Limited X Experiential</td>
<td>12</td>
<td>0.97 (0.12)</td>
</tr>
<tr>
<td>Limited X Standard</td>
<td>10</td>
<td>0.87 (0.16)</td>
</tr>
<tr>
<td>Adequate X Experiential</td>
<td>4</td>
<td>1 (0.00)</td>
</tr>
<tr>
<td>Adequate X Standard</td>
<td>6</td>
<td>0.87 (0.16)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy Level</td>
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<td>0.003</td>
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<td>0.958</td>
<td>0.002</td>
</tr>
<tr>
<td>Report Format</td>
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<td>5.108</td>
<td>1</td>
<td>0.032</td>
<td>0.154</td>
</tr>
<tr>
<td>Literacy X Report Format</td>
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<td>0.125</td>
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<td>0.726</td>
<td>0.004</td>
</tr>
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<td>Residual Error</td>
<td>0.018</td>
<td></td>
<td>28</td>
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<td></td>
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</table>
Table 9.9  Effect of Education and Report Format on Comprehension

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 8th grade</td>
<td>7</td>
<td>0.8 (0.22)</td>
</tr>
<tr>
<td>&gt; 8th grade</td>
<td>25</td>
<td>0.96 (0.08)</td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>0.98 (0.10)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>0.88 (0.15)</td>
</tr>
<tr>
<td>≤ 8th grade X Experiential</td>
<td>4</td>
<td>0.90 (0.20)</td>
</tr>
<tr>
<td>≤ 8th grade X Standard</td>
<td>3</td>
<td>0.67 (0.21)</td>
</tr>
<tr>
<td>&gt; 8th grade X Experiential</td>
<td>12</td>
<td>1 (0.00)</td>
</tr>
<tr>
<td>&gt; 8th grade X Standard</td>
<td>13</td>
<td>0.92 (0.10)</td>
</tr>
</tbody>
</table>

Source | MSS | F | df | p | eta^2 |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Level</td>
<td>0.133</td>
<td>11.516</td>
<td>1</td>
<td>0.002</td>
<td>0.254</td>
</tr>
<tr>
<td>Report Format</td>
<td>0.108</td>
<td>9.368</td>
<td>1</td>
<td>0.005</td>
<td>0.182</td>
</tr>
<tr>
<td>Education X Report Format</td>
<td>0.030</td>
<td>2.574</td>
<td>1</td>
<td>0.120</td>
<td>0.050</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.012</td>
<td></td>
<td>28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Observations by Participants Related to Understanding

In the standard group, twelve (75%) participants needed to look back at the report in order to answer comprehension questions. The majority of these multiple-choice questions pertained to verbatim understanding of numbers (e.g., In a group of 250 people, how many will likely have familial hypercholesterolemia?). These participants had a mix of ages, language preference, literacy levels, and education levels.

In the experiential group, three Spanish speakers needed to look back at the report in order to answer the comprehension questions. These participants were older in age than group average, had limited health literacy, and had an eighth-grade education or less.
Open-Responses by Participants Regarding Understanding

Table 9.10 compares the open-responses during one-to-one data collection sessions. Not one participant who viewed the standard-report commented on what they learned or understood from the report, unlike the participants who viewed the experiential-report. Numerous English-speaking participants who viewed the standard-report volunteered suggestions for improvement (“Nice graphic for you guys, not for us.”), such as focusing on colors, particularly red to capture attention, simplifying words and using few words, and provoking emotion. In contrast, no Spanish-speaking participant, who viewed the standard-report, offered suggestions for improvement and instead said the information was clear and easy to understand. Unlike the cohort that viewed the standard-report, comments were not polarized between the Spanish and English speakers in the group that viewed the experiential-report, and no one volunteered suggestions for improvement.

**Table 9.10  Effect of Report Format on Open-Responses Regarding Understanding**

<table>
<thead>
<tr>
<th></th>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Representative Quotes</strong></td>
<td>Just too many words. Too small words for me to concentrate on any particular one ... the less words the better. The easier, more common words that people use, in general, the better. #11 E</td>
<td>[It] was perfect. It got my attention. #14 E</td>
</tr>
<tr>
<td></td>
<td>In one page it’s like a thousand words <strong>but you don’t see it</strong>. #14 E</td>
<td>If you only tell them to read, they’re not going to read. #9 E</td>
</tr>
<tr>
<td></td>
<td>Too much words... there is too much information. I’m not going to even bother. That’s why people don’t read their discharge papers. It’s too much information. #4 E</td>
<td></td>
</tr>
</tbody>
</table>
I tuned [the video narrator] out because of the words she was using, so I could just concentrate more on the pictures. #4 E

Is a lot on the picture [infographic]. I couldn’t concentrate on even one. #11 E

I just read the red ones and that’s it. Because it’s what stands out. #11 E

When I see under red letters “early death.” That’s the only thing that caught my attention. I looked twice. #4 E

It calls my attention too because I am a woman. So that’s where I went to first. #4 E

People in the market they make commercials to get your attention. It should be done that way. So need to improve…Commercials they improve your emotions. #17 E

Elder people will not like to read or make the attempt to read. They’re just going to say mmhmm or shake their head, and making you assume they understand. #4 E

<table>
<thead>
<tr>
<th>Understanding</th>
<th>I was left as very impressed that high cholesterol can do that. #26 S</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’m just going to select 20 because I just saw 20 but it doesn’t mean anything. #4 E</td>
<td>Extremely easy to understand and tell family member. #22 S</td>
</tr>
<tr>
<td>I don’t know how to relate to that. #4 E</td>
<td>High cholesterol does not hurt. #22 S</td>
</tr>
<tr>
<td>We now live in a visual area, people have social media,…they can even see emoji things… they can relate more to emoji than this...or something with a face. Even with games, they realized people react more easily when it looks like you. That</td>
<td>That image says a lot, [it’s] very strong #22 S</td>
</tr>
<tr>
<td>That way you</td>
<td>Images make more visible on the thing that can happen to the people. With the images one understands more and grasps more when one is reading it. That way you</td>
</tr>
</tbody>
</table>
**doesn’t look like no one.** Not black, not Chinese, Not even whites. #4 E

All this percentage doesn’t mean anything to regular people. They don’t care about percentage. You don’t have any idea what that means, or impact, or who you represent on that percentage. It’s like 20X of who or what? Percentage is useless for the common population. #4 E

*Interviewer:* Do you think people with low health literacy could understand this? *Participant:* Not the words but the graphics, yes. #11 E

When you do video,…you don’t need to show graphic of the blood, or whatever is happening inside, people don’t care about that. I know it’s happening. It’s just that why should I have to care? #4 E

*Participant:* That actually was a little hard to understand. *Interviewer:* What the statistic? *Participant:* Yes. #11 E

I think it’s broken down well enough for you to understand, but for me I have a hard time understanding. #3 E

Easy [to understand] #23 S (comprehension score = 33%)  
Extremely easy #21 S (comprehension score = 63%)

**see the risks and what can happen to you** #27 S

I understood it at once. With looking at the image, we think that's going to happen to me. #30 S

Tells me right away your body was born making cholesterol. I didn’t even know that until now…I thought you get cholesterol from food. I didn’t know your body makes cholesterol! #14 E

This is sometimes from family. Sometimes mother have that and sometimes daughter can have that. Sometimes third generation. Goes stuff little by little. #12 E

One [typically] says that there is high cholesterol and it is by eating a lot of fat food; but here, it is hereditary. It's something genetic and cholesterol. #26 S

I feel informed. Wow, you inherited this from birth! You started out messed up. You started out wrong, and it’s not your fault. #1 E

Somewhat easy to understand. Because a person [who is not able to read] is only seeing pictures. And they can understand that more for the person that can’t read. Because a lot of patients don’t know how to read. So pictures gives them more understanding. #9 E

If the patient cannot read, if they see a picture they can get something clear of what is going on. Because if they see [referring to picture in patient experience slide] that the person/patient is there with the
intubater [sic]. ‘Wow, I could die of this or that could happen to me.’
#9 E

[The man in the video] looked extremely sick. I don’t want to get to that point.
#12 E

It is more shocking and you understand more #27 S

[Response to scary eyes] it is informative. It makes you think. #1 E

Informative. It was good because it tells you how inherited cholesterol strikes your family. Good, testing. Quick. It had bull’s eye on your family, so it’s inherited. #1 E

You know people don’t believe what they read. #1 E

I understood it. I could relate to it. Not because of cholesterol, but because of things that happened to me in my life #1 E

<table>
<thead>
<tr>
<th>Memorability</th>
<th>I remember there was something else in the sentence but I don’t remember. But I do remember “Just getting tested.” #11 E [reported actively struggling with high cholesterol, along with her mother]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>You tell me something like this, how am I going to forget? #1 E</td>
</tr>
<tr>
<td></td>
<td>&lt;Response to watching video of man collapsing from heart attack&gt; I remembered a lot about my husband #22 S</td>
</tr>
<tr>
<td></td>
<td>&lt;Response to watching video of man collapsing from heart attack&gt; I’m like oh my god. So that brought back memories. Don’t want to go there. Never again. #14 E</td>
</tr>
</tbody>
</table>

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Emotion Results

Table 9.11 compares the effect of standard- vs experiential-reports on emotions assessed by the 5-point SAM instrument. Spark lines in the top portion display the valence (negative-positive emotions) and arousal (low-high) experienced by participants while viewing the reports.

Participants who viewed the experiential-report experienced significantly greater change in emotion both valence and arousal, as compared to those who viewed the standard-report.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Emotion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion Valence (range 0–4)</td>
<td>1.7 (0.8)</td>
<td>3.6 (0.6)</td>
</tr>
<tr>
<td>Emotion Valence Across Time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Median)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion Arousal (range 0–4)</td>
<td>1.8 (0.9)</td>
<td>3.7 (0.7)</td>
</tr>
<tr>
<td>Emotion Arousal Across Time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Median)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: All p-values are two-tailed

ANOVA (Tables 9.12 – 9.14) showed a main effect of intervention group and education, but not language and health literacy on emotion. Participants having an education lower than eighth-grade experienced more emotions (p=0.006) than those having a higher than eighth-grade education. There were no significant interaction effects.
Table 9.12 Effect of Language and Report Format on Self-Reported Range of Emotion

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>16</td>
<td>2.84 (1.28)</td>
</tr>
<tr>
<td>English</td>
<td>16</td>
<td>2.68 (1.19)</td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>3.69 (0.48)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>1.71 (0.76)</td>
</tr>
<tr>
<td>Spanish X Experiential</td>
<td>8</td>
<td>4 (0.00)</td>
</tr>
<tr>
<td>Spanish X Standard</td>
<td>8</td>
<td>1.69 (0.69)</td>
</tr>
<tr>
<td>English X Experiential</td>
<td>8</td>
<td>3.62 (0.52)</td>
</tr>
<tr>
<td>English X Standard</td>
<td>8</td>
<td>1.74 (0.86)</td>
</tr>
</tbody>
</table>

Source

<table>
<thead>
<tr>
<th>Factor</th>
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<th>df</th>
<th>p</th>
<th>eta²</th>
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<td>Language</td>
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<tr>
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<td>0.968</td>
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<td>0.334</td>
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<td>Residual Error</td>
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<td>28</td>
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</table>
Table 9.13  Effect of Literacy Level and Report Format on Self-Reported Range of Emotion

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Literacy</td>
<td>22</td>
<td>2.71 (1.17)</td>
</tr>
<tr>
<td>Adequate Literacy</td>
<td>10</td>
<td>2.47 (1.19)</td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>3.69 (0.48)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>1.71 (0.76)</td>
</tr>
<tr>
<td>Limited X Experiential</td>
<td>12</td>
<td>3.67 (0.49)</td>
</tr>
<tr>
<td>Limited X Standard</td>
<td>10</td>
<td>1.76 (0.90)</td>
</tr>
<tr>
<td>Adequate X Experiential</td>
<td>4</td>
<td>3.75 (0.50)</td>
</tr>
<tr>
<td>Adequate X Standard</td>
<td>6</td>
<td>1.62 (0.49)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
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<th>F</th>
<th>df</th>
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<th>eta²</th>
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<tbody>
<tr>
<td>Literacy Level</td>
<td>0.736</td>
<td>1.728</td>
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<td>0.199</td>
<td>0.000</td>
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<td>Report Format</td>
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<td>71.533</td>
<td>1</td>
<td>0.000</td>
<td>0.705</td>
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<td>0.195</td>
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<td>0.662</td>
<td>0.002</td>
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<tr>
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<tr>
<td>≤ 8th grade</td>
<td>7</td>
<td>3.28 (0.95)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 8th grade</td>
<td>25</td>
<td>2.45 (1.17)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experiential</td>
<td>16</td>
<td>3.69 (0.48)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>1.71 (0.76)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 8th grade X Experiential</td>
<td>4</td>
<td>4 (0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 8th grade X Standard</td>
<td>3</td>
<td>2.33 (0.58)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 8th grade X Experiential</td>
<td>12</td>
<td>3.58 (0.51)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 8th grade X Standard</td>
<td>13</td>
<td>1.57 (0.74)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Level</td>
<td>3.074</td>
<td>8.538</td>
<td>1</td>
<td>0.006</td>
<td>0.041</td>
</tr>
<tr>
<td>Report Format</td>
<td>29.913</td>
<td>83.08</td>
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<td>0.000</td>
<td>0.691</td>
</tr>
<tr>
<td>Education X Report Format</td>
<td>0.162</td>
<td>0.451</td>
<td>1</td>
<td>0.507</td>
<td>0.003</td>
</tr>
<tr>
<td>Residual Error</td>
<td>0.360</td>
<td></td>
<td>28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Facial Expressions Results with Representative Quotes

Both groups had a similar range of amount of facial expressions made (i.e., some participants did not make many facial expressions while others made many facial expressions while viewing the report). However, the type of facial reactivity differed. Those who viewed the experiential-report made more positive facial expressions (75% smiled) compared to those who viewed the standard-report (18% smiled). On average, Spanish speakers did not make more facial expressions than English speakers.

As shown in Tables 9.15 - 9.17, some participants barely moved their face while viewing the report, others only reacted to what they perceived be the most “shocking” parts, and others made facial expressions throughout the viewing session of the report, except during the reportedly intense parts.

Table 9.15 showcases a line chart representing data of a participant’s facial expressions while viewing the image displayed below. Also included are representative quotes made by the participant while viewing the image. At the 1:08 marker, the participant explains the reason for her dissatisfaction and confusion regarding how the information is conveyed. Notably, very few facial expressions are made for the rest of the viewing session. The participant summarized her experience at the end: “That make me feeling nothing. I was like what is this all about? Who cares?”
Table 9.15 Affective effects of viewing an image in the standard-report.

<table>
<thead>
<tr>
<th>Sample Image in the Report (top) &amp; Line Chart of Facial Reactions (beneath) (The red color in the line chart represents anger)</th>
<th>Representative Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image_url" alt="Image" /></td>
<td>“[This] graphic because of my Dominican Republic background I was thinking about domino’s. I was thinking about something about food, maybe they’re going to divide the plate. I don’t know any other ethnic group may think about it, but that was the most stupid way of presenting something. Unsatisfied? A LOT!”</td>
</tr>
<tr>
<td>“They feel that this graphic is worth it for people? They think people will relate and feel connected? I don’t feel relaxed. Why you make me feel like I cannot relate? I feel like that’s stupid.”</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.16 displays how a participant did not make any notable facial expressions until the 2:45 marker in the line chart, when a man collapsing displays. The representative quotes show how various participants related to the image and imagined what it would feel like to be in a similar situation.
Table 9.16 Affective effects of viewing an image in the experiential-report.

<table>
<thead>
<tr>
<th>Sample Image in the Report (top) &amp; Line Chart of Facial Reactions (beneath)</th>
<th>Representative Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Pink and yellow colors represent fear and negative feelings. Green represents surprise.)</td>
<td>That can happen to me, it gives me panic. #30 S</td>
</tr>
<tr>
<td></td>
<td>Oh my god, I was so surprised. It was shocking. The man fell down. #14 E</td>
</tr>
<tr>
<td></td>
<td>“The images like the fainting and the other people almost dying that made an impact on me rather than seeing the chart...I was like oooh. Made me look twice. #19 S</td>
</tr>
<tr>
<td></td>
<td>When I saw the video and he fell, my heart jumped. #9 E</td>
</tr>
<tr>
<td></td>
<td>With looking at the image, we think that's going to happen to me. #30 S</td>
</tr>
<tr>
<td></td>
<td>[I feel] very impacted, because imagine... #22 S</td>
</tr>
<tr>
<td>“Frightened, and at the same time, imagine: if one feels this way [like the people in the video] when you are going to feel the same thing that is going to happen to you the house, the children, the work, that gives me anxiety. The butterfly on the belly.” #21 S</td>
<td></td>
</tr>
</tbody>
</table>
Table 9.17 shows the reverse of the previous figure: Here the facial expression line chart displays the participant smiling (white color) mostly throughout her time viewing the images except for the times when viewing the “impactful” segment of images exemplified in the previous table (Table 9.16). The participant’s comments about her experience while viewing the experiential-report match her facial expression results.

Table 9.17 Affective effects of viewing an image in the experiential-report.

<table>
<thead>
<tr>
<th>Line Chart of Facial Reactions (White colors represent smiling. Green represents surprise.)</th>
<th>Representative Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“Happy but shocking.” #22 S</td>
</tr>
</tbody>
</table>

Open-Responses by Participants Regarding Emotions

Open-response reactions to the standard-report tended to be either negative or positive (Table 9.18). In contrast, open-response reactions to the experiential-report tell of an emotional journey:

The standard group began the experiment feeling calm and slightly positive, then proceeded fairly steadily in valance (“Neutral.” “Little scary.” “Bored.” “Nothing.”) and arousal (“Not arousing”) throughout viewing the report.

The experiential group began the experiment feeling calm and slightly positive, then dived into strong negative emotions (“Shocked.” “Surprised.” “Fear.” “Very Impacted.”) with high arousal (“Focused.” “Alert.” “Attentive.”) then fluctuated from strong positive emotions (“Feel altered.” “Excited.” “Very impressed.”) to very negative emotions

Men and women reported similar emotions in both intervention groups.

**Effects on the Standard Group**

Although uncommon, two of the 16 participants in the standard group shared experiencing negative feelings due to reading numbers: “Felt worried from the part where as a young person, say 50 or 60 years, can give you a heart attack” (55 yrs., Female); “Alarmed...the fact that number 250 people can die from lack of information” (69 yrs., Male). [The participant did not comprehend the statistic correctly. It is 1 in 250 people.]

Numerous participants reported feeling satisfied due to the aesthetic appearance of the standard-report (e.g., “nice colors,” “looks good,” “well organized”).

Four participants were observed yawning while viewing the standard-report. Three participants in the standard group needed encouragement to keep their attention on the computer screen during facial expression data collection. One participant fell asleep while viewing the standard-report stating that it was “boring.”

**Effects on the Experiential Group**

In the experiential group, three Spanish speakers reacted notably different to a “scary” image as compared to all others in the group. They shared that it made them feel positive, while other participants’ responses were negative. One participant had recently had a poor experience with her daughter receiving genetic information at our affiliated medical institution. Her negative experience was evident in the data collected from her reactions to the report. Her valance was muted but her arousal was high relative other participants’ responses, and she appeared angry and upset. While viewing the report the first time, she was unable to understand or process the
information well. We had her focus her attention on the calm and positive faces portrayed by the relational agent in the report, while slowly breathing for 5 minutes and provided time for her to vent. Then we had her view the report again. This time she was calm and able to easily comprehend the report. (We used the participant’s initial survey responses in the quantitative data analysis.) She said that “Beta helps with thinking.” Beta tended to influence numerous other participants as well (Table 9.18).

Table 9.18  Effect of Report Format on Open-Responses Regarding Emotions

<table>
<thead>
<tr>
<th>Representative Quotes</th>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td>S = Spanish speaker, E = English speaker</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Neutral or Negative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[I feel] relaxed otherwise I’d read it faster #3 E</td>
<td>I tell you that I scare and at the same time it helps me. #21 S</td>
<td></td>
</tr>
<tr>
<td>So bored. I felt nothing. It doesn't have no impact at all. #4 E</td>
<td>Happy. Because it was showing a person with a happy face #9 E</td>
<td></td>
</tr>
<tr>
<td>Did not do anything to me. #31 S</td>
<td>[Beta] didn’t have something good, like he was worried or something. #9 E</td>
<td></td>
</tr>
<tr>
<td>Arousing? Hell no! #3 E</td>
<td>Scared...because [Beta] is scared #30 S</td>
<td></td>
</tr>
<tr>
<td>You need to make it more emotional and attractive. #8 E</td>
<td>Negative, by the face of [Beta]. He's not very happy. #32 S</td>
<td></td>
</tr>
<tr>
<td>They have to modify that, so it’s more attractive or at least more impactive [sic] #4 E</td>
<td>Happy...[Beta] has a smile. There is a treatment for it #26 S</td>
<td></td>
</tr>
<tr>
<td>I feel like they’re wasting my time. I’m angry because...by this time I feel frustrated. #4 E</td>
<td>I felt a little worried because I see [Beta] as half scared #25 S</td>
<td></td>
</tr>
<tr>
<td>It’s just three sentences which is relatively easy to read. But it didn’t do much in terms of feeling. #11 E</td>
<td>A little disturbed. [Beta’s] face. #14 E</td>
<td></td>
</tr>
<tr>
<td>A little bit &lt;aroused&gt;. Especially when thinking about my children, my future children. That they may have it. It’s a little scary #11 E</td>
<td>Not make me feel positive. [Beta] doesn’t look positive. [Beta] looks like worrying #12 E</td>
<td></td>
</tr>
</tbody>
</table>
I feel overwhelmed…too much information #11 E, #18 S, #17 E

I don’t have to be worry. It’s not something that make me think like, “STOP!”...or something that makes me feel like this is serious. #4 E

**Positive**

Extremely positive and calm because explanation and display. #13 E

It's pretty. It's clear. Feel good. #31 S

I felt very satisfied because I was able to understand it because it was organized part by part. [comprehension score= 54%] #15 S

Excited because they are giving me information I did not know. Excited because they are giving me the chance that I can help myself, help my family. Any information that comes to you can help you and cause excitement; and it is logical that you put into action the fact that you can avoid any disease. #20 S

<table>
<thead>
<tr>
<th>[I feel] negative, by the face of [Beta]. He's not very happy. #32 S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fairly happy because [Beta] is happy #30 S</td>
</tr>
<tr>
<td>Risk of high cholesterol, it scares me. #22 S</td>
</tr>
<tr>
<td>When you say you're at risk for something, it will scare you. #22 S</td>
</tr>
<tr>
<td>You are with the disease and you are not knowing it. It impacts me. #22 S</td>
</tr>
<tr>
<td>Really positive. No depressed. No stay at home. Make me feel: “Yeah! I can do it.” #12 E</td>
</tr>
<tr>
<td>This was great! This was great. This was great. #1 E</td>
</tr>
</tbody>
</table>
Motivation Results

The difference between groups was not statistically significant with respect to motivation to act on the information, which was a variable that combined two items assessed by the 5-point instrument (Table 9.19). Multiple regression models identified two main factors predictive of feeling motivated to act on the information. The predictors of motivation were perceived ease of understanding (standard $p = 0.002$; experiential $p = 0.002$) and the final emotion (valence) when viewing the report (standard $p = 0.010$; experiential $p = 0.027$). For example, if the participant felt very positive at the end of viewing the report, the participant tended to answer that she felt very motivated to act on the information. Reversely, if the participant felt negative (dissatisfaction--not fear) at the end of viewing the report, the participant tended to answer that they felt less motivated to act on the information.

One participant’s data was excluded from this analysis due to participant’s lack of attention during this section of the study.

Table 9.19 Effect of Report Format on Motivation

<table>
<thead>
<tr>
<th>Variables</th>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$M$ (SD)</td>
<td>$M$ (SD)</td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 = not motivated</td>
<td>3.8 (1.5)</td>
<td>4.5 (0.7)</td>
</tr>
<tr>
<td>5 = very motivated</td>
<td>1.7</td>
<td>2</td>
</tr>
</tbody>
</table>

*Note: $p$-values are two-tailed

ANOVA (Tables 9.20 – 9.22) showed no main effect of intervention group, language, health literacy, or education on motivation. There were no significant interaction effects.
### Table 9.20 Effect of Language and Report Format on Motivation

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spanish</td>
<td>15</td>
<td>4.53 (0.74)</td>
</tr>
<tr>
<td>English</td>
<td>16</td>
<td>3.75 (1.43)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.5 (0.71)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.78 (1.46)</td>
</tr>
<tr>
<td>Spanish X Experiential</td>
<td>7</td>
<td>4.57 (0.78)</td>
</tr>
<tr>
<td>Spanish X Standard</td>
<td>8</td>
<td>4.50 (0.75)</td>
</tr>
<tr>
<td>English X Experiential</td>
<td>8</td>
<td>4.44 (0.68)</td>
</tr>
<tr>
<td>English X Standard</td>
<td>8</td>
<td>3.06 (1.68)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>4.751</td>
<td>4.185</td>
<td>1</td>
<td>0.051</td>
<td>0.117</td>
</tr>
<tr>
<td>Report Format</td>
<td>4.300</td>
<td>3.788</td>
<td>1</td>
<td>0.062</td>
<td>0.100</td>
</tr>
<tr>
<td>Language X Report Format</td>
<td>3.281</td>
<td>2.890</td>
<td>1</td>
<td>0.101</td>
<td>0.076</td>
</tr>
<tr>
<td>Residual Error</td>
<td>1.135</td>
<td></td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 9.21 Effect of Literacy Level and Report Format on Motivation

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Literacy</td>
<td>21</td>
<td>4.24 (1.13)</td>
</tr>
<tr>
<td>Adequate Literacy</td>
<td>10</td>
<td>3.90 (1.39)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.50 (0.71)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.78 (1.46)</td>
</tr>
<tr>
<td>Limited X Experiential</td>
<td>11</td>
<td>4.55 (0.72)</td>
</tr>
<tr>
<td>Limited X Standard</td>
<td>10</td>
<td>3.90 (1.39)</td>
</tr>
<tr>
<td>Adequate X Experiential</td>
<td>4</td>
<td>4.38 (0.75)</td>
</tr>
<tr>
<td>Adequate X Standard</td>
<td>6</td>
<td>3.58 (1.69)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>p</th>
<th>eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy Level</td>
<td>0.774</td>
<td>0.543</td>
<td>1</td>
<td>0.468</td>
<td>0.010</td>
</tr>
<tr>
<td>Report Format</td>
<td>3.651</td>
<td>2.559</td>
<td>1</td>
<td>0.121</td>
<td>0.085</td>
</tr>
<tr>
<td>Literacy X Report Format</td>
<td>0.035</td>
<td>0.025</td>
<td>1</td>
<td>0.876</td>
<td>0.001</td>
</tr>
<tr>
<td>Residual Error</td>
<td>1.427</td>
<td></td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 9.22 Effect of Education and Report Format on Self-Reported Motivation

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 8&lt;sup&gt;th&lt;/sup&gt; grade</td>
<td>6</td>
<td>4 (0.82)</td>
</tr>
<tr>
<td>&gt; 8&lt;sup&gt;th&lt;/sup&gt; grade</td>
<td>25</td>
<td>4.12 (1.29)</td>
</tr>
<tr>
<td>Experiential</td>
<td>15</td>
<td>4.5 (0.71)</td>
</tr>
<tr>
<td>Standard</td>
<td>16</td>
<td>3.78 (1.46)</td>
</tr>
<tr>
<td>≤ 8&lt;sup&gt;th&lt;/sup&gt; grade X Experiential</td>
<td>2</td>
<td>3.5 (0.71)</td>
</tr>
<tr>
<td>≤ 8&lt;sup&gt;th&lt;/sup&gt; grade X Standard</td>
<td>4</td>
<td>4.25 (0.96)</td>
</tr>
<tr>
<td>&gt; 8&lt;sup&gt;th&lt;/sup&gt; grade X Experiential</td>
<td>13</td>
<td>3.42 (0.668)</td>
</tr>
<tr>
<td>&gt; 8&lt;sup&gt;th&lt;/sup&gt; grade X Standard</td>
<td>12</td>
<td>1.57 (0.736)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source</th>
<th>MSS</th>
<th>F</th>
<th>df</th>
<th>p</th>
<th>eta&lt;sup&gt;2&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Level</td>
<td>0.070</td>
<td>0.046</td>
<td>1</td>
<td>0.831</td>
<td>0.006</td>
</tr>
<tr>
<td>Report Format</td>
<td>3.381</td>
<td>2.240</td>
<td>1</td>
<td>0.146</td>
<td>0.076</td>
</tr>
<tr>
<td>Education X Report Format</td>
<td>0.011</td>
<td>0.007</td>
<td>1</td>
<td>0.933</td>
<td>0.000</td>
</tr>
<tr>
<td>Residual Error</td>
<td>1.509</td>
<td></td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Open-Responses by Participants Regarding Motivation**

In contrast to results measured by the survey (above), analysis of participants’ voluntary feedback about motivation suggest that differences may exist. In the standard group, there was a dearth of comments about feeling motivated, as compared to the experiential group which had numerous participants voluntarily expressing strong feelings of motivation.

**Effects on the Standard Group**

In the standard group, there was only one participant who provided unsolicited feedback about motivation. All but one of her comments revealed low motivation. Highlights from her feedback are shown in Table 9.23 (see #4 comments). When prompted, another participant who shared she was struggling with high cholesterol, reported feeling motivated by a statistic (see #11 comment). Of note, other participants also had high cholesterol but did not report feeling motivated by the statistic.
A participant, who did not bring his glasses and reported twice he could not see the computer screen clearly, said that the report was easy to understand, looks good, and that it made him feel motivated. When asked what made him motivated, he replied “because one has to always help the family.” His comprehension score was 33%.

**Effects on the Experiential Group**

In the experiential group participants providing feedback uniformly reported high motivation. In fact, two participants voluntarily inquired if their respective family members could view the experiential-report because they thought it could help increase motivation to address their health issue. Another participant shared that viewing the experiential-report made her decide to follow-up on a previously-taken cholesterol test. She remarked she would go the following day to get the results.

**Table 9.24** Effect of Report Format on Open-Responses

<table>
<thead>
<tr>
<th>Standard</th>
<th>Experiential</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Low Motivation</em></td>
<td><em>High Motivation</em></td>
</tr>
<tr>
<td>They show me that this is age, the percentage---what is this all about? It didn't work. To me it was just like...OK. It don’t make me decide to go to the doctor to see if I have that condition or if anyone in my family have that. #4 E</td>
<td></td>
</tr>
<tr>
<td>It’s not going to motivate you to do anything about it. I don’t feel that I will do none of those. Why go to the doctor? I just focus on eat healthy. #4 E</td>
<td></td>
</tr>
<tr>
<td>It is simple and it says [you’re at risk]. But at the same token it’s not an urgent message. It’s not something that, do it or someone is going to &lt;makes a motion like someone is suffering a heart attack.&gt; #4 E</td>
<td></td>
</tr>
</tbody>
</table>

S = Spanish speaker, E = English speaker
It’s not like something that says: “OK you are at risk! This is something you have to take really serious and is important.” It was really light, polite, cool. But nothing that make me go straight from there to the doctor and say we need to do something. #4 E

Motivated

“Early death” Yeah, that’s the only thing that caught my attention, the only thing. …Just had an impression that someone can die. It’s just a scary feeling that I have. I would like to ask the doctor about it. #4 E

[Reason for feeling motivated]
That 90% of the people don’t know. And that maybe I’m one of them. #11 E [reported struggling with high cholesterol, along with her mother]

Yeah, very motivating to tell family to get tested #9 E

Can my sister participate? I want her to see that. I think it will be a wake-up call for her. Maybe… she will get scared and try to do--I would love for her to see that. The man fainting in the back and them giving--when they’re trying to resuscitate in the street. That would be good for her to see. That would motivate her to lose weight. So maybe if she sees that she will try to change #14 E

I always go and I do my checkup because I am afraid for my heart. #21 S [participant’s brother died young from a heart attack]
Relationships Among Understanding, Comprehension, Emotion, and Motivation

Exploratory analysis was done to variables of the same type for each experimental condition (Standard, Experiential) to examine their relationship. This section includes correlational analysis, Chernoff faces, and hierarchical clustering results.

Correlational Analysis

Table 9.25 presents the intercorrelations among five variables on data from the standard condition for 16 participants. The results suggest that 4 out of 10 correlations were statistically significant: Three were greater or equal to \( r = +.62, p < 0.05 \), two-tailed; and one was \( r = -.54, p < .05 \), two-tailed. The latter, correlations of age and comprehension were not significant with other variables. Moderately strong correlations were found between perceived ease of understanding (“Understanding”) with feeling motivated to act on the information (“Motivation”), \( r = .70, p = .002 \) and self-reported emotion (“Emotion”), \( r = .79, p = .000 \).

Moderately strong correlations were also found between emotion and motivation, \( r = .62, p = .010 \). Correlations with the “Emotion” variable were performed using the last valence (negative – positive emotion) the participants reported at the end of viewing the report. According to the peak-end rule (366), people do not judge experiences by the average of every moment. Instead, people judge an experience largely based on how they felt at the most affectively intense moment and at its end. Many of our participants had multiple equally-high “peaks,” so we were uncertain about how to adequately represent “peak moment” as a variable. We proceeded by using the maximum-change-in-valance to calculate the “pseudo” peak moment, acknowledging its limitations to adequately represent the formal construct. Correlations of the pseudo-peak
moment with other variables were not significant. However, correlations with the “end” variable, or the last reported valence, showed statistical significance. We report them in the Tables 9.25 and 9.26.

Table 9.25  Intercorrelations (Pearson Correlation) Among Variables of the Standard-Report

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. UNDERSTANDING</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>0.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>0.461</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. COMPREHENSION</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>0.79</td>
<td>-0.03</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>0.000</td>
<td>0.917</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. EMOTION</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>0.70</td>
<td>0.02</td>
<td>0.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>0.002</td>
<td>0.947</td>
<td>0.010</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>4. MOTIVATION</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>-0.16</td>
<td>-0.54</td>
<td>-0.11</td>
<td>0.19</td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>0.558</td>
<td>0.030</td>
<td>0.676</td>
<td>0.481</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 9.26 presents the intercorrelations among five variables on data from the experiential condition for 16 participants. The results suggest that 3 out of 10 correlations were statistically significant: Three were greater or equal to $r = +.54, p < 0.05$, two-tailed. The correlations of age and comprehension with other variables were not significant. Moderately strong correlations were found between perceived ease of understanding (“Understanding”) with feeling motivated to act on the information (“Motivation”), $r = .81, p = .000$ and self-reported emotion (“Emotion”), $r = .69, p = .003$. Moderately strong correlations were also found between emotion and motivation, $r = .54, p = .032$. 
Table 9.26  Intercorrelations (Pearson Correlation) Among Variables of the **Experiential-Report**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<td>1. UNDERSTANDING</td>
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**Chernoff Faces**

Figure 9.1 is a summary of results depicted through Chernoff faces, each face representing a participant. Each result (e.g., perceived ease of understanding, comprehension, emotion, motivation) is depicted through different facial features (e.g., the wider the face, the higher the comprehension score). (See legend in Figure 9.1 for further details.) Age and education are included as they were statistically significant in some of the exploratory analyses (e.g., older age correlated with reduced comprehension on the Standard-report). Chernoff faces provide an intuitive, fun view to qualitatively assess which participants perceived to understand, were emotionally impacted, and felt motivated to act on the information.
Figure 9.1 Chernoff faces of each participant, with different facial features portraying effects of report format on understanding, emotion, and motivation, plus participants’ respective age and education level.
Hierarchical Clustering

Hierarchical clustering was performed across standard and experiential groups on variables ease of understanding, comprehension, emotion, and motivation to reveal four clusters (Figure 9.2).

Four Chernoff faces summarize and portray the underlying data for each cluster.

Figure 9.2 Results from hierarchical clustering. The horizontal line dividing the circular cluster diagram delineates the experiential group (above) from the standard group (below).
Cluster details are shown in Table 9.27 along with representative facial expression line charts, and representative quotes from participants in each cluster.

(Note: in the “Representative Facial Expression Line Charts,” the green line represents facial expressions of “surprise.” The consistent green mini-peaks in the line charts tend to coincide with the times the image on the computer changed during the experiment.)

**The first cluster** \(n=3\) (100% standard group) comprised of only English-speaking participants with adequate education, younger than average age, and adequate comprehension scores, but reporting hard to understand, little change in emotion, and low motivation. Representative facial expression data corroborates with self-reported neutral/negative emotions which is reinforced by verbal responses.

**The second cluster** \(n=6\) (100% standard group) had opposite features (mix of English & Spanish, less educated, older, easy to understand, low comprehension scores, high motivation) than the first cluster except they both experienced little change in emotions, which is corroborated by the facial expression data. The verbal response reinforces the summary statistics.

**The third cluster** \(n=10\) (70% standard, 30% experiential) comprised of features that were more or less average. In general, facial expression data did not always corroborate with other results. For example, the representative quote for this cluster represents positive emotion while the facial expression data displays a different story.

**The fourth cluster** \(n=12\) (100% experiential group) comprised of optimal features (easy to understand, high comprehension scores, large change in emotion, high motivation). Participants had a mix of inadequate and adequate education, half were Spanish-speaking, and older than average age. Representative facial expression data show that the participant made the maximum number of facial expressions the software is able to classify.
**Table 9.27** Cluster Details Conveyed by Chernoff Faces, Summary Statistics, Representative Facial Expression Line Charts, and Representative Quotes. (Key for abbreviations at bottom of table)

<table>
<thead>
<tr>
<th>Report</th>
<th>Cluster Chernoff Faces</th>
<th>Summary Statistics</th>
<th>Representative Facial Expression Line Charts</th>
<th>Representative Quotes</th>
</tr>
</thead>
</table>
| **STANDARD** | <image> | n: 3  
Easy: 2.7  
Com: 80%  
Emo: 1.1  
Mot: 1.3  
Educ: >8<sup>th</sup>  
Age: 42y  
Eng: 100%  | <image> | “Neutral. I’m not getting what I want.”  
#8 E |
| | <image> | n: 6  
Easy: 4.4  
Com: 67%  
Emo: 1.7  
Mot: 4.6  
Educ: ≤8<sup>th</sup>  
Age: 58y  
Eng: 40%  | <image> | “It explains me well. [But] I do not know if I answer the [comprehension] questions well.”  
#29 S |
| | <image> | n: 10  
Easy: 3.2  
Com: 85%  
Emo: 2.8  
Mot: 3.4  
Educ: >8<sup>th</sup>  
Age: 47y  
Eng: 60%  | <image> | “<I feel> positive ...I have the report that gives me the information, so I cannot be negative.”  
#20 S |
| **EXPERIENTIAL** | <image> | n: 12<sup>**</sup>  
Easy: 4.9  
Com: 93%  
Emo: 4  
Mot: 4.8  
Educ: ≤8<sup>th</sup>  
Age: 55y  
Eng: 50%  | <image> | “Motivated 100%”  
#22 S |

**KEY**  
Easy = Ease of Understanding (1 - 5)  
Comp = Comprehension (0% - 100%)  
Emo = Change in Emotion** (0 - 4)  
Mot = Motivation (1 - 5)  
Educ = Education (≤8<sup>th</sup> or >8<sup>th</sup>)  
* = 30% of participants have ≤8<sup>th</sup> grade education  
Eng: Preference for English rather than Spanish

**Average of Valence and Arousal results**

***One participant in the experiential group was excluded from the cluster analysis due to being excluded from other sections of the analyses.***

****Facial expression software does not identify “fear” as a separate emotion.
Aim 4 Discussion

Our study found that for format and features we should incorporate a colorful multi-media (e.g., text, images, video) graphic novel with an animated, cartoon face serving as a relational agent to communicate nonverbal information (e.g., emotions) through its facial expressions. The experiential-report would be tailored by language preference (Spanish vs English) with slight changes to the designs informed by prior studies with the target audience.(Study 2)

For content, we learned to include the essential message of the genetic test report (vetted by a senior geneticist), information about patient experiences (feeling and facts) of disease impact on life and family, content that builds rapport, content that stimulates emotions (arousal; fear, surprise, hope), and information that conveys gist understanding.

Although there were many examples in the literature on how to present numeric risk information in genetic test reports (257,268,367–370), there was little guidance in the literature on how to develop an experiential genetic test report. To our knowledge, there were no prior examples related to visually helping LHL and LEP individuals intuitively understand that they are at risk through feelings and to see what they are at risk for.

Aim 5 Discussion

Understanding
There were significant differences in understanding between the standard- and experiential-reports according to various measures. Participants who viewed the standard-report indicated the report was harder to understand than those who viewed the experiential-report, on perceived ease of understanding ($p=0.010$) and comprehension ($p=0.039$). Most participants (75%) had a difficult time processing the numbers in the standard-report. They either failed to initially pay attention to the numbers, and/or they were unable to recall the numbers when answering verbatim comprehension questions. As for gist comprehension, participants having an education higher than eighth-grade comprehended the reports better ($p=0.002$) than those having an eighth-grade education or less. Of note, unlike in the standard group, no one in the experiential group volunteered suggestions for improvement.

There were a few differences by language preference. Spanish speakers reported higher perceived ease of understanding ($p=0.040$) than the English speakers. No Spanish-speaking participant who viewed the standard-report offered suggestions for improvement, and instead, many said the information was easy to understand.

One of the desired outcomes from viewing the genetic reports is to tell a family member about the information.(371) Kaphingst et al, (372) reports that Latinos (OR = 1.85; $p = .001$) have greater interest in discussing information with family than Whites. However, our findings suggest that Latinos’ desire to share information with family may differ based on type of report format they receive. That is, findings suggest that participants who viewed the experiential-report have a higher likelihood of being able to verbally share the genetic test information with a family member. This is due to the fact that after viewing the experiential-report, many participants voluntarily shared correct interpretations of what they learned from the report. In contrast, not one participant voluntarily verbalized anything that she learned after viewing the standard-
Further, in the standard group, many of the participants’ comments indicated disinterest to engage and difficulty concentrating due to too much information and not being able to relate. Some comments indicated that the report was easy to understand, however, comprehension scores did not support these statements.

It is generally known that individuals with LHL have difficulty processing risk numbers such as probability; however, it is not clear how Latinos with LHL and LEP interpret risk numbers that are supported by visualizations (such as icon arrays and bar charts). Some great work has been done examining effects of risk graphics on individuals who have LHL. For example, Hawley et al found that pictographs are the best method for conveying probabilistic information, particularly for those with low numeracy. Their findings were corroborated by McCaffery et al, who demonstrated that for adults having low education and literacy, pictographs performed well when displaying small numerators (<100/1000). Zikmund-Fischer et al extended their pictograph work by investigating icon type performance. They found that restroom icons performed the best overall but were no better than ovals and blocks for individuals with low literacy. However, we found that even with the use of the recommended restroom icon pictographs, numbers were often misinterpreted, ignored, and forgotten by most participants (75%). This may suggest that even with the help of supportive visualizations, numbers may be difficult to process, relate to, and be found meaningful by Latinos with LHL and LEP. Thus, the numbers + visual aides may confer little benefit and may even do harm for these individuals. For example, one of the participants felt “Alarmed” by a statistic she incorrectly interpreted that was embedded in a pictograph.

There are few examples in the literature regarding understanding risk through feelings. We found one related study. Morrow et al report that individuals were able to feel and
understand risk information by viewing a combination of a graphic (a bar of green, yellow, red colors with happy and frowny glyphs) and video of a care provider verbally reporting the outcomes of test results). This multi-channel communication of test results is promising. However, it may leave many individuals “experientially-blind.” For some, the problem is not that people do not understand that there is a problem, it is that people may not see how the problem could affect their life. Being provided a valence-label that a test result is bad or good does not provide understanding of what is at risk. As one participant who viewed the experiential-report explained:

“The images make more visible on the thing that can happen to the people… you see the risks and what can happen to you.”

**Emotions**

There were significant differences in emotions between the standard- and experiential-reports according to various measures. Participants who viewed the experiential-report experienced significantly greater change in emotion both valence and arousal, as compared to those who viewed the standard-report. Participants having an education lower than eighth-grade experienced more emotions ($p=0.006$) than those having a higher than eighth-grade education. Facial behavior in the experiential-report group had more incidences of positive facial expressions than in the standard-report group. Open-response reactions to the standard-report tended to be either negative or positive. In contrast, open-response reactions to the experiential-report describe an emotional journey. Men and women reported similar emotions in both intervention groups. A couple of participants who viewed the standard-report reported feeling bored, as opposed to the general aroused state of the experiential group. One participant fell asleep while viewing the standard-report, while a handful yawned.
To our knowledge there have been few studies investigating the emotional impact of viewing health risk information in visualizations. Although not risk information per se, as previously discussed, Morrow et al (376) provided gist labels and a video explanation of high cholesterol test results and found that participants reported affective feelings appropriately. The researchers assessed the emotional reactions of twelve older adults (average age 77 years, range 65–89 years, 67% females) who were native English speakers. Our work contributes to the literature on affective responses to test results and risk information as we assessed reactions by non-native speakers with LHL and LEP. Another example of assessing emotional response to health information presented in visual format is a study conducted by Daniëlle et al (377) on university students in the Netherlands. The researchers found that emotional impact differed by risk presentation format (percentages, frequencies, and population figures (e.g., 20 black human figures and 80 white human figures)). Population figures had the biggest emotional impact and risks presented as population figures were evaluated as significantly greater than the risks presented in other formats. This comparison between numbers vs graphics corroborates with our findings. Numbers seem to have less effect on emotions compared to visuals, even for educated individuals. Of note, in their study the population figures were rated as harder to understand compared to the numbers. The researchers attribute this to the high education level of their participants who were accustom to numbers and percentages to consume risk information.

**Motivation**

There was no significant difference in motivation between the standard and experiential groups according to survey measures, however, other measures indicate there may have been a difference. It is not surprising that survey data did not capture a significant difference in attitudes on motivation between the experiential- and standard-reports. We are aware that survey results
have been noted for having high social desirability bias in the Latino community.\(^{(378)}\) Moreover, we note that responses to the survey question assessing motivation to tell family, may have been particularly biased in both groups, because the Latino participants showed sensitivity to stimuli related to family. As one participant, who despite not being able to see the report due to not bringing his glasses, indicated, he felt very motivated to tell his family because “one always has to help the family.” So, we are mindful when interpreting the motivational survey data as they may have been inflated in both intervention groups.

Findings from the literature suggest that participants who viewed the experiential-report may have an increased likelihood of sharing the information with family members compared to those who viewed the standard-report. That is, researchers like Berger et al \(^{(343)}\) have found that arousal increases likelihood of sharing information. Participants who viewed the experiential-report felt high arousal. In contrast, behavioral observations and self-report data indicated low arousal and low interest in some participants who viewed the standard-report. As previously mentioned, numerous people were viewed yawning, looking away from the report, and one person even fell asleep. This type of behavior was not observed in the experiential group. Further, open-responses suggest that there was higher motivation in the experiential group. Numerous participants, during the open comment session, voluntarily shared how they felt motivated. Not one participant who viewed the standard-report voluntarily shared that she felt motivated. Instead, the only voluntary comments related to motivation were about feeling unmotivated. When probed, one young participant who had adequate education and health literacy, reported she felt motivated due to reading a statistic. She went on to share that she was already concerned about her high cholesterol because as a young person she had to take medication for it. She expressed she was worried she had the genetic condition because her mother was struggling with high cholesterol as well. This may suggest that for individuals who
are already feeling concerned and have adequate health literacy, they may benefit from receiving the standard-report. Of note, this participant happen to view the experiential-report after the end of the experiment, and reported that she preferred the experiential-report and asked if her mother could view the experiential-report. Likewise, another participant in the experiential-report group asked if her family member could view the experiential-report. In contrast, no one who viewed the standard-report asked if their family member could view the standard-report. Lastly, one participant expressed the experiential-report prompted her to go the following day to check on past cholesterol tests.

**Relationships Among Understanding, Comprehension, Emotion, and Motivation**

**Standard-Report Reactions**

Reactions to the standard-report clustered into three groups. We will focus our discussion on two, which we call the dangerous and the undesired, because they presented the most interesting findings. The third group, which we call the lukewarm, reported tepid results on all measures.

**The Dangerous Group: How aesthetic appeal may mislead the uninformed**

Perhaps the most important takeaway from what we call the dangerous group is that aesthetic appeal, when coupled with low comprehension, may mislead uninformed participants into feeling confident about their ability to understand the report and may influence feelings of motivation to act.

We found that aesthetic appeal of information may have induced positive affect, which may in turn have influenced positive attitudes in ease of understanding and motivation. Participants in
this group perceived the report to be clear, well organized, and “looked good.” They attributed their feeling good to the clarity of the information and the aesthetics of the report. Through regression analysis, we found that their positive feelings predicted their positive attitudes towards perceived ease of understand and motivation. These findings corroborate with others: Fazio et al., found that aesthetics can influence positive feeling (379), and psychological literature reports that feelings (emotions) are sometimes the driving force behind our attitudes and behavior. (380) However, attitudes of perceived understanding did not correlate with true understanding. Indeed, this cluster of participants demonstrated the lowest comprehension in the entire sample (by behavior, questionnaire, and verbal response). Moreover, these individuals had minimal education, which means they favor using their feelings to make decisions rather than analyzing information. This may suggest that for those who had trouble comprehending the content, their attention focused on what the report looked like, because aesthetics was the most obvious and accessible stimulus.

Perceptions of clear aesthetic design may have increased belief in understanding. Alter et al found that the clearer and easier information was to consume, the more confident people felt that they understood the information. (381) This is phenomena known as perceptual fluency. (326) Kiani and Shadlen provide evidence that confidence leads to decision-making. (382) That is, people make decisions when they feel confident.

The danger here is that aesthetic clarity of information may improperly induce confidence of understanding, and in turn, may increase decision to act. Action with poor understanding sets the stage for unfavorable outcomes.
Undesired Group: How comprehension is not enough

Traits in the undesired group are the opposite from the dangerous group.

The lesson learned from the undesired group is that designing risk information reports solely to maximize comprehension is not enough to motivate individuals. This is congruent with what has been implied throughout this discussion—that information alone does not motivate individuals to act.

Participants in this group had some of the highest comprehension scores among those who viewed the standard-report. However, they were the least motivated. They also reported that they found the information harder to understand, compared to the dangerous group, despite being more educated. In addition, they were unsatisfied with the aesthetics, commenting that the report needs to be improved to be more attractive and to include emotion. Perhaps differences in perceptions of the aesthetics between the undesired group and the dangerous group may partly be attributed to cultural influences. Everyone in the undesired group preferred to speak English, unlike in the dangerous group which was mixed. As discussed in Study 2, language is often used as an indicator of cultural orientation. The burgeoning field of cultural psychology has often demonstrated the subtle differences in the way individuals process information—differences that appear to be a product of cultural experiences. There is clear evidence that sustained experiences may affect both brain structure and function. Thus, it is reasonable to posit that sustained exposure to a set of cultural experiences will affect neural structure and function and produce different interpretations. Participants whose English is proficient may have had more exposure to America’s richly visual culture, which served as the comparison to which the aesthetics of the report were judged. As one participant complains:
“Those type of graphic I saw it 25 years ago [when the participant was in the Dominican Republic]. Now it is old. Now they have to modify that, so it’s more attractive or at least more impactive [sic]… We now live in a visual area, people have social media, people have access to things, they can even see emoji things… they can relate more to emoji than this. You can ask some with 60 years with emojis, they will tell you more easier [to relate]. Or something with a face. Even with games, they realized people react more easily when it looks like you. That doesn’t look like no one. Not black, not Chinese, Not even whites. That doesn’t look like no one.”

The participant touches upon another important finding. These participants and those in the dangerous group, did not provide any evidence that suggests they experienced the affective risk information in the reports. That is, they did not feel the risk information, even though they comprehended it. The brain’s dual information needs to understand risk, were not met. This may be due to not being able to relate to the report, as the participant reported.

Together, the two groups (dangerous and undesired) comprised of a little over half of the group that viewed the standard-report. The rest was comprised of the lukewarm group. Perhaps these are not desired outcomes.

**Experiential-Report Reactions**

The majority (80%) of those who viewed the experiential-report felt the risk information and understood the information. Reactions were not as divided in this group, as compared to the group that viewed the standard-report. Unlike in the standard group, there were no complaints about the aesthetics of the report. In fact, the aesthetics of the report seemed altogether ignored. This may indicate that the report was appropriately designed. A common mantra in user experience design is: “The best interfaces are the ones you don't notice. They facilitate total absorption in what one is doing in the interface.”
Indeed, the visualizations appeared to support quick transportation into the lives of others’ experiences. “I understood it at once. With looking at the image, we think that's going to happen to me.” #30 S

**Impact of patient-experience content delivered through visuals**

To our knowledge, this is the first incorporation of real patient-experience content (videos, images, quotes) from the literature and gray literature into a genetic test report. The data suggest that the patient-experience content impacted the participants.

“The images like the fainting and the other people almost dying that made an impact on me rather than seeing the chart… I was like oooh. Made me look twice.” #19 S

“It is more shocking and you understand more.” #27 S

“Felt changed because of what patients say about the condition.” #18 S

The patient-experience content helped turn abstract concepts of the dangers of high cholesterol into concrete meaningful experiences for the experientially blind: “I was left as very impressed that high cholesterol can do that.” For others who had endured previous traumatic experiences, their experiences of viewing the experiential-report were reinforced by their previous negative experiences. They demonstrated what Barrett calls “top-down” influence. This is when the brain recombines prior experiences and relates them to the one presented, making sensory input meaningful. For example, participants said: “I understood it. I could relate to it. Not because of cholesterol, but because of things that happened to me in my life;” “I’m like oh my god. So that brought back memories. Don’t want to go there. Never again.”

Unlike in the standard-report, no participant reported not knowing where to look or feeling overwhelmed by too much information. Contrary to the observed behavior with the standard-report, participants maintained their attention on the experiential-report during the viewing
session. Participants reported relating to and feeling impacted by various emotional images and words. For example, some felt most aroused by seeing the impact on family, for others it was not being able to work, and for another, it was seeing a picture of an intubated patient. Thus, we believe it is important that experiential-reports furnish various emotional stimuli because people are different and react to emotional stimuli differently (385) at different times in their life.(386)

**How a Cartoon Relational Agent Can Guide and Invoke Feelings**

It was unclear at first whether the Latino community would be able to relate to a mute cartoon emotive head. Turns out, the relational agent (RA) was well received. To our knowledge, such an RA has not been used in the low health literate Latino community. Both English and Spanish speakers related to and were influenced by “Beta,” the RA. Specifically, participants looked to Beta for guidance on how to feel and think about the information and where to look to consume the information. For example, participants reported feeling: “Scared… because [Beta] is scared;” “Happy…[Beta] has a smile. There is treatment for it.” Interestingly, the participants’ reported emotions changed in accordance with Beta’s changing facial expressions. Beta even influenced a participant to feel motivated because the participant perceived Beta to be motivated: “You identify yourself with [Beta] too. So one is motivated too.” Beta seemed to be an effective agent at supporting communication of affective-information.

We were curious whether the men’s emotions would change according to Beta’s changing facial expressions because the literature suggests that men do not read faces as well as women do. The men in our sample did not appear to have trouble discerning Beta’s facial expressions, and their emotional evocations reflected Beta’s facial emotion.
These results suggest that one may be able to influence and design an emotional experience for Latinos with LHL and LEP by using an appropriately designed RA. Of note, Bickmore et al found that RAs were not as compelling in high literate individuals. Putten et al proposes that relating to an RA has to do with personality rather than other socio-demographic factors. (387) We considered assessing personality for this study. However, presently, to our knowledge, personality types are not typically assessed nor stored in the medical record nor typically assessed in research studies. Thus, designing an RA for a specific personality type or investigating which personality type works well with an RA and which does not, would have little practical value because personality type is generally not available. While we surmise that some participants liked Beta more than others, evidence for this did not surface in the data collected.

One might say that Beta helped the participants feel more engaged with understanding the information because participants were attentive to him while viewing the report. This is congruent with findings from other researchers such as Bickmore et al, who have shown how an RA can help LHL individuals attend to medical information and increase engagement. (300,301,388) However, their RAs spoke and had torsos with arms which were used to direct attention. Nonverbal affective-information seemed to be less emphasized on the faces of their RAs, as compared to our RA. To our knowledge, other researchers did not base their RA’s facial expressions on “evidence-based” facial expressions to communicate specific emotions. Our RA used its animated eyes to guide where to look on the report and participants followed where the RA looked. Instead of verbally speaking, we used word bubbles such as those used in graphic novels, which the participants did not appear to have difficulty understanding. Other researchers have found the graphic novel format effective at communicating health information to the Latino community. For example, Chan et al, found that a Fotonovella, a graphic novel, was effective at
communicating preventative health information to Latinos. They did not have an RA in their graphic novel, however.

As a participant said: “Beta helped with thinking.” #10 E

*How emotions should be wielded with knowledge*

While the intense emotions participants felt reportedly helped them: “I tell you that I scare and at the same time it helps me,” the experiential-report was not designed for, nor should be shared with, individuals who are already feeling highly aroused, agitated, or scared. According to arousal theory, high levels of arousal or emotions can hinder cognition. One of the participants was in a state of high arousal when viewing the experiential-report so we needed to help her calm down before viewing it. Of note, the experiential-report can easily be adapted to evoke less arousal, which we found during our pilot study (e.g., by changing Beta’s face, colors, images, video). Information resources that furnish affective-information need to be matched to appropriate mental and emotional states of the individual. This intervention may work well in the first two stages of change, for example, in the transtheoretical model, which is a framework for understanding and intervening with human intentional behavior change. The first two stages, the precontemplation and contemplation stages, are when individuals are not intending to change and those who are contemplating change.

One emotional reaction experienced by numerous participants may have contributed to attention to and processing of the information: surprise. After viewing the report, some participants remembered and commented on information learned when they felt surprised. It may appear that information associated with surprise may be more memorable than non-surprising information. This corroborates with findings by Fenker et al, who report that participants remembered words better when they were associated with unexpected stimuli.
Literature suggests that surprise functions to allocate attention to a stimulus, thereby encouraging subsequent analysis of its implications for the individual. Leveraging surprise may work well to influence individuals who are more inclined to ignore risk information because they feel they already know about the condition (i.e., high cholesterol), and who hold attitudes and values that are inconsistent with the information contained in the report.

Expectations play a large role in how information is interpreted. Of note, this report may not provide an experience of surprise or shock for individuals who are told, before viewing, that the report is meant to manipulate emotions and has a shocking scene. The brain will then expect provocative emotional stimuli which will dampen the effect of the surprise.

**Strengths**

There are a number of strengths in our study. First, the report was iteratively designed with the target audience’s (community members’) feedback. Community members were randomly approached on different days and times in different settings. We applied theories, literature, and lessons learned from Studies 1-3 to guide design and content.

For the evaluation, we used random assignment and mixed methods; we collected diverse data types using various methods of measurement including subjective and objective standard instruments and investigated the of depth experience through qualitative measures. We designed the experiment to curb social desirability bias where possible. We also employed a range of analysis methods and cross-checked results through triangulation. There were two interviewers (one for each language preference: Spanish vs English). This may have influenced data collected for the Spanish- vs English-speaking groups. We tried to minimize differences by following a standard interview guide. Next, we used theory-based approaches to guide the development and evaluation. Lastly, although the data in the experiential- and standard-reports were hypothetical,
there is considerable precedence to the use of hypothetical methodologies and strong evidence to show that behaviors based on real or hypothetical situations are highly correlated.(393,394)

**Limitations**

Limitations of our study include the generalizability of our findings, especially given the small sample size. The study was conducted at a single community center and academic center in an urban location, and therefore, our results may not be generalizable to other settings and Latino populations. The genetic information provided in the reports were hypothetical. This could affect the ability to generalize findings beyond an experimental setting.

**Contributions**

**Theory**

There was a theoretical contribution that came out of our work. We applied the experience framework to a novel area: risk communication for Low Health Literate Individuals. This demonstrated a novel way to organize and understand patient experiences with health information, using the four "Realms of Experience". Lessons learned from each Realm of Experience informed our design of Study 4. The framework also helped identify a gap in the literature that we sought to fill with this study regarding the emotional effects of information on patients. This framework may be useful for others who conduct research in patient experiences, to guide the design and evaluation of their studies.

**Methods**

This study made two methodological contribution to visualizations as a biomedical informatics method. First, we contributed a novel method of developing an informatics solution. We researched and applied findings and theories from various fields such as psychology,
neuroscience, perception, visualization, cultural studies, and communication to guide the selection of design features and content to support effective communication. We also reviewed relevant literature to leverage the expertise of other researchers who examined patient experiences; we then weaved their findings into the report's content.

Second, this study made a methodological contribution in evaluation of visualizations as a biomedical informatics method. We aimed to measure emotional impact of the stimuli using a standard self-report scale and by unobtrusive facial analysis software that labels the emotions of facial behavior using machine learning techniques. We further supplemented these data with open-response data related to emotion. Asking the question of, “How does this make you feel” in informatics is relatively new. We found the data collected from this question especially helpful in deciphering the results. We encourage others to consider investigating the emotional impact of informatics interventions where applicable, because emotions play a large role in human behavior and decision-making.

Finally, we contributed a novel mixed-methods evaluation approach to understand the patient experience of health information. We triangulated a rich, diverse data set gathered using a range of methods (e.g., behavioral observation, facial analysis software, open-responses, multiple-choice questionnaire, survey) and collected various data types (quantitative and qualitative) and employed various analysis methods (e.g., ANOVA, directed content analysis, image analysis, regression analysis, clustering, visualization) that helped surface meaningful insights that would have otherwise not been discerned using one or even two evaluation methods.

**Substantive**

There were two substantive contributions:
Study 4 made a substantive contribution to visual approaches for risk communication. Methods to communicate risk information have emphasized supporting comprehension of numbers and probabilities; however, numbers are challenging for individuals with LHL and LEP to understand, and may not be effective at increasing motivation to act on risk information. We introduced a visualization method to support intuitive, visceral understanding of risk information. This approach could facilitate easier, quicker and more impactful communication of risk information for individuals with LHL and LEP, compared to previous approaches.

Study 4 made a substantive contribution to vicarious experiential learning (VEL). VEL is the process of learning vicariously: “The behavior of observers can be substantially modified as a function of witnessing other people’s behavior and its consequences for them.” (30) VEL is a promising method to quickly communicate information between individuals with minimal effort. However, it has generally been untapped, as the literature for it scant. Furthermore, it is unclear if VEL through visualizations has been investigated. Study 4 contributes to this effort. Findings suggest that through the medium of visualizations, individuals with LHL and LEP were able to instantly grasp gist-understanding and affect-understanding of risk information. VEL through visualizations appeared to provide a more complete understanding of risk than descriptions through text and numbers + visuals aids. This is ripe territory for further investigation.

**Future Steps**

In future studies, the relational agent (RA) could be used to convey emotions in other informatics solutions for Latino individuals with LHL and LEP, as the RA’s many faces are standardized “boilerplates” that could easily be applied. Specifically, studies may want to evaluate how the image size of the RA affects interpretation. We first introduced a larger image of the RA then reduced its size later in the report as familiarity with the RA increased. However, we noted that
some participants were slower at recognizing the RA’s facial expression in the smallest image of the RA. One participant even misinterpreted a facial expression, which emphasizes the need for testing with the target population. For individuals who have difficulty reading faces (e.g., individuals with autism), the RA may not be helpful. Contrary to Ekman et al’s findings (395), Gendron et al (396) contend that not all cultures interpret facial expressions the same way. Hints of this in our study were exemplified by three of our Spanish-speaking participants who reported positive feelings while the rest of the cohort reported negative feelings when viewing a “scary” pair of eyes. This reinforces that it is important to test all visuals used in health communication interventions with the target population.

Future studies could consider focusing on younger populations as well as suburban and rural communities. Sharot et al (386) report that information integration alters with age. Specifically, younger and older adults do not internalize negative information as much as middle aged individuals. The youngest participants in our sample were not younger than 25 years, it is unknown how young individuals would react to the two reports.

Next, researchers may want try automatically scraping quotes from patient experience studies to include in the experiential reports. Our efforts to do so were hampered by unyielding older manuscript formats. We anticipate the body of patient experience studies will grow, which will offer easier formats to automatically scrape texts of interest.

Finally, future studies may also want to add audio narration and use actors to convey affective information in patient experience quotes.

**Conclusion**
Findings suggest that report format may affect responses to genetic test result information. Specifically, findings suggest that reactions to viewing a “standard” genetic test report by Latino individuals with low literacy, numeracy, and English proficiency varied between poor to mediocre on understanding, appropriate emotional interpretation, and motivation to act on the information. These traditional techniques for conveying risk information provide incomplete knowledge to the brain, in order for it to understand and act on risk information. Thus, we aimed to provide risk information in two ways to help Latino individuals with low literacy, numeracy, and English proficiency easily understand and “feel” risk vicariously through experiential visualizations. This technique differs sharply from traditional approaches emphasizing deliberation and conscious effort. We designed, and report favorable outcomes of, a visual dual-information level genetic test report housing gist information and affective information that improves the experiential meaning of genetic risk information.

Our study helps shed light on how and when visuals designed with two information channels (affective and cognitive) may facilitate meeting the dual information needs of the brain to process understanding of risk. Such a report may help improve understanding of risk.

More research is needed to uncover underlying individual differences in the cognitive processing of visually represented health risks, as our findings indicate there may be differences in how information was processed within the same racial/ethnic group based on language preference.

Our study contributes to the literature by identifying ways that emotions influence decision processes in the low health literate Latino community. This research has implications for understanding and motivating healthy behaviors. Visuals that include affective information are currently an under-tapped resource with potential for improving the meaningfulness of risk information.
Chapter 11

General Discussion

This final chapter, we present a discussion of the significance of our research contributions, strengths and limitations of the studies, followed by recommendations for future research.

The studies presented in the preceding chapters represent efforts 1) to utilize clinical informatics techniques to understand the patient experience with health information and 2) to leverage that understanding to inform the design of an informatics solution using visualizations to enhance the patient experience with health information. The studies focused on individuals most vulnerable to poor health outcomes. We used Pine and Grove’s Experience framework to guide our investigation into understanding and enhancing the patient experience with biomedical information for vulnerable individuals. Figure 11.1 summarizes our approach to both study and design for an optimal patient experience.
We used this framework because each construct in the experience framework is important in the process of making information meaningful, which is a goal of biomedical informatics. (1) Patients who do not have a good experience, as defined by the experience framework, often fail to find meaning in data and health information, as evidenced in Study 4.

As with patient experiences, information needs vary along the continuum of the health state. So to provide a good experience with health information, we studied patient experiences in various health states in Studies 1 – 4. Each study explored a different “realm” in the experience framework with patients in different health states. While there have been many studies investigating the patient experience with health information (397–403), until now they have not been framed in an experience framework to elucidate empty “realms” that have not been explored (397–400,404–409). We will discuss the significance of our findings in each study and how Studies 1-3 informed the design of an informatics solution in Study 4.

**Figure 11.1** Guide to how concepts from the Experience framework relate to each study, and how lessons learned from each study inform the Study 4.
**Study 1: Understanding the Patient & Family Experience in the Inpatient Setting**

In study one, we investigated a relatively new information landscape for patient-centered applications, the inpatient setting. With burgeoning popularity of inpatient personal health records (IPHR), little was known about what patients would find meaningful and useful in these IPHRs. In this study (Chapter 3), we learned that inpatients and their family members have high interest in receiving and understanding information relevant to understanding the status of their care, their treatment, and what to expect. We discovered that providing information in a user-friendly format has the potential to reduce anxiety, prevent medical errors, and facilitate patient activation. For example, after viewing the user-friendly patient medication list, a family caregiver was able to identify a medication dosing error and notify a nurse. Developing information displays that are easy to understand for patients can contribute to providing positive patient experiences and ultimately improve health outcomes.

There were two primary ways inpatients found the information in IPHRs meaningful. First, meaningful information was that which inpatients understood how to use and take action on, such as medications. Second, meaningful information was shared information. That is, it was meaningful to patients that their medical information was shared with them, as they viewed it as their property. Newcomb’s ABX communication model clarifies that all communication is a means of sustaining relationships between people. Thus, access to medical information is meaningful and important because it is a means of sustaining the trust relationships between the patient and provider (or researcher). The findings from this study support development of the informatics solution in Study 4 to easily share personal medical information with patients.
Study 2: Understanding the Caregiver Experience in the Community Setting

In Study 1 we investigated the inpatient experience with health information; In Study 2 we investigated caregiver experience with health information in a community setting, specifically the experiences of Latinos with limited health literacy (LHL) and limited English proficiency (LEP). To overcome language barriers and to enhance our ability to understand their experience, we developed a novel semi-automated method to analyze data collected about their experience and information needs. Little is known about the Latino family caregiving experience and their information needs. However, analyzing experiences of vulnerable populations can be challenging. As briefly mentioned, numerous barriers thwart ease of accurate data collection and partnership in research, such as language and cultural differences and social power imbalance. Moreover, collecting information needs from emotionally distraught individuals, which the caregivers were, is challenging. To overcome these barriers, we built upon a qualitative method (collage method) that captured vulnerable patients’ experiences, to develop a new method to semi-automatically analyze experiences and information needs of LHL, LEP Latinos. We analyzed collages created by the Latino caregivers with LHL and LEP leveraging the novel semi-automated method, which helped us discover differences in the sample that had not been noticed through other traditional research methods. The difference lay between language preferences of Spanish and English within the Latino group. (In anthropology, language-preference is often used to indicate cultural orientation(410)) Upon further investigation, we found that these two groups had different information needs that suggested that the Spanish-speaking individuals may be enduring a more challenging experience. Our findings support the notion of cultural differences in structural arrangement of information. Kitayama and Doherty (249,411) confirm that different cultures prefer different information arrangements in user interfaces. Moreover, in
Chapter 2 we discussed how the same information layout can be interpreted differently by persons of different cultures. To optimize acceptance and usage of informatics solutions by individuals from different cultures, it may be important to understand the structural design preferences of the target audience. Thus, we applied the structural arrangement of information that the Latinos with LHL and LEP created in this study, to the design of the information solution in Study 2. Further, the discovery that there is a difference between language preference within the same ethnic group informed the design and analysis for Study 2 to consider assessing for differences that may surface between language preferences among the research participants.

**Study 3: Investigate an Informatics Solution**

While in Study 1 and 2 we investigated patient experiences with information in the inpatient and community settings, in Study 3, we looked for an informatics solution to enhance an inadequate experience: the patient experience with advance directives (AD). We interrogated the literature to understand why patients were having a poor experience with ADs. We found one reason patients are not finding ADs meaningful is because they come in a format that is uninviting and impenetrable, particularly for individuals with LHL and LEP. Many individuals who do not understand ADs, end up making undesirable choices. The impact of this is costly in dollars, but more importantly in quality of life. Through literature review, we investigated how visualizations, a format preferred by LHL and LEP individuals(42), can increase interest to understand complicated health information such as advanced care information. This information is particularly challenging to convey effectively for various reasons, which we detail in Chapter 5. However, there are compelling studies that demonstrate how visuals can easily and effectively communicate heavy information with encouraging outcomes. Our investigation into visualizations yielded promising opportunities to help improve the meaningfulness of AD
information. Based on our findings, we proposed using a novel format that furnishes more meaningful, “experiential” interpretations of the AD information. The format would come in the form of a visualization that provided immersive experiences where details that ADs describe can be seen and thus quickly understood by even the illiterate and non-English speakers. Our findings informed Study 4 on the optimal format to use to render complicated information impactful, easily digestible, and meaningful.

**Study 4: Aim 4: Develop a visual experiential-report prototype for vulnerable individuals and collate examples of a standard-report**

In study four, Aim 4, we harvested the findings of our early work Study 1-3 and sewed them, along with various theories, into the development of a novel experiential genetic test report (experiential-report) to communicate risk information to Latino individuals with LHL and LEP. According to the experiential framework, to provide the best experience, elements from each realm must be incorporated into the experience. Thus, by pooling the lessons learned from Studies 1-3 that explored patient experiences in different realms of the experience framework, we aimed to siphon aspects from each realm to design an optimal patient experience with genetic test information using visualizations.

For Study 4, the last realm that remained to be explored was the entertainment realm. Any cursory dive into the entertainment literature will find that entertainment is about “manipulating emotions.” Entertainers aim to deliver emotions, because people want to feel--evidenced by the multibillion-dollar entertainment industry. Thus, for Study 4, Aim 4, we focused a literature search on how to evoke emotions in the experiential-report. This converged with the literature on how emotions play a significant role in how human beings process risk information. Our findings
regarding the importance of including affective-information when communicating risk information influenced the design and content of the experiential-report and the study design in Aim 4 of Study 4.

As there was little guidance in the literature on how to design an experiential-report, we reexamined our prior analyses of patient experiences in Studies 1-3, examined the literature detailing patient experiences with the health condition described in the genetic report, and performed an environmental scan to assemble materials to vividly paint the patient experience for our participants in Aim 5, Study 4. Through vicarious experiential learning, we aimed to visually convey the potential disease experience indicated in the genetic test report. To support the communication of affective-information, we emphasized conveying emotions through facial expressions of a relational agent (RA), which literature suggested could be helpful to include.

The design of the experiential-report ended up veering away from typical risk visuals, which focus on supporting comprehension of numbers and probabilities. To supplement these types of risk visuals, we provided a method to communicate risk that allowed individuals with LHL and LEP to understand they were at risk by feeling, rather than through cognitive processing. We felt compelled to attempt this approach because, especially for these individuals with LHL and LEP, it is hard to find meaning in numbers and probabilities. This was confirmed in our findings in Study 4, Aim 5.

**Study 4: Aim 5: Evaluate experiential-report prototype compared to standard-report through data triangulation**

In Study 4, Aim 5, we investigated the effects of viewing the experiential-report compared to a standard-report comprised of real examples of genetic test reports and information. The standard-report was less effective than the experiential report on effects of understanding,
emotions, and motivation on all measures, except for differences in motivation, which were not significant on the survey measures although observed behavior and open-responses suggested there was a difference. Numbers supported by visuals were poorly processed; They were either not noticed or quickly forgotten by 75% of Latino participants with LHL and LEP.

The standard group smiled less while viewing the report compared to the experiential group. The last-felt emotion at the end of viewing the reports, predicted perceived ease of understanding and motivation. Also, perceived ease of understanding predicted feeling motivated to address the health issue.

As hinted by Study 2, we examined if there were differences between language preferences. Indeed, there were a few. Spanish speakers in the standard group reported higher perceived ease of understanding ($p = 0.040$) than the English speakers. They also did not volunteer any suggestions to improve the standard-report, unlike the English speakers. This was not due to lack of speaking. Indeed, the Spanish speakers tended to talk more than the English speakers, but they did not talk about improving the reports. These findings contribute to literature on how Latino individuals with LHL and LEP process standard-reports, as this has been a relatively unexplored area.

An important lesson learned is that patients can feel informed and confident that they easily understand information, but, care providers should make note, that feeling was not associated with actual understanding. Further, our findings suggest that clear, aesthetically pleasing visuals may contribute to misleading feelings of understanding and in turn increase motivation for individuals having limited education.

Moreover, we found that understanding genetic risk information, that is, knowing one has inherited risk for a disease condition, did not correlate with motivation to act on the information.
This is corroborated by findings from a recent systematic review and others (284), reporting that neither family history of a disease, nor receiving genetic risk information motivated healthy behavior. According to Slovic et al (265), knowing is not enough, care providers need to help patients feel concerned about the risk.

An interesting finding from Study 4 is that there may be ways to help people feel concerned. People tend to care about things that erode their wellbeing. Perhaps vividly visualizing future disease states of people to whom viewers can relate could help people feel concerned about avoiding similar threats to wellbeing. Such vicarious experiential learning may support easy cognitive and visceral understanding of risk information. Findings from Study 4 provide supporting evidence that vicarious experiential learning may work to effectively communicate risk information, if the experiences are appropriately designed. By leveraging this method, risk information may become more meaningful, easy to consume, and motivating to individuals with LHL and LEP.

We are not advocating for, nor did we aim to, vicariously transfer through visuals emotions that were insincere or contrived. As we learned in our early investigations into patient experiences (Studies 1 – 2, and Study 4, Aim 4), illness impacts not just the body but also the mind (in Study 1, inpatients were anxious; in Study 2, caregivers were emotionally distraught). Emotional suffering is a significant part of the patient experience. This information is often not properly conveyed, if conveyed at all, to “future” patients who are at risk for health conditions.

(As exemplified by the standard-report, typical patient risk information resources convey risk information through text, numbers and emotionally-impoverished graphics, which disable affective-information from making an impact.(Study 4))
However, this information is important to convey to future patients. This is because avoiding suffering is one of the main instinctive drivers of the human brain. Tapping into the instinctive anti-suffering drive may prove more effective than merely exposing information (housed in ineffective visuals) to individuals with LHL and LEP that requires slow, taxing cognitive processing.

Moreover, communicating arousing information increases the likelihood that it will be remembered and shared than non-arousing information. Thus, future patients may be able to recall their risk easier if they receive risk information that increases their arousal, especially if they are housed in effective visuals. (Chapter 2)

Videos and visual aids such as pictographs have been lauded for being effective visuals; however, findings in Study 4 demonstrate that the “medium is not the whole message.” That is, both intervention groups received visuals (graphics and videos), but one group had a good experience (understood, felt motivated, was impacted), while the other had mixed effects ranging from undesirable to average outcomes.

As we’ve discussed, the visual medium can significantly affect interpretations of information; but not all visuals are equally effective, and thus must be tested by the target audience. Visuals must be tested because as our study indicated they can influence emotions, which influence attitudes and possibly health decisions. With effective visuals combined with elements from the four realms of experience, there is great potential to design effective informatics solutions that support meaningful understanding of the health information.

Strengths
There are a number of strengths in our study. We used a theoretical framework to guide the investigation, development, and evaluation of the studies. Second, the report was iteratively designed with the target audience's (community members’) feedback. Community members were randomly approached on different days and times in different settings. We applied theories, literature, and lessons learned from Studies 1-3 to guide design and content. For the evaluation, we used random assignment and mixed methods; we collected diverse data types using various methods of measurement including subjective and objective standard instruments and investigated the of depth experience through qualitative measures. We designed the experimented to curb social desirability bias where possible. We also employed a range of analysis methods and cross-checked results through triangulation. There were two interviewers (one for each language preference: Spanish vs English). This may have influenced data collected for the Spanish- vs English-speaking groups. We tried to minimize differences by following a standard interview guide. Next, we used theory-based approaches to guide the development and evaluation. Lastly, although the data in the experiential- and standard-reports were hypothetical, there is considerable precedence to the use of hypothetical methodologies and strong evidence to show that behaviors based on real or hypothetical situations are highly correlated. (393,394)

Limitations

The research presented in this dissertation has several limitations. The first set of limitations relates to the degree to which results can be generalized. While one of our goals was to study the patient experience, we did not study all the types of patient experiences in the continuum of health and disease. The population of the patients and community members involved were limited in size and to one academic center and one Latino community in an urban location. Most of the Latino community members were from the Dominican Republic, therefore, our
results may not be generalizable to other settings and Latino populations. Other overall limitations to the generalizability of our findings include the fact that all research was conducted in a large, urban community and academic medical center.

Other limitations specific to studies include the following:

Study 1 had several unique limitations. First, all of the participants were post-operative cardiac surgical patients in the post-ICU step-down unit. These patients may not be representative of all hospitalized patients. Second, twenty-four patients were approached, and fourteen patients completed interviews. This could lead us to overestimate the number of patients or family members that would use an inpatient personal health record. Third, there is the potential for response bias since the study was not blinded and participants may have chosen to answer questions in a way they thought was favorable to the researchers. A subset of answers, such as to questions about participants’ daily Internet use and the time participants spent interacting with the application, could have been subject to recall bias. Finally, IPHRs may vary in content, usability, and function and thus the experience of participants in this study with the application may not generalize to experience with other IPHR applications.

In Study 4, the genetic information provided in the reports were hypothetical. This could affect the ability to generalize findings beyond an experimental setting.

**Contributions to:**

**Theory**

There was a theoretical contribution that came out of our work. We applied the experience framework to a novel area: risk communication for LHL individuals. This contribution demonstrated a novel way to organize and understand patient experiences with health
information, using the four "Realms of Experience." Lessons learned from each Realm of Experience informed our design of Study 4. The framework also helped identify a gap in the literature that we sought to fill with this study regarding the emotional effects of risk information on patients. This framework may be useful for others who conduct research in patient experiences, to guide the design and evaluation of their studies.

**Methods**

There were four methodological contributions of this work.

First, Study 2 made a methodological contribution to analyzing visualizations as a biomedical informatics method. We supplemented the qualitative method of analyzing collages by introducing an automated method of analyzing visual organization of content, that represented participants’ experiences and information needs. By leveraging this new method, it helped us detect a difference between the participants that was undetected through other traditional methods (e.g., focus groups). It also provided insight into watching out for that difference in subsequent studies.

Second, Study 4 made a methodological contribution to developing visualizations as a biomedical informatics method. Specifically, we researched and applied findings and theories from various fields such as psychology, neuroscience, perception, visualization, cultural studies, and communication to guide the selection of design features and content to create a visual informatics solution. We also reviewed relevant literature to leverage the expertise of other researchers who examined patient experiences; we then weaved their findings into the content of the visual informatics solution.

Third, Study 4 made a methodological contribution in evaluation of visualizations as a biomedical informatics method. We aimed to measure emotional impact of the stimuli using a
standard self-report scale and by unobtrusive facial analysis software that labels the emotions of facial behavior using machine learning techniques. We further augmented these data with open-response data related to emotion. Asking the question of, “How does this make you feel” in informatics is relatively new. We found the data collected from this question especially helpful in deciphering the results. We encourage others to consider investigating the emotional impact of informatics interventions where applicable, because emotions play a large role in human behavior and decision-making.

Lastly, in Study 4, we contributed a novel mixed-methods evaluation approach to understand the patient experience of health information. We triangulated a rich, diverse data set gathered using a range of methods (e.g., behavioral observation, facial analysis software, open-responses, multiple-choice questionnaire, survey) and collected various data types (quantitative and qualitative) and employed various analysis methods (e.g., ANOVA, directed content analysis, image analysis, regression analysis, clustering, visualization) that helped surface meaningful insights that would have otherwise not been discerned using one or even two evaluation methods.

**Substantive**

There were five substantive contributions:

First, Study 1 made a substantive contribution to the information needs of inpatients. Increasing patient engagement has been recognized to improve health outcomes. However, patients cannot engage with their care if they have no information about their care. Hospitalized patients have traditionally had little access to their medical information. Little was known about their information needs. In this study, we assessed inpatients’ experiences with an inpatient personal health record (PHR) and assessed for information needs not being fulfilled by the inpatient PHR.
Our findings contribute to the understanding of what information is helpful and meaningful to hospitalized patients.

Second, Study 2 made a substantive contribution to the information needs of Latino Dementia caregivers with LHL and LEP. Managing the care of a Dementia patient requires a plethora of information. However, Latino Dementia caregivers’ specific information needs are not well understood. To fill this gap in knowledge, we assessed Latino Dementia caregivers’ experience and information needs; The findings contribute to the understanding of Latino Dementia caregiver’s information needs.

Third, Study 3 made a substantive contribution to a visual approach for advance directives (AD). ADs are difficult to construe for individuals with LHL and LEP due to their text-heavy format, which contributes to the AD’s lack of use, misuse, and ineffectiveness. We proposed an informatics solution, an “experiential” visualization, that could depict the information in the ADs to support instant, easy understanding and sharing of the information. Such visualizations may augment understanding in ways that information conveyed through text alone cannot.

Fourth, Study 4 made a substantive contribution to visual approaches for risk communication. Methods to communicate risk information have emphasized supporting comprehension of numbers and probabilities; however, numbers are challenging for individuals with LHL and LEP to understand, and may not be effective at increasing motivation to act on risk information. We introduced a visualization method to support intuitive, visceral understanding of risk information. This approach could facilitate easier, quicker and more impactful communication of risk information for individuals with LHL and LEP, compared to previous approaches.

Finally, Study 4 made a substantive contribution to vicarious learning (VL). VL is the process of learning vicariously: “The behavior of observers can be substantially modified as a function of
witnessing other people’s behavior and its consequences for them.” (30) VL is a promising method to quickly communicate information between individuals with minimal effort. However, it has generally been untapped, as the literature for it is scant. Furthermore, it is unclear if VL through visualizations has been investigated. Study 4 contributes to this effort. Findings suggest that through the medium of visualizations, individuals with LHL and LEP were able to instantly grasp gist-understanding and affect-understanding of risk information. VL through visualizations appeared to provide a more complete understanding of risk than descriptions through text and numbers + visuals aids. This is ripe territory for further investigation.

Future Steps

There is a rudimentary understanding of how to provide vulnerable patients “great experiences” with health information. Perhaps the experience framework could help guide future studies and informatics solutions in staging great experiences for vulnerable patients.

Results from Study 4 support further investigation into providing great experiences with health information by using the VL through visualization approaches. Moreover, future studies could continue to use visuals and behavior theories to investigate ways to influence behavior. Human beings are mimics. Perhaps seeing a visual of other people like oneself headed toward the local hospital may be more compelling, rather than reading text indicating she should go to the doctor. One way to visualize such scenarios could be through augmented reality (AR) and virtual reality (VR). AR is a visual medium that offers interesting possibilities to create engaging visuals to easily communicate health information to LHL and LEP individuals. As AR/VR technologies mature, future studies could investigate opportunities to provide immersive experiences of illness, treatment, self-management, and prevention using these media.
Conclusion

How information is presented—the format—is instrumental in how people process and act on the information. If health professionals do not understand how to effectively communicate information to LHL and LEP patients, communication inequalities will deepen health disparities. Understanding health information is central to preventing and managing illness; however, many individuals with LHL and LEP have poor experiences (finding it hard to understand, not motivating, unappealing, and lacking impact) when trying to process health information. When individuals have poor experiences with critical health information, it leaves them vulnerable to numerous adverse health outcomes. Individuals with LHL and LEP have difficulty processing health information, so are especially exposed to health disparities. Strategies are needed to facilitate improved experience of health information to support ease of understanding and increased desire to process and act upon, at times, complex information. Visualizations may help overcome barriers to improve the patient experience with health information. We attempted to fill knowledge gaps in the vulnerable population literature regarding effective communication strategies aimed to improve patient experience with health information. We sought to do this by leveraging visualization “to affect thro’ the eyes,” what we fail to convey to individuals with “word-proof ears.”

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Appendix A: Study 1 Interview Questions

User Background:

1. What is your age? Record gender as well.

2. What is your profession? Level of education?

3. Do you know your medical conditions? Do you know your medications and what they do? How knowledgeable would you say you are about your health?

4. Do you have a smartphone? How much time do you spend each day using the internet or apps on your smartphone on average?

5. Do you have a desktop or laptop computer? Do you have internet on your computer? How much time do you spend each day on your computer on average?

6. Do you have a tablet computer? How much time do you spend each day on your tablet on average?

7. Do you have a personal health record? Who do you use it for (self, children, parents)? How frequently do you use it?

8. Do you look up information about your health online? What websites do you use?

General Inpatient PHR Questions:

1. What do you think about patients receiving an inpatient personal health record like the one you used?

2. What information do you think patients would like to see while they are in the hospital?

3. What information should patients not have access to?

4. What questions have you asked your doctors while in the hospital? What do you think about patients being able to ask questions or make comments to their care team in the application? Is this useful?

5. Should this be one-way or two-way communication? (ie should the patient send messages in
which a member of the care team responds in person, or should patients and the care team communicate electronically through the application).

6. What do you think about patients entering their own pain scores? Could this replace the scores recorded by nursing?

7. Patient’s will still have access to their records when they leave, but how long should patients have access to the special features of the inpatient PHR, such as staff profiles or ability message with your team, after the hospital stay?

Questions about application (myNYP):

1. What do you think about the myNYP Inpatient application?

2. What was most useful about the application? What was least useful?

3. What do you think if anything is missing from the application? What do you wish we had included?

4. Was it easy to find what you needed? Did you find navigating through the application confusing?

5. Was the information accurate?

6. What did you think about x (care team, hospital medications, allergies, home medications, notepad, pain)? What would you add or change to them? (If they did not use it, show it to them and ask for their opinion)

7. Was the text the right size? How was it entering notes on the iPad?

8. How much time would you say you spent looking at the application? What else did you use the iPad while you had it? (We want to get a sense of what patients might use iPad for apart from our application)