

AUTOMATING CANCER GENETIC COUNSELING WITH EMBODIED CONVERSATIONAL AGENTS:

A COMPUTATIONAL FRAMEWORK FOR GENETIC RISK COMMUNICATION

A dissertation submitted by

Shuo Zhou

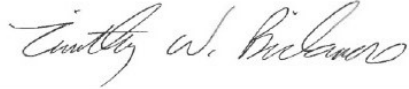
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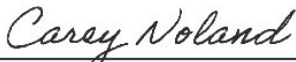
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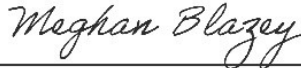
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ABSTRACT

Genetic risks can inform how genes affect an individual's likelihood of developing hereditary cancer syndromes. Effective communication of genetic risk is increasingly important for cancer prevention and treatment. Based on an individual's risks, existing medical guidelines can recommend risk-reducing behaviors such as genetic screening, cancer screening, lifestyle behavior change, medications, or preventive surgeries. Therefore, it is important that individuals understand their genetic risks and adhere to these screening and risk reduction guidelines. While human genetic counselors are effective at communicating risks and motivating adherence to medical guidelines, many people do not have access to these experts, and existing self-help materials are not effective, especially for individuals who have difficulty understanding health or numeric concepts. Furthermore, receiving and comprehending genetic risk does not always guarantee that people will engage in recommended risk-reducing behaviors.

Automated approaches that feature a pedagogical embodied conversational agent (ECA) functioning in the role of a virtual genetic counselor, may address these barriers. In this dissertation, I propose a computational framework for genetic risk communication, driven by intelligent tutoring systems architecture and techniques, risk communication principles, and information processing theories. I report the design and evaluation of three prototypes for breast cancer genetic counseling, implemented based on the presented framework through an iterative and incremental process. The implemented prototypes are able to communicate to users about their breast cancer genetic risks, and motivate at-risk individuals to adhere to breast cancer prevention and detection guidelines.

Evaluation of the first prototype examines the acceptance of a virtual genetic counselor. The second prototype leverages the architecture and techniques of intelligent tutoring systems to provide adaptive risk education based on dynamic user comprehension assessments. Adopting information processing theories, the third prototype extends the design to provide adaptive adherence motivation. A final randomized between-subject evaluation study with 30 women comparing the adaptive virtual counselor to a non-adaptive one and a control condition, demonstrated the efficacy of the implemented adaptation mechanisms. Women in the adaptive condition had significantly greater knowledge gain in breast cancer genetics compared to women in the other two conditions.

Findings from these evaluation studies demonstrate the efficacy of multidimensional tailoring and adaptation of risk communication based on user traits and dynamic assessments. This dissertation contributes to the field of genetic risk communication by presenting ECA-based automated approaches to risk communication and adherence motivation. This work also provides empirical evidence that pedagogical ECAs can be used effectively for health education and counseling.

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CHAPTER ONE:

INTRODUCTION

1.1 BACKGROUND

Genetic risks can inform individuals about how the genes they are born with affect their likelihood of developing certain diseases, such as hereditary cancer syndromes. Advancements in genetics and genomics research call for greater efforts to increase the general public's awareness of genetic risks and their implications for an individual's health (Lea et al., 2011). Based on a person's risks, existing medical guidelines can recommend screening and risk-reducing behaviors, such as genetic screening, cancer screening, lifestyle behavior change, medications, or preventive surgeries.

Imagine this scenario - a woman in her twenties is seeking information regarding her probability of getting breast cancer, after being informed that a family member of hers has tested positive for a BRCA mutation, or otherwise referred to as a BRCA pathogenic variant. A quick search online reveals that she may now have much elevated risks for breast and ovarian cancer. Depending on her risk and other relevant factors, medical guidelines may recommend different screening procedures, that include clinical breast exam, mammogram, and breast MRI. So, for this young woman, how can she find out if she has inherited a risk-conferring genetic mutation? How can she find out more about her increased risk of developing breast cancer? What options are available for her to reduce her lifetime cancer risk?

More than any time in history people face challenging situations like this one due to the ever-increasing demand for and access to genetic testing (Clark et al., 2021; Read et al., 2020). Effective genetic risk communication is vital in helping individuals make appropriate health related decisions and adhere to screening and risk-reducing guidelines (O'Doherty & Suthers, 2007). Adherence to recommended medical guidelines has been found to be increasingly important in cancer prevention and treatment. For example, an increase in breast cancer screening rates in recent years contributed in part to the decrease in breast cancer mortality rates, which dropped from 33.1% in 1990, to 20.1% in 2015, due to a combination of early detection screening and advancement in treatments (Byers et al., 2016; Han et al., 2018). Although awareness of cancer genetic risks has improved, studies still showed massive under-utilization of genetic testing related services, for example, less than 20% of eligible individuals with a history of breast or ovarian cancer have received genetic testing in the United States, and most have never discussed testing with a health care provider (Childers et al., 2017; Evans et al., 2020).

For the past decades there has been a significant explosion in both the demand and the need for genetic counseling, with genetics and genomics playing an increasingly critical role not only in prenatal screening or rare single-gene disorders, but also in many other conditions such as diabetes, heart disease, and cancer (Lea et al., 2011; Wang & Watts, 2007). While human genetic counselors are effective at communicating risk and motivating adherence, a majority of at-risk individuals do not have access to these experts, due to various logistical barriers, and a reported national shortage of genetic counselors in the United States (Peterson et al., 2018).

In addition to lack of access, difficulties in understanding genetic risks represent another barrier to adherence, given the complexity of the risk information. Communication of

genetic risk often involves discussing complex genetic concepts, and a large amount of numerical or statistical information, including relative risk, absolute risk, probabilities, and frequencies (Ancker & Kaufman, 2007; Apter et al., 2008; Lea et al., 2011; Marteau, 1999). Understanding numerical or statistical risk information remains a difficult task, even for highly educated individuals, and more so for those who have limited health literacy and limited health numeracy (Ancker & Kaufman, 2007; Apter et al., 2008; Golbeck et al., 2005; Lea et al., 2011; Peters et al., 2007). In the United States, more than one-third of adults have limited health literacy (Kutner, Greenberg, Jin, et al., 2006), which is the ability to read, understand, and act on health information (Andrus & Roth, 2002). More than half have limited numeracy skills (Kutner, Greenberg, & Baer, 2006), meaning they may have limited abilities to access, understand, communicate, and act on numerical, graphical, biostatistical, and probabilistic health information (Golbeck et al., 2005). A cross-sectional study conducted in a suburban Urgent Care setting in northeastern United States identified that more than 40% of adult patients had limited health literacy, and limited health literacy was found to be associated with increased age, less education, and lower income (Alberti & Morris, 2017). Individuals with limited health literacy and limited health numeracy are shown to have poorer health outcomes, and they are less likely to obtain health information from written resources such as educational brochures and the Internet (Ancker & Kaufman, 2007; Apter et al., 2008; Kutner, Greenberg, Jin, et al., 2006; Peters et al., 2007; Rudd et al., 2007). In particular, individuals with limited health numeracy, compared with their more numerate counterparts, often have more difficulty interpreting complex charts and graphics, and have trouble making informed decisions based on numerical risk information (Golbeck et al., 2005; Peters et al., 2007).

While understanding and acting upon genetic risks is challenging, people also have diverse needs in how they receive and interpret such information, particularly complex concepts regarding cancer genetics. “Visual learners” may prefer to see charts illustrating cumulative, absolute, or relative risk, while others may learn better hearing numbers said out loud to them. When discussing risk reduction recommendations, some may favor anecdotal evidence and expert recommendations delivered by a counselor to ground the basic ideas; others would like to hear specific reasoning and see empirical evidence backed up by statistics. This dissertation sought to examine factors that may drive these differences, including prior domain knowledge, health literacy and numeracy, information processing method, and user preferences.

Prior research also suggests that simply ensuring receipt and comprehension of risk information does not necessarily lead to desired behavior change, such as adherence to recommended screening and risk reduction guidelines (Hollands et al., 2016). Researchers have applied several information processing models to risk communication, including the heuristic-systematic model (HSM) of information processing (Chaiken, 1980; Chaiken et al., 1989), a widely recognized model explaining how individuals process persuasive risk messages, aiming to achieve more effective persuasion in promoting risk-reducing behaviors (Trumbo, 1999). However, these information processing theories have not yet been applied to genetic risk communication specifically.

In this dissertation, I focus on addressing these identified concerns in the field of cancer genetic counseling for breast cancer. Breast cancer is the most common cancer worldwide, accounting for about 30% of female cancers, with a mortality-to-incidence ratio of 15% (Loibl et al., 2021). Hereditary breast cancer, also referred to as hereditary breast and ovarian cancer, is

one of the most common hereditary cancer syndromes, most commonly associated with BRCA1 or BRCA2 pathogenic variants, as well as other genetic variants. In this dissertation, BRCA pathogenic variants may also be referred to as BRCA mutations.

As outlined earlier, there is an urgent need for access to tailored quality information regarding cancer genetic counseling due to the dearth of qualified genetic counselors. The prevalence of limited health literacy and health numeracy led to difficulties in understanding genetic risks, even though the general public is becoming more aware of genetic risks and their implications for individuals' health. Given the significant increase in interest in and demand for genetic counseling in various modes of modern communication including telehealth, this dissertation focuses on exploring automated approaches that feature a pedagogical embodied conversational agent (ECA) functioning in the role of a virtual genetic counselor, in order to address these barriers in current practice. The presented approach is able to educate users about their breast cancer genetic risks, and motivate at-risk individuals to adhere to breast cancer prevention and detection guidelines.

1.2 A COMPUTATIONAL FRAMEWORK FOR GENETIC RISK COMMUNICATION

To address the problems outlined above: 1) lack of access to genetic counseling, 2) poor understanding of genetic risks, and 3) low adherence to screening and risk reduction guidelines, I propose an automated approach guided by a new computational framework for genetic risk communication. This framework provides more easily accessible genetic counseling, improve risk comprehension, and promote adherence to risk reducing behaviors.

The proposed computational framework is applied to the field of breast cancer genetic counseling. However, the presented framework is also applicable to other types of risk communication, including risks of other hereditary cancer syndromes, common complex diseases such as diabetes, or environmental hazards.

The presented framework for genetic risk communication leverages the classic architecture and pedagogical strategies of an intelligent tutoring system (ITS) to provide multidimensional adaptation and tailoring based on factors collected on multiple dimensions, including user traits, information processing modes, and real-time comprehension assessments. ITSs are computer tutors able to provide tailored education, while maintaining a dynamic model of an individual's current knowledge state. Traditionally, ITSs have been mostly applied in the context of science-related classroom learning, such as mathematics, physics, or entry-level programming (Anderson et al., 1985; Kulik & Fletcher, 2016). Intelligent tutoring system theories and techniques are particularly relevant to genetic risk communication, as a typical genetic counseling session often resembles a one-on-one tutoring session, involving a significant amount of educational content including numerical risk information. The pedagogical strategies outlined in the proposed framework are also informed by risk communication theories, as well as the HSM, to promote more effective risk education and adherence motivation.

This framework is implemented using a humanoid embodied conversational agent (ECA). ECAs are animated computer characters capable of simulating face-to-face interaction between an individual and a human counselor (Figure 2). Being able to use both verbal and non-verbal behaviors along with other human-like features, ECAs offer many affordances including building long-term rapport with users and simulating an interactive counseling

experience similar to that with a human, while providing an anonymized, non-stigmatizing, and nonjudgmental environment in which users do not feel the pressure or embarrassment that may present in traditional medical settings. Previous research by Bickmore and colleagues has demonstrated that ECAs work effectively as health educators and health counselors in several areas of behavior change research (Bickmore et al., 2010; Bickmore et al., 2015; Zhou et al., 2017; Zhou, Gali, et al., 2014). ECAs are particularly effective for individuals with low health or computer literacy (Bickmore, Pfeifer, & Jack, 2009; Bickmore et al., 2010; Zhou, Bickmore, et al., 2014).

In the presented framework, the ECA plays the role of a virtual genetic counselor, delivering information in interactive dialogues using a number of narrative pedagogical strategies. It can also use visual aids, such as risk charts and other illustrations during the counseling session, just as human genetic counselors do. The virtual counselor determines the appropriate use of different modalities on a moment-by-moment basis, spanning visual aids, verbal anecdotes, and statistical evidence, given traits and preferences of the user and real-time comprehension assessments made during a counseling session.

1.3 RESEARCH QUESTIONS

This work is guided by the following research questions:

RQ1: Will individuals accept a pedagogical ECA as a virtual genetic counselor providing breast cancer genetic counseling?

RQ2: Can an adaptive virtual genetic counselor improve individuals' comprehension of breast cancer genetic risks?

***RQ3:** Can an adaptive virtual genetic counselor improve individuals' intent to adhere to the recommended medical guidelines?*

In this dissertation, through an iterative and incremental development process, I report the implementation of three prototypes (Prototype I, II, III) developed based on the proposed genetic risk communication framework, and three user studies (Evaluation Study I, II, III) evaluating the effectiveness of each prototype, in order to answer the three research questions listed above.

Figure 1 illustrated the evaluation process. Prototype I was developed first, and evaluated in Evaluation Study I to examine the acceptability of providing automated breast cancer genetic counseling using an ECA as a virtual counselor. Evaluation Study I enabled me to collect data and feedback to guide the design and implementation of an improved Prototype II, adapting to dynamic assessments of a user's knowledge state. In Evaluation Study II, Prototype II was evaluated, and results demonstrated that the implemented adaptive genetic risk education improved individuals' comprehension of breast cancer genetic risks. Based on results collected from the first two studies, I developed Prototype III, which incorporated the HSM in order to provide adaptive adherence motivation in addition to the adaptive risk education. Prototype III dynamically adapts its pedagogical strategies based on a user's knowledge state, preferred information processing method, and other user traits including health literacy and risk level (Figure 2). Results from Evaluation Study III demonstrated that the implemented dynamic pedagogy led to greater knowledge gain as well as high intent to follow breast cancer screening and risk reduction guidelines.

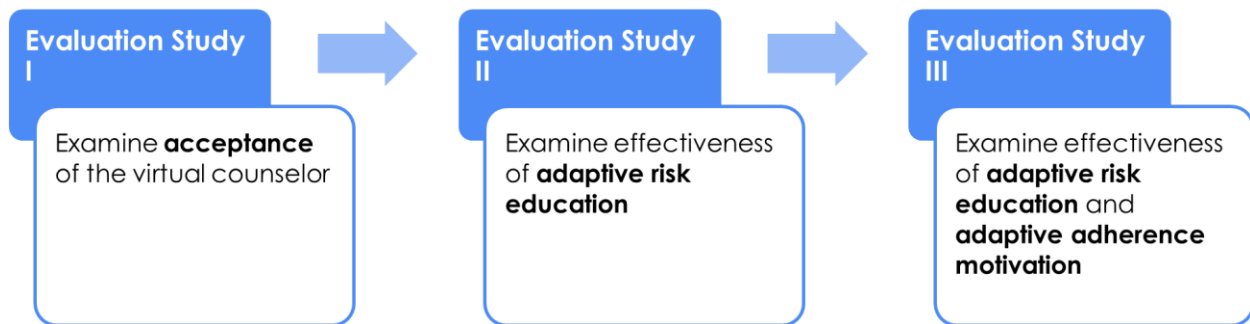


Figure 1: The evaluation process.



Figure 2: ECA virtual genetic counselor.

1.4 CONTRIBUTION

This work contributes to the field of genetic risk communication by presenting automated approaches to risk communication and adherence motivation. The proposed computational framework for genetic risk communication is guided by several theories: its architecture

informed by theories and techniques in ITS, and the design of its pedagogical content guided by risk communication theories and the HSM. Previously, HSM has not been applied to genetic risk communication. The primary contribution of this dissertation is the design of a new computational framework that drives an embodied conversational agent to provide multidimensional adaptation of risk communication, in the context of hereditary breast cancer. This work also provides empirical evidence that an ECA can be used effectively for easily accessible, non-stigmatizing, automated genetic counseling, providing a valuable alternative to traditional solutions as demand outpaces supply. This framework may be further applied to other areas of risk communication.

1.5 DISSERTATION OUTLINE

This dissertation contains eight chapters, organized as follows.

In Chapter 2, I review and discuss prior work related to genetic risk communication, health literacy, health numeracy, and specifically the recommended and validated risk communication principles that were summarized and incorporated into my proposed framework for genetic risk communication. I also review research related to information processing theories that were applied to risk communication, including the HSM. Related work in intelligent tutoring systems and pedagogical agents is also discussed in this chapter.

In Chapter 3, I describe the design and implementation of Prototype I, and report the results from the first acceptance study - Evaluation Study I, which evaluated the effectiveness of Prototype I.

In Chapter 4, based on results and feedback collected from Evaluation Study I, I describe the design and implementation of an improved Prototype II, which provides adaptive risk education based on dynamic comprehension assessments.

In Chapter 5, I report the results from a quasi-experimental study - Evaluation Study II, which examined the effectiveness of Prototype II. Results demonstrated that the implemented adaptive pedagogy led to significant knowledge gain.

In Chapter 6, I describe the final design of the proposed computational framework for genetic risk communication, and the design and implementation of Prototype III. This fully adaptive final prototype was built upon Prototype II, incorporating theories and constructs from the HSM to provide additional adaptive adherence motivation.

In Chapter 7, I report the results from a final randomized between-subject evaluation study, comparing Prototype III to a non-adaptive agent, and a control condition offering standard of care. Results from the final evaluation study demonstrated the efficacy of the implemented fully adaptive virtual genetic counselor.

In Chapter 8, I present my conclusions drawn from the three evaluation studies, and discuss limitations and future research directions.

CHAPTER TWO:

RELATED WORK

2.1 RISK COMMUNICATION

Risk communication is defined as "*any purposeful exchange of information about health or environmental risks between interested parties.*" Specifically, risk communication is the act of conveying or transmitting information between parties about (a) levels of health or environmental risks; (b) the significance or meaning of health or environmental risks; and/or (c) decisions, actions, or policies aimed at managing or controlling health or environmental risks (Covello et al., 1986; Renn & Levine, 1991). Risk communication is a very common and important component in many health interventions including genetic counseling, cancer prevention and treatment, and preconception counseling and intervention (O'Doherty & Suthers, 2007). Individuals are frequently presented numerical risk information, such as disease risks, benefits and risks of undergoing certain medical procedures, and potential outcomes of preventive procedures (Lea et al., 2011). In addition, risk communication often involves communicating the concept of uncertainty, making it very difficult for at-risk individuals to make decisions under uncertain conditions, especially health related decisions. Some individuals tend to simplify probabilistic risk information and perceive such information as in a binary form – something either will or will not happen, or in a form of certainty instead of uncertainty (Lautenbach et al., 2013; Lippman-Hand & Fraser, 1979; O'Doherty, 2005; O'Doherty & Suthers, 2007; Parsons & Atkinson, 1992). The common method in the clinical

environment of using observed population frequencies of an event to estimate a probability, may be conceptually challenging for a lay person (O'Doherty & Suthers, 2007).

It is not always clear how an individual should act upon probabilistic risk information (O'Doherty & Suthers, 2007). Research has shown that individuals do not usually act based upon the actual risk presented to them, but their perception of the risk (Marteau, 1999; Meiser et al., 2000; O'Doherty & Suthers, 2007; Slovic, 1987; Slovic et al., 1980). Therefore, it is not sufficient for clinicians, counselors, or educators to simply provide accurate risk information. They should also assess their patients' perception of the risk information presented to them. Especially during genetic counseling sessions, the counselors or risk communicators should be able to gauge their patients' perception of risks through conversation, receive immediate feedback, and make adjustments on the messages they want to deliver (O'Doherty & Suthers, 2007).

2.2 GENETIC RISK COMMUNICATION

Communicating genetic risks has been an important component of genetic counseling (Austin, 2010). Research to date suggests that the general public are familiar with genetic terms on some level, have generally high levels of interest regarding genetic testing, but limited knowledge and understanding of the underlying concepts (Lea et al., 2011; Peterson et al., 2018). With private, for-profit companies advertising directly to the general public about genetic testing, and with such genetic tests directly available to consumers over the internet, individuals nowadays are much more likely to seek information regarding genetic testing from their healthcare providers (Hollands et al., 2016; Lea et al., 2011; Peterson et al., 2018). However, the field of genetic risk communication is in its infancy, and much research is

needed to determine best practices to maximize people's comprehension of genetic risks, and to promote healthy, risk-reducing behaviors.

During a typical genetic counseling session, patients are often presented risk information in a variety of ways, including relative and absolute risks, probabilities, frequencies, verbal risk descriptions, and possible health outcomes, etc. While at-risk individuals are often required to make major health-related decisions regarding genetic testing, medications, screening procedures, or preventive surgeries, solely relying on their comprehension of risk information (O'Doherty & Suthers, 2007), genetic risks are often difficult to understand, and may be misinterpreted, leading to inappropriate decision-making and ineffective family communication (Jacobs et al., 2018). Genetic counseling often involves providing a large amount of numerical or statistical information (Marteau, 1999). An observational study analyzing transcripts from 115 genetic counseling sessions (Michie et al., 2005) showed that 47% of all risk expressions (32% probabilities, 15% percentages) used in these sessions were numbers. However, clinicians were found to only assess comprehension on 25% of occasions, and on only 9% of occasions when there was no response from patients, raising concern that patients may make decisions or take actions without fully understanding their risks (Michie et al., 2005).

The relationship between genetic risk communication and behavior change has been examined in many studies, especially in the area of cancer screening in the context of familial cancers, such as hereditary breast and ovarian cancer (Botkin et al., 2003; Heshka et al., 2008; Jacobs et al., 2018; Peshkin et al., 2002; Scheuer et al., 2002; Schneider & Schmidtke, 2014), or hereditary nonpolyposis colorectal cancer (Collins et al., 2005; Hadley et al., 2004; Heshka et al., 2008; Schneider & Schmidtke, 2014). These findings showed the receipt of genetic risk

information or genetic testing results in general, did not change perceived risk, but led to increase in screening or other preventive behaviors (e.g., mammogram, colonoscopy, etc.), although the change in behavior was less than expected (Heshka et al., 2008; Lea et al., 2011; Peterson et al., 2018; Schneider & Schmidtke, 2014). There has been mixed evidence regarding the effect of conveying genetic risk information on risk-reducing behaviors in the context of common complex diseases, such as smoking cessation, physical activity, diet, alcohol use, or medication use (Hollands et al., 2016; Lea et al., 2011; Peterson et al., 2018). Overall, no substantial effects on long-term behavior change have been found (Lea et al., 2011). These findings indicate that genetic risk education does not necessarily guarantee that people will make the desired risk-reducing behavior change, calling for better theory-based health education strategies to maximize people's comprehension of genetic risks, and to promote health behavior change.

In prior research, individuals' comprehension after receipt of genetic risk information in general has not been investigated systematically (Lea et al., 2011). Furthermore, there has been very little research examining the effect of health literacy, especially health numeracy, on health behavior change following the receipt of genetic risk information (Lea et al., 2011). The dearth of effect of genetic risk communication on behavior change may be due to the recipients' lack of understanding of the complex risk information. A recent review (Peterson et al., 2018) identified the need for future research on individuals' knowledge after genetic counseling, adherence to tailored screening recommendations, and specifically the effect of health literacy on individuals' comprehension of genetic risks.

2.3 HEALTH LITERACY

Health literacy is defined as the ability to perform basic reading and numerical tasks required to function in the health care environment (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). According to the 2003 National Assessment of Adult Literacy, 36% of U.S. adults have basic or below basic health literacy (Kutner, Greenberg, Jin, et al., 2006), 55% of U.S. adults have basic or below basic quantitative literacy (Kutner, Greenberg, & Baer, 2006). Specifically, underserved populations have lower health literacy as well as lower numeracy skills in general (Kutner, Greenberg, & Baer, 2006; Kutner, Greenberg, Jin, et al., 2006). Individuals with limited health literacy have poorer health outcomes, less knowledge, and less comprehension (Rudd et al., 2007), less likely to obtain health information from written sources (Kutner, Greenberg, Jin, et al., 2006), and are more likely to have difficulties in understanding and using genetic information (Johnson et al., 2005; Lea et al., 2011).

There has been limited research investigating the relationship between health literacy and genetic risk communication (Lea et al., 2011), but findings to date indicate that health literacy may affect understanding of print and oral communication of genetic risk information (Lautenbach et al., 2013; Lea et al., 2011). In general, underserved populations have lower levels of awareness and knowledge regarding genetic risks (Peterson et al., 2018). In a study involving over 600 patients from a medically underserved population, limited health literacy was found to be associated with lower genetic knowledge, lower awareness of family health history, and greater perceived importance of genetic information (Kaphingst et al., 2016). Another study involving nearly 400 African American smokers of low socioeconomic status, found participants had difficulties understanding genetic risk information, and inaccurate

interpretation was more common among those deemed at increased risk compared with those at average risk (Lipkus et al., 2004).

2.4 HEALTH NUMERACY

There has been substantial research on health literacy and the associated outcomes, however, so far there has been very limited research on health numeracy, and how it affects an individual's health outcomes (Apter et al., 2008). Traditionally, health numeracy has been either ignored, or simply treated as a sub-component of health literacy (Golbeck et al., 2005). However, in the most recent two decades, researchers have been arguing that health numeracy should be treated as a separate entity, going beyond the scope of basic quantitative skills to process health information (Ancker & Kaufman, 2007; Apter et al., 2008; Golbeck et al., 2005; Lea et al., 2011). The limited research on health numeracy to date has suggested that limited health numeracy may lead to poorer health outcomes (Ancker & Kaufman, 2007; Apter et al., 2008). Since the effects of health numeracy on risk communication have been much less investigated than the effects of health literacy, in this section, I review what health numeracy means, and how health numeracy affects individuals' comprehension of genetic risks, especially numerical or statistical risk information.

This dissertation adopts the definition of health numeracy proposed by Golbeck et al. (Golbeck et al., 2005), as “*the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions.*” Golbeck et al. (Golbeck et al., 2005) also identified four functional categories of health numeracy, as four overlapping clusters: basic, computational, analytical, and statistical. The two higher level

categories, analytical and statistical, involve the ability to understand concepts such as inference, estimation, proportions, percentages, and frequencies. Particularly, the statistical category includes abilities to critically analyze quantitative health information, and to understand statistical concepts such as randomization. This level of health numeracy is critical for tasks such as interpreting complex graphs, assessing risks, and determining preference of treatment based on risks. All of the above tasks are essential in the field of genetic risk communication.

Lipkus and Peters (Lea et al., 2011; Lipkus & Peters, 2009) summarized six main functions of health numeracy, in the context of genetic risk communication (Table 1). Based on a conceptual model proposed by Apter et al. (Apter et al., 2008), function 1-2 demands an individual’s ability to describe, function 3-4 demands the ability to interpret, and function 5-6 demands the ability of decision-making.

Table 1: Six functions of health numeracy for genetic risk communication (Lea et al., 2011).

Item	Functions of Health Numeracy
1	Numeracy facilitates computations.
2	Numeracy encourages more information seeking and greater depth of processing.
3	Numeracy improves interpretation of the meaning of provided numbers.
4	Numeracy facilitates assessments of likelihood and value.
5	Numeracy increases acceptance of numerical data.
6	Numeracy can promote behavioral change.

2.4.1 Health Numeracy and Risk Communication

People are facing a rapidly growing amount of quantitative or numerical information every day in either written or electronic health communication, including medication schedules, nutrition information, laboratory results, and risks and benefits of therapies (Ancker & Kaufman, 2007). However, past research has also demonstrated that many people lack the basic numeric skills to interpret percentages, probabilities, and frequencies, regardless of their level of education (Ancker & Kaufman, 2007; Lipkus et al., 2001; Peters et al., 2006; Schwartz et al., 1997), even though such information is commonly found in risk education materials. Even highly educated individuals have been shown to have difficulty with relatively simple numeracy questions related to risk communication (Lipkus et al., 2001). Lipkus et al. found that for a general 3-item numeracy scale and an expanded 7-item scale, only 18% and 32% of participants correctly answered all of the questions, respectively. Approximately 16% to 20% incorrectly answered the most straightforward questions regarding risk (e.g., *which one represents the biggest risk: 1%, 5%, or 10%?*) (Lipkus et al., 2001).

In general, low health numeracy has been associated with lower comprehension and less use of health information (Fagerlin et al., 2011; Peters et al., 2007). Individuals with limited health numeracy, compared with their more numerate counterparts, also have more difficulty utilizing numerical information to make informed decisions regarding their health, such as following complex health regimens, evaluating benefits and risks of different health options, and weighing short-term against long-term benefits (Peters et al., 2007). For example, Schwartz et al. found that women with high numeracy were more accurate in estimating risks, whereas those less numerate overestimated the benefits of mammography to their lifetime cancer risk (Schwartz et al., 1997; Wright et al., 2009).

Individuals with low numeracy are also found to be more prone to framing effects and numerical format effects (Ancker & Kaufman, 2007; Peters et al., 2007; Peters et al., 2006). They are less informed by numerical information, and more influenced by other non-numeric sources of information or irrelevant affective considerations, such as their emotions, mood states, and trust or distrust in physicians and the health systems (Peters et al., 2007; Peters et al., 2006). Whereas, individuals with high numeracy tend to have more precise affective responses towards numerical information (Peters et al., 2006), and are more likely to retrieve and use appropriate numerical principles, therefore they are less susceptible to framing effects (Peters et al., 2006).

2.5 RECOMMENDED GENETIC RISK COMMUNICATION

PRINCIPLES

Over the past decades, researchers in health and risk communication have conducted extensive research regarding how risk information should be presented to individuals in order to improve comprehension, promote informed decision-making, and encourage health behavior change. This body of research covers areas such as general rules for genetic risk education, presentation of numerical risk information, framing effects, and use of graphics. Particularly, graphics have been shown to improve attention to, recall, and comprehension of numerical and statistical health information; specifically, individuals with limited health literacy are more likely to benefit from the use of graphics (Apter et al., 2008; Houts et al., 2006).

In this dissertation, I integrate these guidelines and recommendations into 20 recommended principles for genetic risk communication (Table 2), that specifically address concerns related to limited health literacy and limited health numeracy. These 20 principles are

incorporated into the computational framework for genetic risk communication proposed in this dissertation.

Table 2: Recommended genetic risk communication principles.

Item	Principles	Explanations	References
1	Communicate using plain language.		(Fagerlin et al., 2011)
2	Providing only key information is more effective.	The presentation format should always make the most important information easier to perceive and evaluate, requiring less cognitive efforts.	(Apter et al., 2008; Fagerlin et al., 2011; Lautenbach et al., 2013; Peters et al., 2007)
3	Always present absolute risks.	There is mixed evidence regarding whether relative risks should be presented along with absolute risks. But existing guidelines agree that absolute risks should always be presented.	(Fagerlin et al., 2011; Gigerenzer & Edwards, 2003; Peters et al., 2007; Visschers et al., 2009)
4	Use multiple formats to present statistical risk information.	Existing guidelines suggest that the format of frequencies is preferable to the format of percentages.	(Ancker & Kaufman, 2007; Fagerlin et al., 2011; Lautenbach et al., 2013; Visschers et al., 2009)

Item	Principles	Explanations	References
5	Simplify the numerical concept to reduce the required inferences and calculations.	<ul style="list-style-type: none"> • Use the same denominator when presenting frequency information (e.g., 1 of 1,000 and 20 of 1,000). • Use a small denominator (e.g., 100) when possible. 	(Apter et al., 2008; Lautenbach et al., 2013; Peters et al., 2007; Visschers et al., 2009)
6	High level statistical concepts generally should be avoided.	<ul style="list-style-type: none"> • The format of number needed to treat (NNT) is not recommended. • Concepts such as confidence intervals should be avoided. • The usage of decimals is not recommended. 	(Fagerlin et al., 2011; Peters et al., 2007; Visschers et al., 2009)
7	Provide a step-by-step description of a probability calculation.	E.g., when presenting risky situations that include false positives, such as screening test results.	(Visschers et al., 2009)
8	Use verbal expressions along with numerical information.	Use verbal expressions, such as “common”, “rare”, “seldom”, “sometimes”, “more often than not”, together with numerical probabilities, to contextualize the risks.	(Apter et al., 2008; Visschers et al., 2009)
9	Use an incremental risk format to highlight how treatment changes risks from preexisting baseline levels.		(Fagerlin et al., 2011)

Item	Principles	Explanations	References
10	Use different graphs based on the numerical information presented.	<ul style="list-style-type: none"> • Pictographs or frequency diagrams can be used to present risk and benefit information. The random highlighting of a frequency diagram can be used when explaining the concept of chance. • Bar graphs are particularly effective in making multiple comparisons and depicting relative risks. • Histograms and pie charts can be used to emphasize part-to-whole concepts such as percentages. • Line graphs effectively communicate trends. • Scatter plots effectively display variability. 	(Ancker & Kaufman, 2007; Apter et al., 2008; Fagerlin et al., 2011; Lautenbach et al., 2013; Lipkus & Hollands, 1999; Peters et al., 2007; Price et al., 2007; Schapira et al., 2006; Visschers et al., 2009)
11	Pay attention to framing effects.	Present both positive and negative outcomes, or gain- and loss-framed numerical risk information (e.g., survival and mortality rates) to reduce framing effects.	(Ancker & Kaufman, 2007; Apter et al., 2008; Armstrong et al., 2002; Lautenbach et al., 2013; O'Doherty & Suthers, 2007; Peters et al., 2007)

Item	Principles	Explanations	References
12	Be aware of the order effects when presenting risks and benefits.	E.g., the recency effect.	(Fagerlin et al., 2011)
13	Provide summary tables.	A quick summary can potentially help minimize the problem of recency effect.	(Fagerlin et al., 2011)
14	Recognize that comparative risk information can be persuasive.	E.g., risk information based on individuals' demographics.	(Fagerlin et al., 2011)
15	Reinforce the time interval over which a risk occurs.	E.g., a lifetime risk versus a 10-year risk.	(Fagerlin et al., 2011)
16	Pay attention to emotions.	Emotions may influence perception and adoption of numerical risk information.	(Lautenbach et al., 2013)
17	Tailor communication to patient profiles.	Risk information should be tailored to an individual's specific genetic profiles and other characteristics.	(Lautenbach et al., 2013)
18	Engage recipients in communication.		(Lautenbach et al., 2013)
19	Confirm comprehension.	Evaluate comprehension after delivery of risk information.	(Apter et al., 2008)

Item	Principles	Explanations	References
20	Assess health numeracy.	A brief individualized assessment of numeracy may be useful for tailored risk education in the clinical setting.	(Apter et al., 2008)

2.6 INFORMATION PROCESSING MODELS

Past research in risk communication suggests that simply providing sufficient information does not necessarily lead to desired health attitudes and behavior change, such as adherence to risk reduction guidelines (Hollands et al., 2016). The perception of risk information also depends on the context in which the information is communicated (Visschers et al., 2009). Several cognitive models of information processing have been applied in risk communication, in order to deliver persuasive and effective risk messages towards attitude and behavior change. Among these models, the heuristic-systematic model (HSM) is well established and commonly used.

Developed by Chaiken (Chaiken, 1980; Chaiken et al., 1989) in the early 1980s, the HSM was proposed initially as an alternative model to another commonly applied theory called the elaboration likelihood model (ELM) (Petty & Cacioppo, 1986). The HSM has since then been widely recognized as a communication model that explains how individuals perceive and process persuasive messages.

2.6.1. The Elaboration Likelihood Model

The ELM, developed by Petty and Cacioppo (Petty & Cacioppo, 1986), states that people process persuasive messages through two distinct routes: a central route and a peripheral route. Elaboration refers to the amount of effort an individual is able to utilize to process a

persuasive message. Under the central route, an individual possesses a higher level of motivation and ability to process the message, taking a great deal of effort to thoughtfully consider information relevant to the presented message, resulting in reasoned attitude that is relatively more enduring, and predictive of behavior change. On the contrary, if this individual does not possess enough motivation or cognitive ability to process the information presented, he/she will undertake the peripheral route, to rely on heuristics or other positive/negative cues to arrive at a quick judgement of the received message. Under the peripheral route, less effort is required from the message receiver, and factors such as the credibility of the source, or the attractiveness of the information will play an important role in the decision-making process, resulting in a less durable attitude change compared with what achieved via the central route.

2.6.2 The Heuristic-Systematic Model

The HSM states that individuals process persuasive messages in a systematic or a heuristic way. While the ELM describes the central and peripheral routes as two separate routes for processing received information, the HSM states that systematic and heuristic processing may occur independently, or simultaneously. The systematic way of processing occurs when an individual carefully examines the information, using comprehensive cognitive processing. The heuristic way occurs when an individual relies on simple inferential rules learned from past experience and other rules of thumb, without fully processing the semantic content of the arguments presented. Thus, heuristic processors tend to be more easily persuaded by expert opinions, compared with systematic processors. However, persuasion achieved via systematic processing tends to be more persistent, and more predictive of future behavior change, whereas attitude changes formed via heuristic processing alone will be more susceptible to counter arguments, less stable, and less predictive of behavior change (Chaiken, 1980). Health

educators prefer that people process information systematically, as it will more likely lead to informed decision making, and potentially more persistent effects on long term health behavior change (Visschers et al., 2009).

One important principle defined in the HSM is the sufficiency principle (Chaiken & Ledgerwood, 2012), which states that people's minds tend to process information in the most economical way, with the least amount of effort. Thus, individuals tend to use heuristic processing when under time constraints or when arguments are deemed inconsequential or irrelevant. However, people are motivated to arrive at valid and accurate judgments, or to form desired attitudes towards the given facts. In order to reach an accurate conclusion, individuals may be motivated to exert additional cognitive effort, balancing their preference for minimal efforts with the desire to reach judgmental confidence (Chaiken & Ledgerwood, 2012; Trumbo, 1999).

2.6.3 Applying HSM to Genetic Risk Communication

For the past decades, there has been considerable research undertaken to apply HSM to risk communication (Etchegary & Perrier, 2007; Griffin et al., 1999; Trumbo, 1999; Trumbo, 2002). Several factors have been identified that predict how an individual processes risk information, including cognitive capacity, self-efficacy, motivation, and information sufficiency (Fazio & Towles-Schwen, 1999; Trumbo, 1999; Visschers et al., 2009). Individuals' cognitive capacities may be estimated using their education level, health literacy, and health numeracy. Self-efficacy is defined as an individual's belief in his/her ability to acquire and make use of information to arrive at a judgement concerning risk (Trumbo, 1999). Motivation can be measured using an individual's perceived importance of the present situation related to risk. Information sufficiency is defined as whether people think they hold enough information for

decision-making with the least effort (Trumbo, 1999). Higher motivation is found to predict systematic processing: motivated individuals are more willing to actively seek and analyze information to make an informed decision. Higher self-efficacy predicted both heuristic and systematic processing, and more likely heuristic processing. Perceived lack of information led to systematic processing, while perceived information sufficiency led to heuristic processing. Heuristic processing was also shown to be associated with lower risk perceptions, whereas systematic processing was associated with higher risk perceptions (Trumbo, 1999).

In general, the systematic way of processing is more likely to lead to behavior change in long term, as the decision is made after deliberation. Health educators prefer that people process information systematically, as it will more likely lead to informed decision making, and potentially more persistent effects on health behavior change (Visschers et al., 2009). However, people do not always possess the motivation or abilities to process information systematically, and in this scenario, they commonly follow three heuristics (Visschers et al., 2009): *anchoring*, *availability*, and *simulation*. The anchoring heuristic states that individuals tend to estimate a risk based on the first number or figure introduced, and neglect what is presented later in the message (Lautenbach et al., 2013; Visschers et al., 2009). The availability heuristic states that individuals perceive the risk information more likely, if it is made more available in memory. The simulation heuristic states that risk information that is more concrete and easier to simulate in memory, is preferred compared with more abstract information.

The HSM is particularly applicable to genetic counseling. During a typical genetic counseling session, patients are usually presented a significant amount of information within a relatively short period of time. Unmotivated individuals under time pressure may find the amount of information presented excessive, thus choosing to process it using simple heuristics

with the least effort, regardless of their cognitive capacity (Visschers et al., 2009). However, people may switch to more in-depth deliberation, if the situation changes and the issue under discussion is found to be more personally relevant.

Limited research to date has investigated how information processing methods affect attitude and behavior change related to genetic counseling. Prior research investigating the effects of genetic risk communication on cancer screening behaviors found that individuals who tested positive for genetic mutations were more likely to adhere to screening procedures (Heshka et al., 2008), suggesting a higher level of motivation may promote systematic processing, leading to desired adherence behaviors. Additional research is needed to investigate whether the desired behavior change is achieved via systematic processing, potentially associated with a higher level of perceived importance and motivation.

2.7 EMBODIED CONVERSATIONAL AGENTS AS HEALTH COUNSELORS

Prior research states that face-to-face counseling and empathy play important roles in genetic counseling. Patients who underwent genetic testing without individual face-to-face counseling showed increased anxiety, depression, and cancer-related distress following testing results disclosure, and some patients needed enhanced support (Jacobs et al., 2018). In addition, patients' satisfaction with their genetic counseling experience was found to be positively associated with perceived provider empathy and sensitivity (Peterson et al., 2018).

Currently, a significant shortage of genetic counselors nationwide leads to the fact that many individuals do not have access to genetic counselors, and many primary care providers are tasked with explaining genetic risks and interpreting genetic testing results without

assistance (Peterson et al., 2018). Non-genetics providers may lack adequate communication skills, or quantitative skills for explaining numerical risk information (Ancker & Kaufman, 2007), or lack the knowledge or training regarding genetic testing (Peterson et al., 2018). Furthermore, many primary care providers reported that they were underprepared or not confident in discussing genetic information with patients (Peterson et al., 2018).

Embodied conversational agents are animated computer characters designed to simulate face-to-face interaction with a human counselor, using speech, gaze, and other non-verbal behaviors, capable of expressing empathy and other emotions (Zhou, Bickmore, et al., 2014). ECAs have been demonstrated to work effectively as health educators and health counselors, particularly for individuals with limited health literacy (Bickmore et al., 2010; Bickmore, Pfeifer, & Paasche-Orlow, 2009; Bickmore et al., 2015; Zhou, Bickmore, et al., 2014; Zhou, Gali, et al., 2014). Bickmore and colleagues have conducted a series of studies looking at how pedagogical ECAs can help explain complex medical documents to individuals with low health literacy, and in general found participants' experience and satisfaction of the process were improved (Bickmore et al., 2015; Zhou, Gali, et al., 2014). An ECA genetic counselor capable of documenting family history with patients was shown to be highly effective when used by participants from an underserved patient population; however, this system was not designed to educate patients about genetic risks (Wang et al., 2015). Another web-based conversational agent system implemented in the form of a chat bot was reported (Ponathil et al., 2020), capable of collecting family health history. Limitations of this research include the use of fictional family history information in the evaluation study and that the system does not offer counseling based on the information collected.

2.8 INTELLIGENT TUTORING SYSTEMS (ITS)

The research on intelligent tutoring systems dates back to the 1970s and 1980s, and ITSs have been applied to multiple fields in recent years, including elementary science topics, algebra, physics, as well as programming and advanced computer theory (Al-Nakhal & Naser, 2017; Anderson et al., 1985; Hamed & Naser, 2017; Hooshyar et al., 2015; VanLehn et al., 2020; VanLehn et al., 2021). The aim of developing ITS is to provide students with the same level of instructional advantage a human tutor may provide (Anderson et al., 1985; Sleeman & Brown, 1982). One advantage of ITS is its ability to adapt to an individual's current knowledge state dynamically during a tutoring session, using the most beneficial pedagogical strategies (Ohlsson, 1986).

Intelligent tutoring system techniques are especially important to the task of genetic risk communication, as a significant portion of genetic counseling sessions are spent educating patients about genetics, hereditary risks, and risk-reducing behaviors. There are a lot of similarities between a one-on-one tutoring session and a genetic counseling session, as prior research in genetic risk communication suggests that a genetic counselor should always gauge and confirm a patient's comprehension, and make adjustments in his/her explanations (Apter et al., 2008; O'Doherty & Suthers, 2007), similar to what a human tutor usually does.

Utilizing concepts and theories from artificial intelligence and cognitive sciences, intelligent tutoring systems are capable of guiding learners through steps of a problem solution, providing hints and feedbacks as needed from expert knowledge databases (Kulik & Fletcher, 2016). By definition, an intelligent tutoring system includes four major components (Kulik & Fletcher, 2016; Sottolare et al., 2013). First, the domain model: an explicit domain

knowledge model that contains the set of skills and knowledge in the domain being taught. This usually contains the knowledge, concepts and rules ideally an expert would possess. Second, the student model: a dynamic student model that keeps track of the student's knowledge, performance, and may also track the student's cognitive, affective, and other psychological states that evolve during the course of teaching. Third, the pedagogical model: a pedagogical model that takes the domain knowledge model and the student model as input, and chooses tutoring strategies and actions based on the current assessments. And last, the user interface: a multimodal interface that takes in the student's input and produces output in different types of media. This is the primary way a student uses to communicate with the system.

A meta-analysis of the effectiveness of ITSs (Kulik & Fletcher, 2016) reviewed results from 50 controlled evaluations, and found that in 92% of the 50 studies, students who received intelligent tutoring outperformed students in control conditions, i.e., conventional classes, and tutoring gains were larger than 0.25 standard deviations in 78% of the 50 studies. The median effect was 0.66 standard deviations compared with control conditions. Specifically, Kulik and Fletcher found an average effect size of 0.40 in 18 studies that evaluated the effectiveness of ITS in elementary and high school mathematics. It approves that ITSs can be very effective instructional tools, and the average effect size of intelligent tutoring can be considered at least moderate. However, the effectiveness of ITSs tended to be stronger in evaluations that measured outcomes based on locally developed tests (average effect size = 0.73), whereas much smaller in evaluations that used standardized tests (average effect size = 0.13) (Kulik & Fletcher, 2016).

2.8.1 Learning from Human Tutors

Extensive research has been conducted to look at the tutoring strategies and techniques a human tutor would use, in order to guide the design of intelligent tutoring systems (Merrill et al., 1992; VanLehn et al., 2003). A human tutor is defined as someone providing students with one-on-one instructions (Merrill et al., 1992). Most tutoring dialogues between tutors and students were found to focus on steps of solving a problem, and the sequential and hierarchical structure of the problem-solving steps could serve as a basis for designing the dialogue structure of an ITS (VanLehn et al., 2003).

Human tutoring is found to be a highly interactive process. Successful human tutoring techniques include providing frequent feedback to students during the discourse interaction, emphasizing the difficulty of the task to promote a sense of challenge while allowing failure to be attributed to something else other than the students' own abilities, as well as indirectly drawing students' attention to an error by asking questions (Fox, 1991; Lepper et al., 1990; Merrill et al., 1992). These tutoring techniques have been applied to various ITSs, and have been found to lead to the most efficient learning, including setting goals, providing short immediate feedback, locating errors, and providing immediate error correction and explanation (Anderson et al., 1995; Corbett & Anderson, 2001; Ohlsson, 1986).

In particular, impasses during problem solving is found to be a key component in successful human tutoring, associated with knowledge gain (VanLehn et al., 2003). A typical learning opportunity involves the tutor suggesting a goal, the student trying first and then often reaching an impasse, and then the tutor giving subsequent explanations. This suggests that an optimal tutoring strategy may be to: 1) let the student reach an impasse; 2) provide hints or ask questions, and lead the student to find the right solution; and 3) provide

explanations only if the student has tried and failed. Merrill et al. also concluded that tutors should allow students to do most of the problem solving, allowing them to learn by doing, as a central part of learning occurs when students attempt to solve problems themselves (Anderson, 1983; Merrill et al., 1992).

2.8.2 Student Modeling

One of the potential advantages of an intelligent tutoring system over a human tutor is that a computer tutor may be designed to adapt to an individual student's needs dynamically, at each moment during a tutoring session, providing the most beneficial instruction or explanation to the student (Ohlsson, 1986). One important aspect of developing adaptive intelligent tutoring systems is to construct a detailed model of the student's cognitive state, or in other words, student modeling. In the field of ITS, the term student model is used as an abstract representation of the learner in the system. And generally, a student model is the system's beliefs about the learner's knowledge (Holt et al., 1994). Researchers have employed various approaches to implement modeling of a student's knowledge state. One common approach is to infer students' knowledge of the subject matter based on their performance, such as their questions, answers or solutions to questions, test scores, or exam results (Anderson et al., 1995; Ohlsson, 1986).

The process of inferring a student's cognitive state from his/her performance is originally defined as cognitive diagnosis (Anderson, 1983; Ohlsson, 1986). Ohlsson categorized cognitive diagnosis into four kinds (Ohlsson, 1986): 1) performance measures, e.g., test scores, or exam results; 2) overlay models, which is a method of laying what the student has already learnt, over the representation of the entire subject matter, i.e., comparing the student's knowledge or behavior with that of an expert; 3) error descriptions, e.g., the system can catch

the pattern of incorrect answers on a set of questions, in order to infer the false beliefs or incorrect facts the student might have acquired; and 4) simulations, such as having a runnable simulation model which performs like the specific student in the knowledge domain. Similarly, another review of student modeling in ITS (Brusilovskiy, 1994) summarized three most significant kinds of student models: overlay models, error models, and genetic models.

Sottolare et al. (Sottolare et al., 2013) summarized four types of student modeling in a more recent article. First, *knowledge tracing* as used in the Cognitive Tutors (Anderson et al., 1995). This approach tracks a student's progress through each of the monitored actions and builds a profile of the student's strengths and weaknesses in a step-by-step fashion. The student model is updated each time the student performs a correct or incorrect action, or requests a hint. Second, *constraint-based modeling*. Constraint-based computer tutors compares a student's actions with correct solutions represented as a series of declarative statements defined as constraints, each composed of a relevance condition and a satisfaction condition. Students are tracked while they solve problems by examining whether specific constraints are relevant or satisfied. Third, *knowledge space models*, which essentially are fine-grained overlay models. The domain model represents a large number of possible knowledge states on a topic, while the student model keeps track of which knowledge states are mastered by the student. The student's competence is reflected by the number and types of problems that the student is capable of solving. The last type of student model, *expectation and misconception tailored dialogue*, is typically found in ITSs that are able to hold a conversation with the student in natural languages, such as the AutoTutor (Graesser et al., 2004). When answering questions asked by the tutor, good answers and errors articulated by the student are defined as

expectations and misconceptions, and were scored. This type of modeling usually involves semantic analysis of the students' answers in natural languages.

2.8.3 Design Principles for the Pedagogical Model

A large body of research has been done to review instructional and pedagogical strategies that are grounded by science and empirical studies. Strategies and techniques employed by both human tutors and computer tutors are reviewed and summarized. Sottolare et al. emphasized that designing for adaptive ITSs should include the following: providing comprehensive student models that incorporate students states, traits, demographics, and historical data such as previous performances; supporting both macro-adaptive strategies, such as adaptation based on pre-training student traits, and micro-adaptive instructional tactics, such as adaptation based on state changes during training; supporting individual differences such as skill acquisition, retention, and performance; and modeling appropriate pedagogical strategies and tactics of expert human tutors to develop a comprehensive pedagogical model (Sottolare et al., 2014).

The Cognitive Tutors, one of the earliest applications of ITSs, were developed by Anderson and colleagues, and have been applied to teaching programming languages, geometry, and algebra, etc. The design of Cognitive Tutors was guided by a set of eight principles based on the Adaptive Control of Thought - Rational (ACT-R) theory of learning and performance (Anderson, 1983; Anderson et al., 1995; Anderson & Lebiere, 1998; Koedinger & Corbett, 2005). Koedinger and Corbett later reviewed and rephrased the six most frequently used design principles for intelligent tutoring systems, as listed in Table 3 (Koedinger & Corbett, 2005).

Table 3: Six design principles for intelligent tutoring systems (Koedinger & Corbett, 2005).

Item	Design Principles for Intelligent Tutoring Systems
1	Represent student competence as a production set.
2	Provide instruction in the problem-solving context.
3	Communicate the goal structure underlying the problem solving.
4	Promote a correct and general understanding of the problem-solving knowledge.
5	Minimize working memory load.
6	Provide immediate feedback on errors.

The first principle suggests that the instructional design should not be based only on an analysis of the domain content per se, but mainly the way in which students think about the content. A production set is a set of production rules defined as a series of if-then expressions, that represent a particular action, step, or a piece of knowledge component in a particular state of a task. The modularity of production rules in a production set offers the possibility to track the student's progress and diagnose specific student strengths and weaknesses. The third principle states that the tutor should decompose the initial problem into successive subgoals, and make explicit goal structure available, possibly by communicating through help messages. The fifth principle also emphasizes that making the goal structure visible can help reduce working memory load, thus help improve performance. Specifically, the sixth principle for immediate feedback is shown to be the best tutoring style (Anderson et al., 1995). Immediate short feedback and immediate error correction leads to the most efficient learning (Corbett & Anderson, 2001). This finding is consistent with (Merrill et al., 1992), which concludes that human tutors tend to provide immediate feedback after each step.

In (Ohlsson, 1986), Ohlsson analyzed teaching tactics and teaching strategies used in ITS providing adaptation in both content and form of instruction to the learner. In particular, Ohlsson reviewed teaching tactics relevant to cognitive skills, such as those involved in elementary mathematics, to shed some light upon the various actions an intelligent tutoring system needs in its behavioral repertoire. These teaching tactics include setting goals, giving feedback, locating errors, and explaining errors. These recommended tactics align with the design principles proposed by Anderson and colleagues (Anderson et al., 1995; Koedinger & Corbett, 2005).

Sottolare et al. (Sottolare et al., 2014) also suggested that an adaptive intelligent tutor needs to launch the right pedagogical strategies at the right moment according to the student model, maximizing learning and motivation while minimizing training time and costs. These design principles and recommendations align with the research conducted in the field of genetic risk communication, that counselors should always assess their audiences' perceptions of risk information being discussed at the moment, and make adjustments accordingly (O'Doherty & Suthers, 2007).

2.8.4 Pedagogical Agents

Pedagogical agents are ECAs implemented in a computer-facilitated learning environment. Graesser and colleagues developed the AutoTutor system, which is capable of teaching reading comprehension, computer literacy, or physics to learners, with an ECA in the role of a tutor (D'Mello & Graesser, 2012; Graesser et al., 2005; Graesser et al., 2004; Graesser et al., 1999). AutoTutor can hold a conversation with the learner in natural language, simulating the discourse patterns and pedagogical strategies of a human tutor. AutoTutor's pedagogical mechanisms were implemented based on the strategies used by ordinary school tutors who

were not highly trained in tutoring techniques, yet still very effective. The authors recorded and analyzed over 100 hours of naturalistic tutoring sessions of these unskilled tutors, and found that these normal unskilled tutors did not use most of the ideal tutoring strategies identified in the field of education and ITS. The tutor and the learner usually took part in a mixed-initiative dialogue, and the tutor usually took control. The AutoTutor system was designed to simulate the mixed-initiative dialogue moves between the unskilled tutors and the students. A recent version of AutoTutor is able to construct a cognitive model of students' knowledge levels by analyzing their typed or spoken responses, dynamically tailoring the interaction based on an individual student's development (D'Mello & Graesser, 2012).

In a follow-up study for the AutoTutor system, the authors examined which factor accounted for AutoTutor's facilitation of learning, the system's dialogue mechanisms, or the medium through which the dialogue moves were delivered (Graesser et al., 2003). In an experiment with 81 college students, each student learned from AutoTutor, textbook, or nothing in the control condition. The AutoTutor intervention was delivered through one of the four media conditions: printed text only, speech only, animated character, or animated character with printed text. The results confirmed that, especially with deep reasoning questions, AutoTutor facilitated learning via its dialogue mechanisms, but the format of the animated character also had subtle effects on learning. AutoTutor was also found to be most effective when there was an intermediate gap between the student's prior knowledge and the expert knowledge, but not particularly effective with students who already had high domain knowledge, nor when the subject matter was too difficult (D'Mello & Graesser, 2012; VanLehn et al., 2007).

D'Mello and Graesser (D'Mello & Graesser, 2012) recently reported a newer version of the AutoTutor system, the Affective AutoTutor, which was capable of automatically detecting and responding to individual students' emotional states as well as their cognitive states. Evaluation studies showed that Affective AutoTutor resulted in dramatic improvements in learning compared with the original AutoTutor system, particularly for students with low domain knowledge.

Pedagogical agent systems that involves two agents to form a three-party conversations are also found to be effective (Graesser et al., 2017). Trialogues usually involve two agents taking on different roles such as tutors and peers, while interacting with a human. Trialogue systems with two agents are able to model social interactions and arguments between a tutor and a peer, while the peer/tutee agent is also able to solicit help from the human learner, and work with the human to collaborate on completing tasks. An AutoTutor system designed to teach adult learners about reading comprehension was reported, particularly tailored for low literate adults. This system consists of two agents, a teacher agent and a peer agent, capable of forming three-party conversations with the user, asking questions, and providing feedback. Adaptation was achieved through providing learning materials based on the user's reading level, providing lessons of multiple difficulty levels based on user performance, and enabling various patterns of interaction through trialogues, including human observations, human helping peer agent, and human competing with peer agent (Fang et al., 2019; Lippert et al., 2019; Shi et al., 2021).

Another pedagogical agent system, BRCA Gist (Widmer et al., 2015; Wolfe et al., 2018; Wolfe et al., 2016; Wolfe et al., 2015), is a web-based intelligent tutor built on a platform similar to AutoTutor. BRCA Gist is able to teach women general concepts related to breast cancer and

genetic testing, using natural-language dialogues entered as text input via a web browser. However, learning with BRCA Gist resembles more of a classroom experience rather than a counseling session, and it does not provide information a patient would typically receive from a genetic counselor, such as tailored risk rates and risk reduction recommendations.

2.9 SUMMARY OF RELATED WORK AND CONTRIBUTION

While there has been a considerable amount of prior work done in the field of risk communication, researchers have called for more work in the field of genetic risk communication, especially the effects of health literacy, health numeracy, and information processing modes on genetic risk comprehension. This work sought to address these gaps identified in prior research, and in particular, to examine risk comprehension after receipt of genetic counseling.

This work contributes to the field of genetic risk communication, by presenting automated approaches for cancer genetic counseling, particularly tailored for individuals with limited health literacy and limited health numeracy. The proposed computational framework leverages the architecture of an intelligent tutoring system to provide multidimensional adaptation based on user traits and real-time comprehension assessments. This framework is also guided by validated risk communication theories and the HSM, to provide more effective risk education and adherence motivation, tailored to users' health literacy and risk level.

This dissertation contributes to the field of Human Computer Interaction by demonstrating the feasibility of simulating a face-to-face genetic counseling experience, using a pedagogical ECA acting in the role of a virtual genetic counselor. I explored the affordances of ECAs in providing automated web-based cancer genetic counseling, offering valuable

empirical evidence that pedagogical ECAs can be used effectively for risk education and counseling. Amidst a global pandemic that fundamentally reshaped our healthcare system, this work calls for researchers to explore the use of ECAs in other domains of health counseling.

CHAPTER THREE:

ACCEPTABILITY OF PROVIDING AUTOMATED BREAST CANCER GENETIC COUNSELING (PROTOTYPE I & EVALUATION STUDY I)

3.1 AUTOMATED GENETIC COUNSELING WITH AN EMBODIED CONVERSATIONAL AGENT (PROTOTYPE I)

An initial Prototype I was developed to evaluate the acceptability of providing breast cancer genetic counseling using a virtual counselor. Prototype I was able to educate users about their breast cancer genetic risks, and also motivate them to adhere to the recommended breast cancer screening guidelines.

The virtual genetic counselor is an animated embodied conversational agent (ECA) developed and rendered in the Unity3D game engine. The ECA's dialogue system architecture is illustrated in Figure 3. The ECA's dialogues are scripted using a custom scripting language based on the Hierarchical Transition Network models. The dialogues are designed as a series of hierarchical conversational states, compiled into executable codes to input into a state-based dialogue manager that decides the ECA's next action, based on user responses and other pre-defined variables. Nonverbal behaviors are generated using BEAT (Cassell et al., 2001), including facial displays of emotions, head nods for acknowledgment, hand gestures for emphasis, gaze shifts to signal turn-taking, and body posture shifts to signal topic changes.

User variables such as first name, age, and responses during the conversation, are stored in a persistent database. The ECA speaks using a TTS speech synthesizer, synchronized with the nonverbal behaviors generated using BEAT (Cassell et al., 2001). Users are able to converse with the agent by selecting utterance options from a multiple-choice menu on the screen, updated at each turn of the conversation.

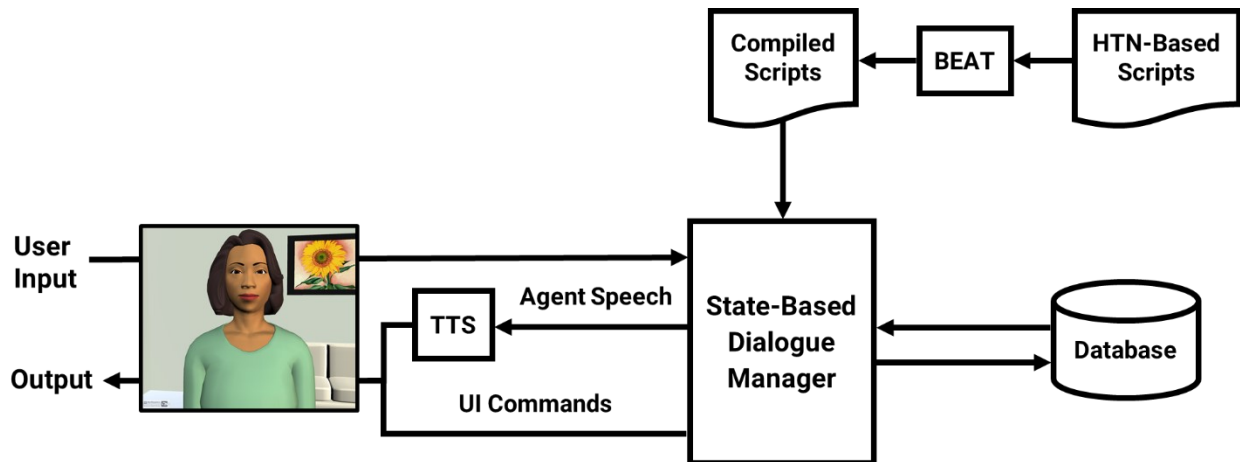


Figure 3: ECA dialogue system architecture.

3.2 VIRTUAL COUNSELOR DIALOGUE DESIGN

The design of the virtual counselor’s conversation emulates actual genetic counseling sessions previously videotaped at the Dana-Farber Cancer Institute. The virtual counselor starts with a short greeting and social chat conversation, designed to establish trust and rapport with its users, followed by different educational modules that cover topics typically discussed during a genetic counseling session.

The virtual counselor begins by giving an overview of the session, then first educates the user about hereditary breast cancer, and about genetics and mutations. After the general educational content, the virtual counselor educates the user about their risk of developing

breast or ovarian cancer based on age, and in particular, explains the statistical risk information related to BRCA genetic mutations using different visual aids recommended for genetic risk communication, such as pictographs, pie charts, line charts, and bar charts (Figure 4). At the end of the session, the virtual counselor explains the recommended breast cancer screening guidelines, what genetic testing means, and what the user can do regarding genetic testing and breast cancer screening.

At the end of each module, the virtual counselor asks users short quiz questions specifically designed for each educational module. Depending on the dialogue content and user responses, the length of the conversation varies, and users are asked to answer 5 to 7 short quiz questions. The design of the virtual counselor's pedagogical strategies is guided by the twenty genetic risk communication principles discussed in Chapter 2.

3.2.1 Genetic Risk Communication Educational Modules

The educational modules implemented in Prototype I are as follows:

Hereditary breast cancer. This module talks about the definition of hereditary breast and ovarian cancer, its prevalence in the general population, and how one may be at risk for hereditary breast cancer. The virtual counselor also explains the definition of risk.

Genes and mutations. In this module, the virtual counselor discusses the basic facts about genes, chromosomes, and genetic mutations. Specifically, the virtual counselor explains what BRCA mutations are, and the relationship between BRCA mutations and hereditary breast and ovarian cancer.

BRCA1 and BRCA2 genetic risks. In this module, the virtual counselor explains to the user a woman's specific genetic risks for breast and ovarian cancer, whether she has a BRCA1, or BRCA2 mutation. Information regarding lifetime risk for breast and ovarian cancer associated with BRCA mutations are provided by a risk prediction clinical decision support tool called ASK2ME, which provides absolute cancer risk predictions for various genetic mutations related to hereditary cancers (Braun et al., 2018). The virtual counselor also discusses other risk factors including ethnicity and family medical history, and how these risk factors might affect an individual's risk.

Recommended screening guidelines. In this module, the virtual counselor talks about the recommended medical guidelines for breast cancer screening.

Genetic testing. In this module, the virtual counselor educates the user about genetic testing, particularly BRCA genetic testing, and the possible results one may receive from a genetic test.

Adherence motivation. The virtual counselor motivates the user to follow the recommended breast cancer screening guidelines, and also suggests BRCA genetic testing, if the user may be at risk for hereditary breast cancer.

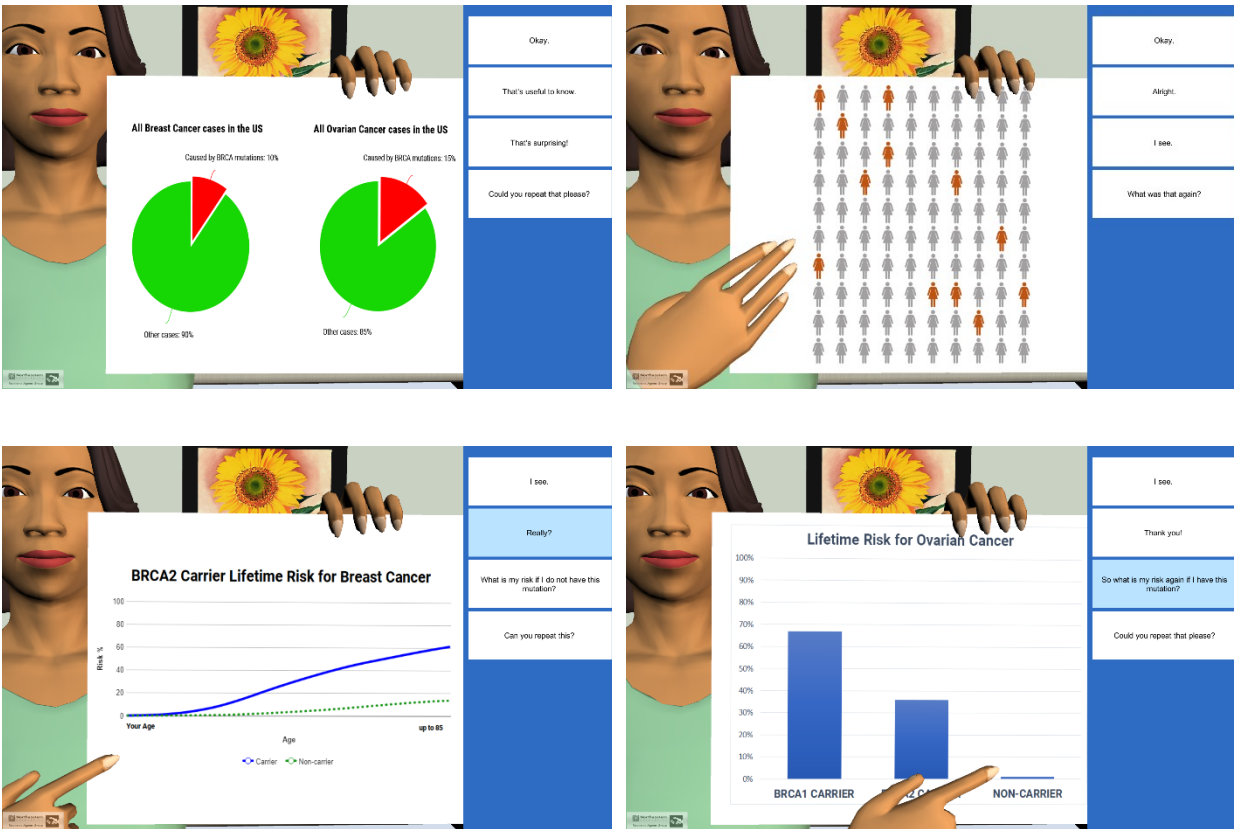


Figure 4: The virtual counselor uses different visual aids when explaining statistical risk information.

3.3 ACCEPTANCE STUDY (EVALUATION STUDY I)

To better understand whether people would accept an embodied conversational agent as a virtual genetic counselor, a pilot study (Evaluation Study I) was carried out to evaluate the acceptance of Prototype I. The aim of this study was to examine whether the virtual counselor (Figure 4) was able to improve participants' comprehension of genetic risk information. A quasi-experimental study was conducted to examine knowledge gain after interaction with the virtual counselor. Participants were asked to interact with the virtual counselor (Tanya) in a single 30-minute counseling session on a desktop computer. Measurements were collected both

immediately before and after their interaction with Tanya. This study was approved by our university IRB. Participants were recruited from our university campus and through online advertising, and were compensated for their time.

3.4 METHODS

3.4.1 Procedure

Before interacting with the virtual counselor, participants completed baseline questionnaires assessing their demographics, health literacy, health numeracy, and their prior knowledge about breast cancer genetics. Participants then interacted with the virtual counselor for approximately 30 minutes on a desktop computer. After interaction, participants completed questionnaires assessing their breast cancer genetics knowledge again, their satisfaction with the virtual counselor and the counseling experience, as well as their intentions to follow the recommended risk reduction medical guidelines. A semi-structured interview was conducted at the end of the session, focusing on participants' overall impression of the experience, and how they felt about interacting with a virtual genetic counselor. Participants' feedback regarding the different pedagogical strategies used by the virtual counselor to explain numerical and statistical information was also collected, as well as how they felt about answering quizzes during the interaction.

3.4.2 Measures

Breast cancer genetics knowledge. Participants' knowledge of breast cancer genetics was the primary outcome measure in this study, assessed using an 11-item true-false scale. This

measure was mainly modified based on an instrument developed by National Center for Human Genome Research (NCHGR) Cancer Genetic Studies Consortium, which has been validated in previous research (Lerman et al., 1997; Lerman et al., 1996; Scherr et al., 2016; Vadaparampil et al., 2010). Each item was scored as 1 if the participant answered correctly, and 0 if answered incorrectly or left blank. The overall score ranged from 0 to 11. Participants were measured immediately before and after their interaction with the virtual counselor.

Health literacy. Health literacy was assessed at baseline, using the Newest Vital Sign instrument (Weiss et al., 2005).

Health numeracy. Health numeracy was assessed at baseline, using a validated instrument (Lipkus et al., 2001), consisting of 11 questions. Each question was scored as 1 if the participant answered correctly, and 0 if answered incorrectly or left blank. The overall score ranged from 0 to 11.

Self-report scales. After interaction with the virtual counselor (Tanya), participants' experience with her was measured using a series of 7-point single-item scales (Table 5). Participants' trust in the virtual counselor was measured using a 5-item Likert scale, modified based on a 5-item semantic differential sub-scale for measuring participants' perception of an ECA's trustworthiness (Nunamaker et al., 2011). Participants' perceived BRCA genetic risk and intention to obtain BRCA genetic testing were assessed before and after participants' interaction with the virtual counselor, using single-item Likert-style scales used in (Lerman et al., 1997).

3.5 RESULTS

3.5.1 Participants

Twelve English-speaking females participated in Evaluation Study I. Participants (N=12) aged 21-63 years old (median=23.5), 41.7% white, 25% Hispanic, 16.7% black, and 16.7% Asian.

Participants' descriptive statistics were computed and reported in Table 4. All participants had at least some college education. Assessed using the Newest Vital Sign instrument (Weiss et al., 2005), two participants (16.7%) had limited health literacy. Participants' scores for the health numeracy instrument ranged from 4 to 11 (median=8.5). In particular, seven participants (N=7) answered more than one question incorrectly, indicating limited health numeracy.

Table 4: Participants' descriptive statistics in Evaluation Study I.

Participants (N=12)	Descriptive Statistics
Age, mean (SD)	29.1 (12.7)
Race/Ethnicity, n (%)	
White, not of Hispanic origin	5 (41.7)
Hispanic	3 (25.0)
Black, not of Hispanic origin	2 (16.7)
Asian or Pacific Islander	2 (16.7)
Education, n (%)	
Some college	3 (25.0)
College graduate	8 (66.7)
Advanced degree	1 (8.3)
Health Literacy, n (%)	

Participants (N=12)	Descriptive Statistics
Adequate	10 (83.3)
Limited	2 (16.7)
Health Numeracy, mean (SD)	8.5 (2.2)

3.5.2 Knowledge Gain

A paired t-test was conducted to compare participants' knowledge about breast cancer genetics before and after their interaction with the virtual counselor. Participants' post-treatment scores for the breast cancer genetics knowledge scale (min=8, max=11, mean=9.8, SD=0.9) significantly increased, compared with their pre-treatment scores (min=1, max=8, mean=4.9, SD=2.2), paired $t(11)=-7.01$, $p<.001$ (Figure 5).

3.5.3 Self-Report Scales

One-sample Wilcoxon signed rank tests were conducted for all single-item scale outcomes, to determine if the sample medians were significantly different than neutral scores of 4 (Table 5). Overall, participants were satisfied with the virtual genetic counselor and the counseling experience. They liked the virtual counselor, trusted her, were willing to continue working with her, and found her very knowledgeable. Participants' trust in the virtual counselor, when measured using a 5-item composite scale, was significantly higher than a neutral score of 4 (mean=6.0, SD=0.6, one sample t-test, $t(11)=11.6$, $p<.001$).

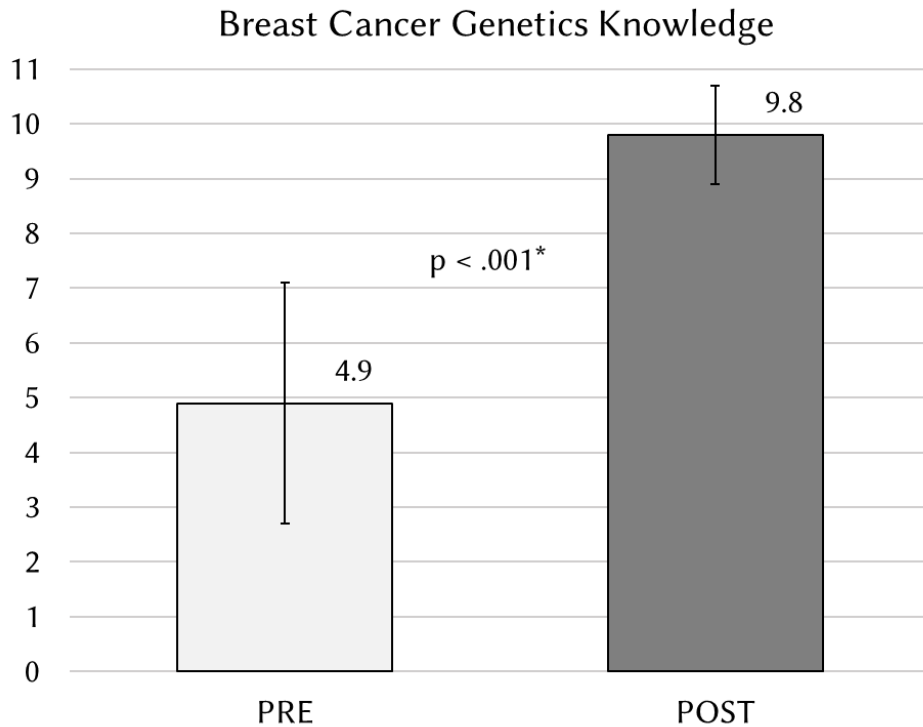


Figure 5: Participants' post-treatment knowledge scores significantly increased compared with pre-treatment scores in Evaluation Study I, $p < .001^*$. Mean scores shown, error bars depicting standard deviations.

When asked about their perceived amount of information received, participants' ratings were not significantly different than 4 (just right), but significantly higher than 1 (too little), one-sample Wilcoxon, $p < .01$, and significantly lower than 7 (too much), one-sample Wilcoxon, $p < .01$. Participants were willing to follow the recommended medical guidelines, and were also willing to talk more about genetic risks with a healthcare professional. No significant difference was found between participants' ratings for their perceived BRCA genetic risk or genetic testing intention, before and after their interaction with the virtual counselor.

Table 5: Acceptance of and satisfaction with the virtual counselor in Evaluation Study I. Single-item scales. Anchors: 1=“not at all” to 7=“very much” except where noted. One-sample Wilcoxon signed rank tests demonstrating ratings significantly different from neutral (=4).

Single-Item Scales	Median (IQR)	p-value
How satisfied were you with Tanya?	6 (0.25)	<.01*
How satisfied were you with the entire experience?	6 (0.5)	<.01*
How much would you like to continue working with Tanya?	6 (1.25)	<.01*
How much did you like Tanya?	5.5 (1)	<.01*
How much did you trust Tanya?	6 (1.25)	<.01*
How knowledgeable was Tanya?	6 (1)	<.01*
How much information did you get? (1=too little; 4=just right; 7=too much)	4 (1.25)	n.s.
How likely would you make a commitment to follow the recommended guidelines for breast cancer screening?	6 (2)	<.01*
How likely would you be willing to talk more about your breast cancer risks with your primary care doctor or a genetic counselor?	7 (1)	<.01*

3.5.4 Qualitative Analysis

Responses from the semi-structured interviews were transcribed and analyzed for common themes. Participants reported that they felt the virtual counselor was personable, pleasant, and empathic, and they found the overall experience informative and helpful.

“Very good, she was personable, went at a good pace, provided a lot of information, very informative, transition was smooth...” (P3)

“I didn’t know a lot about those things she talked about. She made it clear and it was easy to follow her. I think I learned a lot from the session.” (P5)

“I think this is a really great way to take something very complex, making it simple and interactive to a point where it makes it applicable to your life, giving different examples that could happen in every day, and also putting out there information that’s really important for people without being very pushy.” (P12)

Four participants shared that they had family members who survived breast cancer (P2, P6, P9, & P11), and were particularly interested in learning more about this topic. Two of them indicated they had some prior knowledge about breast cancer because of their personal experience, although they were not particularly familiar with breast cancer genetics. They appreciated the information provided in the session, and they expressed they would like to seek more information in the future.

“I was familiar with what to do after you get cancer, but I wasn’t familiar with the genes, or anything about that. It scared me, but in a good way, I didn’t know it could be hereditary, I thought it was just a random thing. So I learned a lot, and I definitely will get the gene testing now...I felt like I needed to hear it, cuz my mother got breast cancer about a year ago, but I didn’t know that I would have to be tested at all...” (P2)

“I didn’t know the father could also carry it too.” (P6)

“My grandmother actually has had two mastectomies, that’s why I know. My mother always gets screened, she screened a lot, so I knew you had to get screened earlier...It runs in my

family, my grandmother's sister, and her other sister...I'll probably ask and see if she (grandmother) got the gene testing...I don't know if she has the gene, I don't think she's gone for it, but I'm definitely gonna ask her after this.” (P6)

“I now want to ask my family member what kind of breast cancer she had.” (P9)

“It was really useful information, something I didn't know before, my only knowledge about this was Angelina Jolie, now I got it better what she did, and why she did it...” (P11)

Two participants reported they had some prior knowledge about genes and mutations, because of their academic background, although they also admitted they didn't have knowledge about breast cancer genetics specifically. They suggested the experience could be improved by providing more tailored educational content.

“Since I'm studying biology and stuff, I knew most of the (part) what a gene is...I kind of wish I could've skipped that part, and gotten straight to information about BRCA1/2. I don't really know anything about those specifically, I enjoyed the information just specifically about breast cancer.” (P9)

“I think it would be nice if you could skip the overview portion (genes and mutations), because coming from a health science background, I felt the first 10 minutes were stuff I already knew, but I didn't know about hereditary breast cancer...” (P10)

Participants reported positive feedback for the virtual counselor's different pedagogical strategies to explain numerical and statistical risk information. In particular, participants liked the different graphics displayed by the virtual counselor (Figure 4), and found the graphics helpful and easy to understand.

“I like the statistics, just to have hard numbers, like how much more likely you’re to get cancer, also making it relevant to people who don’t think they are at higher risk, cuz I consider myself in that category. But it’s still interesting to learn about how much higher the risk is, if you do have the gene.” (P8)

“I’m definitely much more of a visual learner. Nice to have visuals just in case you’re spacing out, you can still see that picture.” (P12)

“The graphs were the most important part to me, I was realizing that if you have the gene, then this is you like 60% more at risk, instead of if you didn't have the gene, then you would be like 15% at risk for breast cancer. So that was definitely good, and the visuals were very reassuring, reiterating...” (P6)

“(In the line charts) someone who doesn't have the gene mutation versus someone who has - that was crazy, that really makes me think you should definitely consider testing.” (P9)

“Definitely I liked the visual with the people colored in (frequency pictograph) cuz that’s very helpful...I think the line chart was really crazy, to see that escalated as you’re progressing, as you get older.” (P12)

When asked how they felt about being quizzed by the virtual counselor, participants reported the experience was mostly not stressful. They liked the questions, and they felt the quizzes helped them learn the risk information better.

“I think it was helpful, because it reinforces it, like if I wasn’t paying attention, I wouldn’t know the answer. Her repeating it, and asking me, and testing myself, helped me learn it more.” (P2)

“A little bit uncomfortable, cuz I have to remember...and I’m not that fast with numbers, hard to recall sometimes, but I think I was able to answer most of the questions, I think I got one wrong. The one I got wrong, I asked her to explain it again, and she did, I think I got it after that.”
(P5)

“I felt like they were good, cuz sometimes I got a lot of information, I was just kind of blanking out at points...(answering quizzes) just reiterates what you should know, what you should’ve gotten from what she said...” (P6)

“I liked there were questions throughout, because sometimes I feel I might daydream, but that made sure I was actually focusing.” (P10)

“It was helpful actually, kept me on my toes, because they weren't like crazy questions, but they were all so realistic and practical, like the one she asked about your friend getting genetic testing, so it’s something that could happen in the future, it was very much applicable. She had answered the questions in her comments before, so I didn't feel too nervous about answering them.”
(P12)

These qualitative findings showed that the virtual counselor was well accepted by all participants. Participants were satisfied with the counseling experience, and were willing to share their personal experience involving breast cancer. Furthermore, they were comfortable with Tanya asking quiz questions during the session, and they found Tanya’s pedagogical strategies involving visual explanations help them understand the topic better.

3.6 CONCLUSION

Overall, Prototype I was well accepted by all participants, and highly effective in educating participants about breast cancer genetics. Participants were satisfied with the entire counseling experience. In particular, the virtual counselor's pedagogical strategies were well accepted by all participants, demonstrating possibility of providing genetic counseling using a pedagogical agent. These results were also well supported by findings from qualitative interviews. In conclusion, Evaluation Study I demonstrated the acceptability of providing automated breast cancer genetic counseling, with a pedagogical ECA as a virtual genetic counselor.

CHAPTER FOUR:

ADAPTIVE RISK EDUCATION ADOPTING INTELLIGENT TUTORING SYSTEM TECHNIQUES (PROTOTYPE II)

4.1 ARCHITECTURE OF ADAPTIVE VIRTUAL COUNSELOR (PROTOTYPE II)

Traditional methods of communicating genetic risks that include complex numerical or statistical information are not sufficiently effective, because the communication often happens in one direction, and comprehension assessment seldomly happen after counseling (Peterson et al., 2018). Thus, knowledge gain may be minimal after receipt of genetic risk information, especially for individuals with limited health literacy and limited health numeracy. Patients may have very different needs in how they receive, understand, and act on genetic risk information, depending on their preferences, prior domain knowledge, health literacy, and health numeracy, etc. Providing adaptive risk education based on comprehension assessment and other personal variables may be the key to address these limitations in genetic risk communication. Findings from Evaluation Study I demonstrated that it was feasible and effective to provide genetic risk education with a pedagogical agent. The need for adaptive risk education was also identified during user interviews.

In order to achieve effective genetic risk education, Prototype II was developed, in the modality of a pedagogical embodied conversational agent, adopting the architecture of an

intelligent tutoring system. As illustrated in Figure 6, Prototype II consists of four main components based on the standard architecture of an ITS (Kulik & Fletcher, 2016; Sottolare et al., 2013), a domain knowledge model, a user model, a pedagogical model, and an ECA interface.

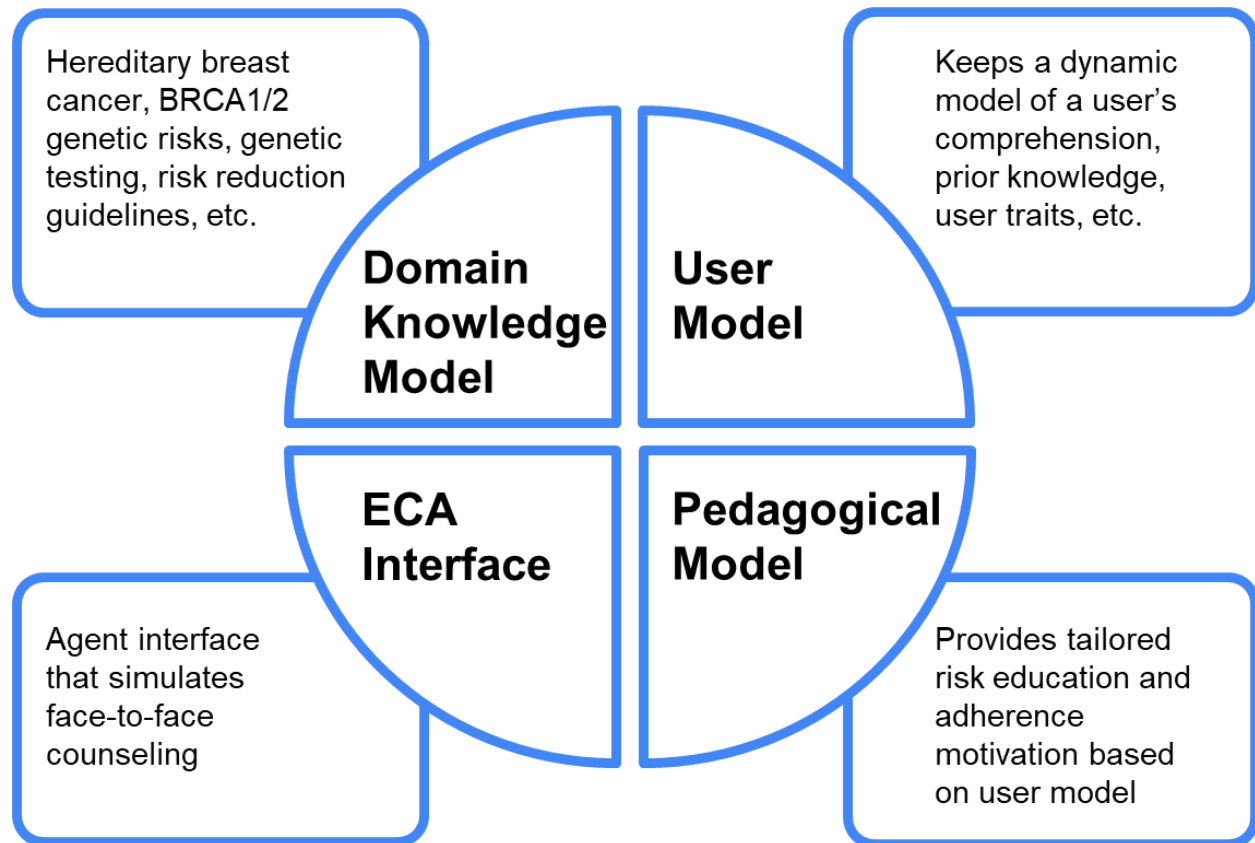


Figure 6: Architecture of the adaptive virtual counselor.

The first component, a domain knowledge model, contains the basic concepts and facts required to teach genetic risks related to hereditary breast cancer, including educational contents on hereditary breast cancer, BRCA genetic risks, genetic testing, and risk reduction medical guidelines, etc.

The second component, a user model, maintains a dynamic model of the user's current comprehension through quiz assessments, as well as other variables assessed at enrollment or during interaction, including prior knowledge, health literacy, and user preferences.

The third component, a pedagogical model, dynamically chooses its pedagogical strategies and explanation methods based on the user model's current assessment, and the discourse context. The design of the user model and the pedagogical model is informed by the 20 genetic risk communication principles summarized in Chapter 2, and successful ITS strategies validated in prior research. Applicable intelligent tutoring tactics and strategies include setting goals, providing short immediate feedback, and explaining errors (Anderson et al., 1995; Koedinger & Corbett, 2005; Ohlsson, 1986). In addition, the design of the pedagogical dialogues is based on actual genetic counseling sessions previously videotaped at the Dana-Farber Cancer Institute.

The last component, an ECA interface, handles the multimodal interaction between the user and the virtual counselor, simulating face-to-face genetic counseling.

4.2 VIRTUAL COUNSELOR SYSTEM DESIGN

The virtual genetic counselor is developed and rendered in the Unity3D game engine as a web application (Figure 7). The counselor's dialogues are scripted using a custom scripting language. The counselor speaks using synthetic speech synchronized with nonverbal behaviors, including facial expressions, gaze shifts, eyebrow raises, head nods, body posture shifts, and hand gestures. Users converse with the counselor by selecting fully constrained utterance options from a multiple-choice menu, updated at each turn of the conversation.



Figure 7: The virtual genetic counselor discusses breast cancer risk with users.

4.3 ADAPTIVE RISK EDUCATION

Prototype II extends the design of Prototype I, to assess the efficacy of ITS-inspired dynamic multimodal adaptation in genetic risk education. The virtual counselor discusses with the user the same educational topics implemented in Prototype I (Chapter 3), including hereditary breast cancer, genes and mutations, BRCA1/2 genetic risks, recommended screening guidelines, genetic testing, and adherence motivation. Yet with Prototype II, the pedagogical content a user receives is tailored based on dynamic assessments and other user traits stored in the user model. The dynamic adaptation to a user's knowledge state is achieved through assessments using quiz questions asked by the virtual counselor throughout the counseling session. While a dynamic and accurate assessment of a user's comprehension is essential, the exact granularity in assessment required in a typical classroom tutoring session is not particularly necessary in health counseling. The pedagogical content in genetic counseling is provided in chunks, and not necessarily offered in a hierarchical sequence. Therefore, even if users do not comprehend a piece of information provided in an earlier topic, they can still benefit from subsequent discussions.

Adaptive genetic risk education is achieved based on the following variables stored in the user model, assessed at baseline or during the interaction:

User preferences. Users' preferences regarding narrative or visual risk explanations are assessed at the beginning of the interaction, and stored in the user model. Users later receive pedagogical content adapted to their preferences: users who prefer visual explanations receive visual aids designed based on the recommended risk communication principles, while users who prefer narrative explanations receive minimal visual aids. The virtual counselor offers alternative risk explanations when applicable.

Prior knowledge screening. At the beginning of the conversation, the virtual counselor assesses the user's prior knowledge about breast cancer, and genes and mutations, using a series of true or false questions modified based on validated measures (Alwan et al., 2012; Fitzgerald-Butt et al., 2016; Godfrey et al., 2016). Example questions are listed in Table 6. Based on screening outcomes, users with adequate prior knowledge receive adapted educational content, though they are given options to review any skipped content. Users who fail the screening receive a more comprehensive review of the related topics.

Dynamic comprehension assessments. Users receive tailored educational content based on periodic quiz assessments of their knowledge state. Users who fail comprehension assessments may be given alternative risk explanations, or offered to have an abbreviated review of previous relevant topics. In total, users are asked 5 to 7 quiz questions, based on the dialogue context, on average 1 or 2 question for each topic. Users may choose to skip some of the quiz questions.

Table 6: True-false questions for screening users' prior knowledge, modified based on validated measures (Alwan et al., 2012; Fitzgerald-Butt et al., 2016; Godfrey et al., 2016).

Item	True-False Questions for Prior Knowledge Screening
Breast Cancer	
1	Breast cancer is the most common cancer in women worldwide.
2	Breast cancer affects only females.
3	Family history of breast cancer decreases a woman's risk of having breast cancer.
4	Age increases breast cancer risk in women.
Genes and Mutations	
1	Genes are inside of cells.
2	A parent passes both copies of each gene, to his or her child.
3	Altered or mutated genes can cause cancer.
4	A person with a mutated gene may be completely healthy.

User demographics (assessed at baseline). Users receive personalized risk rates based on their age and gender. Lifetime risk for breast and ovarian cancer associated with BRCA mutations are calculated according to ASK2ME, a risk prediction clinical decision support tool (Braun et al., 2018).

Health literacy (assessed at baseline). Health literacy level (adequate vs. limited) is assessed at baseline and stored in the user model. Users with limited health literacy, regardless of their preferences, first see or hear visual aids and risk explanations specifically designed to best help individuals with limited health literacy and/or limited health numeracy, according to

the recommended risk communication principles. Risk explanations or visual aids most commonly used in clinical settings are presented if no validated guidelines exist. The virtual counselor offers additional explanations based on their preferences, (e.g., narrative explanations, alternative visual aids, etc.), if they fail comprehension assessments.

CHAPTER FIVE:

EVALUATION OF ADAPTIVE RISK EDUCATION

(EVALUATION STUDY II)

5.1 STUDY DESIGN

A quasi-experimental study (Evaluation Study II) was carried out to evaluate the effectiveness of the adaptive risk education implemented with Prototype II in improving participants' breast cancer genetics knowledge. This study was conducted remotely online, on a computer via Zoom, where all participants interacted with the adaptive virtual counselor (Tanya) in a single 30-minute session via a web browser. Participants' knowledge about breast cancer genetics were assessed both before and after their interaction with the virtual counselor. A semi-structured interview was conducted at the end of the counseling session, particularly focusing on participants' perceptions of the virtual counselor's adaptive pedagogical strategies.

This study was approved by my university IRB. Participants were recruited through online advertising, and were compensated for their time. Specifically, English-speaking females aged between 18 and 45 were recruited for this study, as younger women were shown to have lower adherence rates to breast cancer screening (American Cancer, 2017; Han et al., 2018).

5.2 PROCEDURE

This study was conducted remotely online via Zoom. At baseline, participants completed online questionnaires assessing their demographics, health literacy, health numeracy, and their prior knowledge about breast cancer genetics. Participants then interacted with the virtual counselor for approximately 30 minutes via a web browser. After interaction, participants completed questionnaires assessing their breast cancer genetics knowledge again, their satisfaction with the virtual counselor and the counseling experience, as well as their intentions to follow the recommended breast cancer screening guidelines. Participants were also asked to rate their perceived level of adaptation. A semi-structured interview was conducted at the end of the session, focusing on participants' perception of the implemented dynamic assessments and adaptive teaching.

5.3 MEASURES

Breast cancer genetics knowledge. Participants' knowledge of breast cancer genetics was the primary outcome measure in this study, assessed using an 11-item true-false scale, validated in previous research (Lerman et al., 1997; Lerman et al., 1996; Scherr et al., 2016; Vadaparampil et al., 2010), ranged 0-11. Participants were measured immediately before and after their interaction with the virtual counselor.

Health literacy. Health literacy was assessed at baseline, using the Newest Vital Sign instrument (Weiss et al., 2005).

Health numeracy. Health numeracy was assessed at baseline, using a validated instrument (Lipkus et al., 2001), ranged 0-11.

Self-report scales. After interaction with the virtual counselor (Tanya), participants' experience with her was measured using a series of 7-point single-item scales (Table 8). Participants' perceived level of adaptation was measured using a single item scale: "*How accommodating/tailored do you feel Tanya was to your preference?*" (Table 8). Participants' trust in the virtual counselor was measured using a 5-item Likert scale, modified based on a 5-item semantic differential sub-scale (Nunamaker et al., 2011). Participants' perceived BRCA genetic risk and self-report intention to obtain BRCA genetic testing were assessed before and after the interaction, using single-item Likert-style scales (Lerman et al., 1997).

5.4 RESULTS

5.4.1 Participants

Thirteen English-speaking females participated in Evaluation Study II. Participants (N=13) aged 19-30 years old (median=22), 46.2% white, 38.5% Asian, and 15.4% black. Participants' descriptive statistics were computed and reported in Table 7. All participants at least graduated high school or equivalent. Two participants (15.4%) had limited health literacy. Using median score as a cut off score (median=10, ranged 4-11), five participants (38.5%) were categorized as having limited health numeracy, answering more than one question incorrectly.

5.4.2 Knowledge Gain

A paired t-test was conducted to compare participants' knowledge about breast cancer genetics before and after their interaction with the virtual counselor. Participants' post-treatment scores for breast cancer genetics knowledge (min=7, max=11, mean=9.5, SD=1.7) significantly

increased compared with their pre-treatment scores (min=0, max=8, mean=4.2, SD=2.6), paired $t(12)=-5.79$, $p<.001$ (Figure 8).

Table 7: Participants' descriptive statistics in Evaluation Study II.

Participants (N=13)	Descriptive Statistics
Age, mean (SD)	22.9 (3.1)
Race/Ethnicity, n (%)	
White, not of Hispanic origin	6 (46.2)
Asian or Pacific Islander	5 (38.5)
Black, not of Hispanic origin	2 (15.4)
Education, n (%)	
High school graduate or GED	2 (15.4)
Some college	3 (23.1)
College graduate	7 (53.8)
Advanced degree	1 (7.7)
Health Literacy, n (%)	
Adequate	11 (84.6)
Limited	2 (15.4)
Health Numeracy, n (%)	
Adequate	8 (61.5)
Limited	5 (38.5)

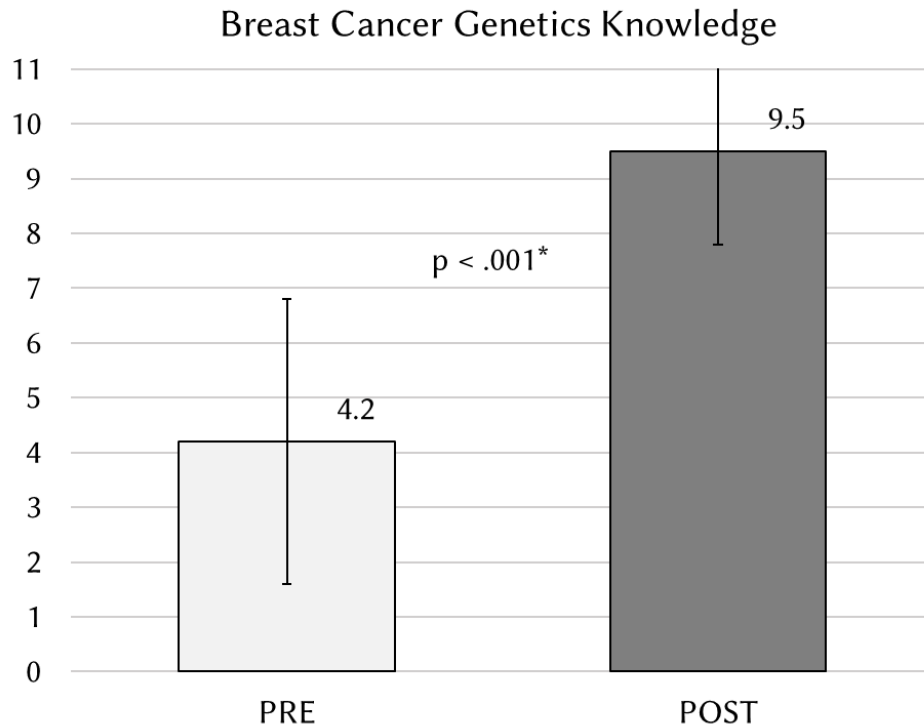


Figure 8: Participants' post-treatment knowledge scores significantly increased compared with pre-treatment scores in Evaluation Study II, $p < .001^*$. Mean scores shown, error bars depicting standard deviations.

5.4.3 Self-Report Scales

One-sample Wilcoxon signed rank tests were conducted for all single-item scale outcomes, to determine if the sample medians were significantly different from neutral (=4) (Table 8).

Overall, participants were highly satisfied with the virtual counselor (median=6) and the counseling experience (median=7). Participants liked the virtual counselor (median=6), trusted her (median=6), and found her very knowledgeable (median=7). In particular, participants found Tanya very accommodating to their preferences (median=7).

When asked about their perceived amount of information received, participants rated neither too much nor too little. Participants were willing to follow the recommended breast

cancer screening guidelines, and were also willing to talk more about their breast cancer risks with a healthcare professional. No significant difference was found between participants' ratings for their perceived BRCA genetic risk or self-report genetic testing intention, before and after their interaction with Tanya.

Table 8: Acceptance of and satisfaction with the virtual counselor in Evaluation Study II. Single-item scales. Anchors: 1="not at all" to 7="very much" except where noted. One-sample Wilcoxon signed rank tests demonstrating ratings significantly different from neutral (=4).

Single-Item Scales	Median (IQR)	p-value
How satisfied were you with Tanya?	6 (2)	<.01*
How satisfied were you with the entire experience?	7 (2)	<.01*
How much did you like Tanya?	6 (2)	.03*
How much did you trust Tanya?	6 (1)	<.01*
How knowledgeable was Tanya?	7 (1)	<.01*
How accommodating/tailored do you feel Tanya was to your preference?	7 (1)	<.01*
How much information did you get? (1=too little; 4=just right; 7=too much)	4 (1)	n.s.
How likely would you make a commitment to follow the recommended guidelines for breast cancer screening?	6 (1)	<.01*
How likely would you be willing to talk more about your breast cancer risks with your primary care doctor or a genetic counselor?	5 (2)	<.01*

5.4.4 Qualitative Analysis

The semi-structured interviews were audio-recorded and transcribed, resulted in 165 minutes of audio files and 122 pages of transcriptions. The interview transcriptions were analyzed following a general inductive approach adopted from (Thomas, 2006): the transcripts were read repeatedly to obtain a general understanding of the content; initial concepts were coded, reviewed, and clustered, to form higher-level themes. The analysis was conducted using the NVivo 12 software. During the interview, participants mainly answered questions regarding their perceptions of the virtual counselor's adaptive pedagogical strategies. The implemented dynamic assessment and adaptation were successfully acknowledged by all participants, and were found to personalize the counseling experience and improve learning. Selective themes were reported here.

5.4.4.1 Limited Prior Knowledge

Most participants did not have the basic knowledge about breast cancer genetic risk, prior to their interaction with the virtual counselor. P1 revealed that even though she had a family history of breast cancer, she had no prior knowledge of the gene mutations related to hereditary breast cancer. *“I definitely learned stuff from Tanya. I didn't really know anything about breast cancer or like the BRCA genes...My aunt actually had breast cancer before 50, and I hadn't even thought that there is this kind of testing that you can do, so I would definitely just go home, and tell my mom, like, hey you should probably get this done, if your sister had breast cancer before 50.”*

P10 had some prior knowledge about the BRCA genes through her college education, yet she expressed she had some common misunderstanding prior to talking with Tanya, and

was glad the misconception was cleared: *“I feel like a lot of the times when we talk about breast cancer, I hear like the BRCA1 and BRCA2 genes, and it always seems like if you have those, it's almost like you're guaranteed breast cancer, so it was nice to know that you still aren't guaranteed to have breast cancer, and there are options even if you have these genes, to prevent breast cancer.”*

5.4.4.2 Graphics Improve Understanding and Recall

The graphics and visual aids used by the virtual counselor helped conceptualize the risk messages delivered, and also made it easy for participants to recall. P4 described how a pictograph helped explain the risk: *“The one I remember the most was she was just explaining the statistics...I think it was like 12 in 100 women will get breast cancer and...she showed like 100 little figurines, and then you know, like 12 of 'em were colored in, to represent how many people would get cancer, so I like that it was really easy to see and you know, conceptualize (with the graphics).”* (Figure 7).

Several participants found the pictographs useful when Tanya explained risks, e.g., *“I'm definitely a visual learner, so I thought it was helpful to be able to actually visualize the risk in terms of like...this many people out of a certain number, or the lifetime likelihood, so I thought it was helpful to see the numbers.”* (P10).

5.4.4.3 Dynamic Assessments Boost Engagement

Participants expressed that answering the periodic quizzes made the experience more engaging, and the process helped them stay focused. P7 stated, *“I thought that it was a good tactic because if you were paying attention, and you're following along, there was no questions that seemed like extremely hard or extremely easy...they were like perfectly aligned with what she was explaining to you...And I thought that it helped me personally because as I went through, I*

knew that there was gonna be a question or a couple of questions after each section. So it kind of made me pay more attention while I was participating and helped me to better understand the material that she was trying to get through.”

P09 also mentioned that the quizzes left her with more questions to think about, “...*they can give you a clue on what you should think after that topic. They can leave you with questions to think about.”*

5.4.4.4 Dynamic Adaptation Personalizes the Learning Experience

All participants mentioned that they noticed some level of adaptation during the session, and they appreciated the amount of adaptation provided by Tanya. Participants felt they received educational content that was tailored based on their prior knowledge, which made the counseling experience more personalized and effective, e.g., “*I’m glad she didn’t, you know, tell me about the stuff that I already knew, but she wanted to make sure that I did understand it.”* (P4), and, “...*she also did the quizzes, so she figured out what I knew, and she didn’t have to repeat what I already knew, it was nice.”* (P13).

Several participants appreciated they were able to see more visual aids after they expressed their preferences during the conversation. P5 stated, “*I was able to have those visual aids...and also in a way, um, that was specific and individualized. For myself, that’s great.”*

P7 described that she was a visual learner and particularly liked this feature, “*I really loved the choices that were given between like a verbal explanation or if you prefer to see this (with visual aids). Me, personally, I’m more of a... like I need to be a hands-on...kind of look, see, do-it-myself learner, so I really liked it there was that option.”*

5.4.4.5 Increased Awareness of Breast Cancer Genetic Risk

Talking with the virtual counselor successfully raised awareness of breast cancer genetic risk for all participants. Participants felt the discussion with Tanya prepared them for a future conversation with a healthcare professional. P11 expressed, “...I was alarmed at the need to get, you know, breast cancer screening, which I think is a good thing, right? Like I think Tanya did her job in the sense that I'm a bit more wary of getting screenings earlier and just understanding really what the numbers might look like.” P10 also stated, “I feel very informed...if I wanted to talk to a physician or genetic counselor, I think I would know the right questions and be prepared to like have that conversation with them.”

5.5 CONCLUSION

Overall, results from Evaluation Study II showed that the implemented adaptive virtual genetic counselor was well accepted by the participants, and was effective in educating participants about breast cancer genetic risk. Significant knowledge gain was found after participants' interaction with the adaptive agent. Participants were highly satisfied with the virtual counselor, and the counseling experience. No significant result was found regarding participants' self-report genetic testing intentions. Qualitative findings from user interviews confirmed that the implemented adaptive risk education was successfully acknowledged by all participants. Participants found the tailored experience personalized, and was highly effective in improving their understanding and recall of the risk information.

Additional work is needed, to investigate how to effectively motivate at-risk individuals to follow the recommended breast cancer risk reduction medical guidelines. In the next

chapter, I will discuss the implementation of a Prototype III, incorporating information processing theories into genetic counseling, to achieve more effective adherence motivation. In addition to maintaining a dynamic model of the user's comprehension, the virtual counselor in Prototype III also adapts to other constructs defined in the heuristic-systematic model (HSM) of information processing (Chaiken, 1980; Chaiken & Ledgerwood, 2012; Chaiken et al., 1989), a well-established and commonly used model explaining how individuals process persuasive risk messages.

CHAPTER SIX:

ADAPTIVE RISK EDUCATION AND ADHERENCE MOTIVATION INCORPORATING INFORMATION PROCESSING THEORIES (PROTOTYPE III)

6.1 VIRTUAL GENETIC COUNSELOR DESIGN

A Prototype III was implemented, based on findings drawn from Evaluation Study I and Evaluation Study II. The heuristic-systematic model (HSM) of information processing was incorporated into the design of Prototype III, in order to effectively motivate at-risk individuals to adhere to breast cancer risk reduction medical guidelines. Additional adaptive mechanisms were also incorporated into Prototype III, based on user feedback collected from Evaluation Study I and II. Prototype III is able to provide adaptive breast cancer genetic counseling, driven by intelligent tutoring system techniques, risk communication principles described in Chapter 2 and (Zhou & Bickmore, 2021), and the heuristic-systematic model of information processing. Figure 9 illustrates the system architecture of Prototype III, with new or modified content compared with Prototype II highlighted in red. Prototype III consists of four main components: a domain knowledge model containing the educational content necessary to teach users about hereditary breast cancer and promote risk reducing behaviors; a user model storing dynamic assessments of user comprehension, preferred information processing method, and other constructs defined by the HSM, as well as user traits such as health literacy and risk level; a

pedagogical model dynamically selecting its pedagogical strategies based on the user model's current state and the discourse context; and an ECA interface simulating face-to-face counseling between the user and the virtual counselor.

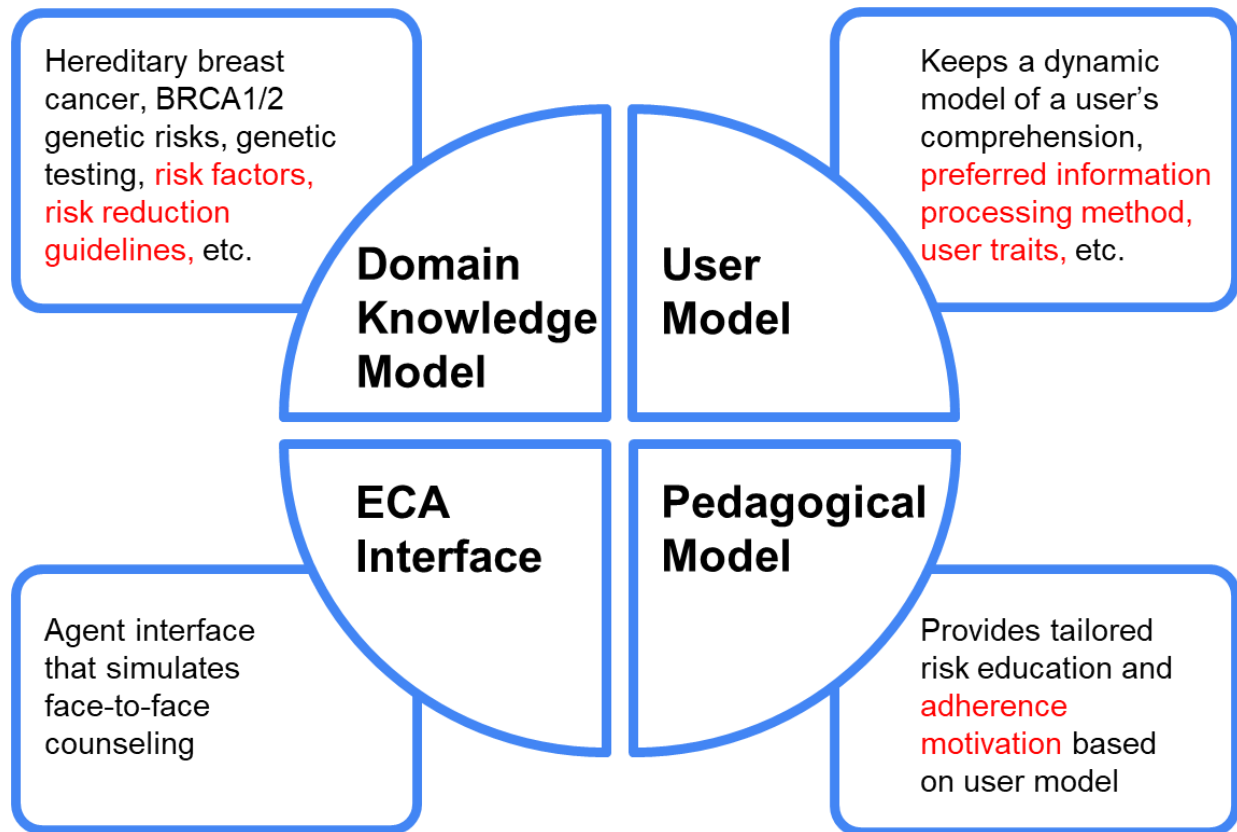


Figure 9: Architecture of Prototype III – a fully adaptive virtual genetic counselor.

The virtual counselor system was developed with the Unity 3D game engine as a web application (Figure 10). The ECA's dialogue is driven by a hierarchical transition network-based dialogue engine, with ECA's contributions to the dialogue made using template-based text generation, synthetic speech, and conversational nonverbal behaviors such as hand gesture, facial display, and proxemics. User contributions to the dialogue are fully constrained, and made by selecting an utterance from a menu, dynamically updated at each speaking turn.



Figure 10: The ECA interface of the virtual genetic counselor.

6.2 THE COMPUTATIONAL FRAMEWORK FOR GENETIC RISK COMMUNICATION

Figure 11 illustrates the final design of the proposed computational framework for adaptive genetic risk communication. The dialogue structure component illustrates the educational content contained in the domain knowledge model. The design of the virtual counselor's counseling dialogues consists of two main topics, *Risk Education* and *Adherence Motivation*. The *Risk Education* dialogues emulate genetic counseling sessions with a human counselor previously videotaped at the Dana-Farber Cancer Institute. As shown in Figure 11, the virtual counselor begins by giving an overview of the session, first educating the user about hereditary breast cancer, genes and mutations, followed by pedagogical content regarding BRCA mutations. The virtual counselor explains the elevated risk of breast and ovarian cancer caused by BRCA mutations, offering to provide personal risk rates tailored to the user's age and gender. Subsequent *Adherence Motivation* dialogues focus on motivating the user to follow breast cancer prevention and detection medical guidelines. The virtual agent offers pedagogical content including explaining genetic testing for BRCA mutations, other breast cancer risk factors, and breast cancer screening and risk reduction medical guidelines.

Content regarding breast cancer prevention and detection guidelines are modified based on guidelines recommended by the National Comprehensive Cancer Network (National Comprehensive Cancer Network, 2020a, 2020b, 2020c). The length of the session varies, subject to user selections during the dialogue.

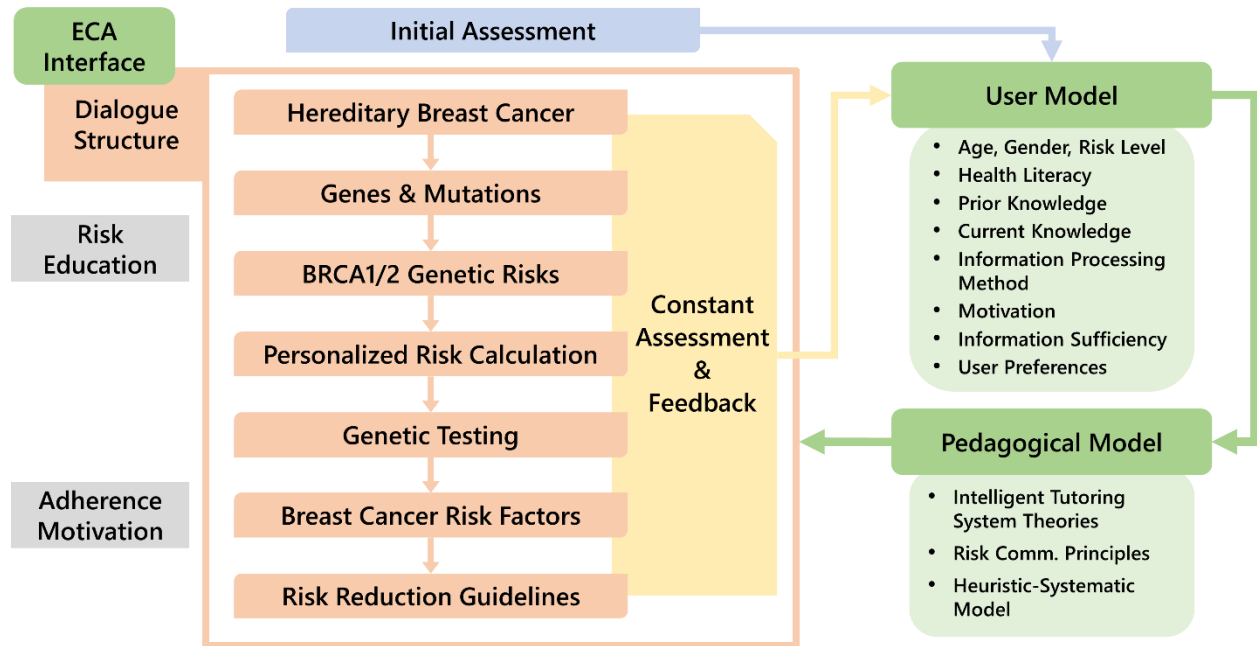


Figure 11: The computational framework for adaptive genetic risk communication, applied to breast cancer genetic counseling.

6.3 ADAPTATION MECHANISMS

Three major types of adaptation mechanisms are implemented, providing dynamic adaptive risk education and adherence motivation for hereditary breast cancer.

6.3.1 Comprehension Assessment

Users' prior knowledge and current comprehension regarding hereditary breast cancer are both assessed during the interaction.

Prior knowledge. The virtual counselor starts the session by evaluating a user's prior knowledge on breast cancer, as well as genes and mutations, using a series of true or false questions embedded within the counseling conversations, modified based on validated measures used in (Alwan et al., 2012; Fitzgerald-Butt et al., 2016; Godfrey et al., 2016). Based on screening outcomes, users may be given options to bypass certain modules completely, or to receive an abbreviated version adapted to their prior knowledge.

Current knowledge. After completion of each educational module, the virtual counselor assesses users' current knowledge state using 1 or 2 quiz questions. Users who fail comprehension assessment will be given alternative explanations, as well as options to review previous modules. Users' current knowledge state is then updated in the user model. Users are asked a total of five to seven quiz questions, depending on the dialogue context. The design of the quiz assessment component is guided by successful intelligent tutoring techniques, including providing short immediate feedback, and explaining errors (Anderson et al., 1995; Koedinger & Corbett, 2005; Ohlsson, 1986).

6.3.2 Preferred Information Processing Methods

Aside from teaching genetic risks, the virtual counselor also attempts to motivate users to adhere to breast cancer prevention and detection medical guidelines, and helps them make informed decisions whether genetic testing is necessary. The design of the counselor's persuasive dialogues is guided by conclusions drawn from applying HSM to genetic risk

communication. Users' *preferred information processing method* and current level of *motivation* are assessed at the beginning of the counseling session to determine whether they are heuristic processors or systematic processors, and stored in the user model. Users' level of motivation is assessed again after completion of the Risk Education component, and perceived *information sufficiency* is assessed later in the session before discussions of other breast cancer risk factors. Users' preferred information processing methods are reevaluated and updated after each new assessment. A major increase in motivation and a low level of perceived information sufficiency will result in a heuristic processor being reevaluated as a systematic processor, and vice versa. Assessment questions are modified based on validated measures used in (Trumbo, 1999), displayed as 7-point scales using a slider UI component embedded in the counseling conversations. Based on the user's preferred information processing method currently stored in the user model, the virtual counselor presents different arguments adapted to either heuristic processors or systematic processors, using persuasive strategies particularly effective for each.

Systematic processor. When tailoring to the systematic method, the virtual counselor focuses more on making robust arguments with supporting evidence. For example, while motivating users to follow the recommended medical guidelines, the virtual counselor presents validated scientific evidence, accompanied by detailed statistical findings from empirical studies published in research articles, and presents additional statistical visualization if applicable.

Heuristic processors. When tailoring to the heuristic method, the virtual counselor focuses on presenting expert recommendations as well as anecdotal evidence, with less emphasis on statistical information.

6.3.3 User Traits

The pedagogical content provided by the virtual counselor is also tailored based on several additional user variables, assessed both at baseline, and during the interaction, including a user's age, gender, breast cancer risk level, health literacy, and personal preferences.

User preferences. The users' preferences regarding visual or narrative risk explanations are obtained and stored in the user model earlier in the session. Users who prefer visual explanations are presented visual illustrations (Figure 12) designed based on the recommended risk communication principles discussed in (Zhou & Bickmore, 2021). Visuals most commonly used in clinical settings are presented if no validated guidelines exist. Users who prefer narrative explanations are presented minimal visual illustrations, with numerical information presented directly as numbers shown on a piece of paper, when key statistics are being discussed.

Health literacy. A user's level of health literacy is assessed before the start of the session, and stored in the user model. For users with limited health literacy, regardless of their preferences, the virtual counselor first provides risk explanations following risk communication principles specifically addressing issues related to limited health literacy, including using recommended visual illustrations. Users are offered additional risk explanations based on their preferences (e.g., narrative explanations, or other types of visuals if available), if they fail comprehension assessments.

Age, Gender, and Risk Level. The virtual counselor offers to provide personalized risk rates based on a user's age and gender. Lifetime risk for breast and ovarian cancer associated with BRCA mutations are calculated based on information provided by a risk

prediction clinical decision support tool called ASK2ME, which provides absolute cancer risk predictions for various genetic mutations related to hereditary cancers (Braun et al., 2018). Tailored breast cancer screening guidelines are provided based on a user's risk level (high vs. average risk).

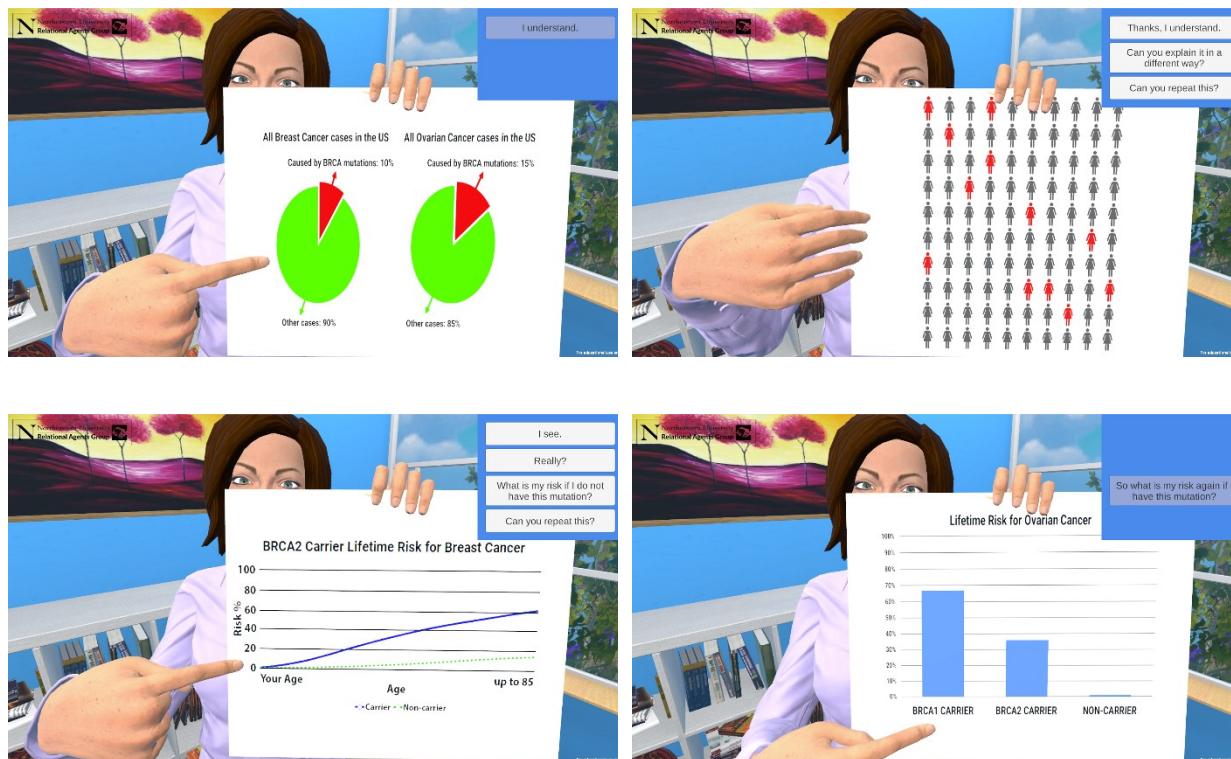


Figure 12: The virtual counselor uses different graphics when explaining numerical risk information.

CHAPTER SEVEN:

EVALUATION OF THE ADAPTIVE BREAST CANCER GENETIC COUNSELOR (EVALUATION STUDY III)

7.1 STUDY DESIGN

A between-subject study was carried out to evaluate the effectiveness of the implemented adaptive mechanisms on genetic risk communication. English-speaking females aged between 18 and 45 were targeted for recruitment, as younger women were found to have lower adherence rates to breast cancer screening (American Cancer, 2017; Han et al., 2018).

Advertisements were posted in an online community associated with a university located in the northeastern region of the United States. Participating candidates were pre-screened for their risk level. Women with either a first-degree relative who was diagnosed with breast cancer, or a family member who tested positive for a BRCA mutation, were identified as at high risk for breast cancer. Women who either had been diagnosed with breast cancer or tested for BRCA mutations, were excluded from the study as they possibly had already received some genetic counseling. This study was approved by IRB and participants were compensated for their time.

Participants were randomly assigned to one of three conditions: adaptive, non-adaptive, and control. This study tries to examine the following hypotheses:

H1: Genetic counseling with an adaptive virtual counselor will lead to greater gain in participants' knowledge about breast cancer genetics and the recommended medical guidelines, compared to a non-adaptive and a control one.

H2: An adaptive virtual counselor will perform better at motivating participants to adhere to the recommended medical guidelines, compared to a non-adaptive and a control one.

7.2 STUDY CONDITIONS

7.2.1 Adaptive Condition

In the adaptive condition, participants interacted with the implemented adaptive virtual counselor (Tanya).

7.2.2 Non-Adaptive Condition

A non-adaptive version of Tanya was developed, providing equivalent counseling as in the adaptive condition. However, other than being addressed by their first names, all participants in the non-adaptive condition had exactly the same conversation with Tanya, without receiving assessment of any kind, or any tailored personal risk rates. In addition, non-adaptive Tanya's conversational dialogues were modified to mostly use third-person narration while discussing risk information, for example, "a woman's risk of developing breast cancer," instead of "your risk of developing breast cancer" as primarily used in the adaptive condition.

7.2.3 Control Condition

The control condition is designed to provide standard of care genetic risk education. After first having a comparable social conversation as in the other two conditions, a control version of Tanya would ask the participants to watch two educational videos and read four educational

brochures about hereditary breast cancer, one by one displayed full screen. The educational videos used in this study were produced by the U.S. Centers for Disease Control and Prevention (CDC), featuring a human female genetic counselor discussing hereditary breast cancer and the BRCA mutations. The brochures were designed based on contents obtained from the CDC and the National Cancer Institute (NCI) websites. The videos and brochures together provided relatively comparable educational information as the other two conditions, although not through conversations with Tanya. To balance the total time needed to complete the session in each condition, and to prevent users from clicking through the educational content, each video and brochure included was implemented to be associated with a timer, and a user was not able to advance to the next topic, until the assigned time limit was up.

7.3 PROCEDURE

Participants completed the study remotely on a computer via Zoom. At baseline, participants completed questionnaires assessing their demographics, health literacy, health numeracy, and knowledge of breast cancer genetics. Participants then interacted with the virtual counselor via a web browser in a single session for approximately 30 minutes. After the interaction, participants completed questionnaires assessing their knowledge of breast cancer genetics, knowledge of screening and risk reduction guidelines, satisfaction with the counseling experience, their perceived level of adaptation, and their intention to adhere to the recommended medical guidelines. In addition, participants' perceived breast cancer susceptibility, benefits of mammogram, barriers of mammogram, as well as their perceived genetic risk and intention to have BRCA genetic testing were measured both before and after their interaction with the virtual counselor. A semi-structured interview was conducted at the end of the session, focusing on participants' overall impression of the experience. At the end of

the interview, participants were debriefed about the randomization process, with details regarding all three study conditions.

7.4 MEASURES

Demographics. Participants' demographic information was collected at baseline, including age, gender, and ethnicity. Participants' breast cancer risk level was determined based on a pre-screening questionnaire: participants with either a first-degree relative who was diagnosed with breast cancer, or a family member who tested positive for a BRCA mutation, were identified as at high risk; others were identified as at average risk.

Health literacy. Participants' health literacy was assessed at baseline, using the Newest Vital Sign instrument (Weiss et al., 2005), which is a validated measure assessing multiple dimensions of health literacy including numeracy, total score ranged from 0-6. Participants who scored lower than 4 were categorized as having limited health literacy.

Health numeracy. Participants' health numeracy was assessed at baseline, using a validated instrument (Lipkus et al., 2001), total score ranged from 0-11. Participants who answered 2 or more questions incorrectly were categorized as having limited health numeracy.

Breast cancer genetics knowledge. Participants' knowledge of breast cancer genetics was the primary outcome measure in this study, assessed using an 11-item true-false scale, modified based on a validated instrument used in past research (Lerman et al., 1997; Lerman et al., 1996; Scherr et al., 2016), total score ranged 0-11. Participants were measured immediately before and after their interaction with the virtual counselor.

Medical guidelines knowledge. Participants' knowledge of breast cancer prevention and detection medical guidelines was assessed after their interaction with the virtual counselor,

using a 10-item true-false scale, developed based on the educational content provided by the virtual counselor, total score ranged 0-10.

Perceived breast cancer susceptibility, benefits of mammogram, and barriers of

mammogram. Participants' perceived breast cancer susceptibility, perceived benefits of mammogram, and perceived barriers of mammogram were measured using a modified

Champion's Health Belief Model Scale validated in prior research (Champion, 1999; Moreira et al., 2020), including 3 items for assessing breast cancer susceptibility, 5 items for assessing benefits of mammogram, and 3 items for assessing barriers of mammogram. Participants were measured both before and after their interaction with the virtual counselor.

Self-report scales. After interaction with the virtual counselor, participants' satisfaction with the experience was measured using a series of 7-point single-item scales (Table 9, Item 1-6).

Participants' trust in the virtual counselor was measured using a 5-item Likert scale, modified based on a 5-item semantic differential sub-scale used in (Nunamaker et al., 2011). Participants' perceived level of adaptation was measured using a series of self-report 7-point scales (Table 9, Item 7-15). Participants' perceived BRCA genetic risk and intention to obtain BRCA genetic testing were assessed before and after their interaction with the virtual counselor, using single-item Likert-style scales used in (Lerman et al., 1997) (Table 9, Item 16-17). Perceived amount of information received, and perceived session length were measured using Item 18-19, Table 9.

Self-report familiarity with breast cancer prevention and detection guidelines and intention to adhere to these medical guidelines were measured using Item 20-23, Table 9.

Table 9: Self-report scales measuring satisfaction, perceived adaptation, and adherence to risk reduction medical guidelines.

Item	Self-Report 7-Point Scales	Anchor 1	Anchor 7
1	How satisfied were you with Tanya?	Not at all	Very satisfied
2	How satisfied were you with the entire experience?	Not at all	Very satisfied
3	How much would you like to continue working with Tanya?	Not at all	Very much
4	How much do you like Tanya?	Not at all	Very much
5	How much do you trust Tanya?	Not at all	Very much
6	How knowledgeable was Tanya?	Not at all	Very knowledgeable
7	How accommodating / tailored do you feel Tanya was to your preferences?	Not at all	Very accommodating
8	The information I received regarding breast cancer was tailored to my needs.	Strongly disagree	Strongly agree
9	I feel Tanya provided the information based on what I knew.	Strongly disagree	Strongly agree
10	Tanya understood my preferences and explained the risk information the way I wanted.	Strongly disagree	Strongly agree
11	The information on breast cancer risks was tailored to my understanding and knowledge.	Strongly disagree	Strongly agree

Item	Self-Report 7-Point Scales	Anchor 1	Anchor 7
12	I feel Tanya provides the same information for everyone.	Strongly disagree	Strongly agree
13	I think Tanya really tried to understand what I wanted and provided information just to my liking.	Strongly disagree	Strongly agree
14	The information on the recommended medical guidelines to reduce breast cancer risk was provided in a way that was most appropriate for my situation.	Strongly disagree	Strongly agree
15	The information on breast cancer was communicated in a way that was tailored to my preferences.	Strongly disagree	Strongly agree
16	In your opinion, how likely is it that you have a mutated breast cancer gene?	Not at all	Very likely
17	At the present time, which of the following statements describes you best? (1=Not considering genetic testing. / Haven't thought about it. 2=Considering genetic testing. 3=Probably will have genetic testing. 4=Definitely will have genetic testing.)	NA	NA
18	How much information did you get? (4=Just right)	Too little	Too much
19	How much time do you feel your interaction with Tanya took? (4=Just right)	Too short	Too long

Item	Self-Report 7-Point Scales	Anchor 1	Anchor 7
20	How familiar are you with the recommended medical guidelines for breast cancer prevention and detection?	Not at all	Very familiar
21	At this moment, how motivated are you to follow the recommended medical guidelines for breast cancer prevention and detection?	Not at all	Very motivated
22	How effective do you feel Tanya was in motivating you to follow the recommended medical guidelines for breast cancer prevention and detection?	Not at all	Very effective
23	How likely would you make a commitment to follow the recommended guidelines for breast cancer prevention and detection?	Not at all	Very likely

7.5 DATA ANALYSIS

A power analysis was conducted to determine the sample size for Evaluation Study III. The effect size of adaptive teaching offered by the virtual counselor on breast cancer genetics knowledge gain was calculated, based on results from Evaluation Study I for dependent samples. Based on Cohen's criteria, the calculated effect size ($d=2.0$) was considered large. With a significance level of 0.05 and 90% power, the sample size needed for a large effect size for a one-way ANOVA with three groups is approximately 8 participants in each group.

Thirty-two participants were recruited for this study, while two did not finish due to system malfunction. Data collected from these two participants was removed prior to data

analysis, therefore the final analysis was conducted with data from thirty participants. Both quantitative and qualitative data were collected from each participant. Data analysis was completed using R, version 3.6.1.

7.6 RESULTS

7.6.1 Participants

Participants' descriptive statistics were computed and reported in Table 10. Thirty participants (N=30) completed the study, aged 18-33 years old (median=22.5), 46.7% white, 36.7% Asian, 10% Hispanic, and 6.7% black. All participants at least graduated high school or equivalent. Three participants (10%) had limited health literacy assessed using the NVS, and ten participants (33.3%) had limited health numeracy based on the health numeracy scale. Participants' NVS scores were found to be highly correlated with their health numeracy scores, $r(28)=0.73$, $p<.001$. The three participants with low health literacy were also identified as having low health numeracy. Six participants (20%) were identified as having high risk for breast cancer.

Table 10: Participants' descriptive statistics in Evaluation Study III.

Participants (N=30)	Descriptive Statistics
Age, mean (SD)	22.4 (3.8)
Race/Ethnicity, n (%)	
White, not of Hispanic origin	14 (46.7)
Asian or Pacific Islander	11 (36.7)
Hispanic	3 (10)
Black, not of Hispanic origin	2 (6.7)

Participants (N=30)	Descriptive Statistics
Education, n (%)	
High school graduate or GED	4 (13.3)
Some college	10 (33.3)
College graduate	12 (40)
Advanced degree	4 (13.3)
Health Literacy, n (%)	
Adequate	27 (90)
Limited	3 (10)
Health Numeracy, n (%)	
Adequate	20 (66.7)
Limited	10 (33.3)
Breast Cancer Risk Level, n (%)	
Average Risk	24 (80)
High Risk	6 (20)

Eleven participants were randomly assigned to the adaptive condition (N=11), ten in the non-adaptive condition (N=10), and nine in the control condition (N=9), see Table 11. The distributions of low health literacy, low health numeracy, and high-risk participants across study conditions were found to be balanced, using Chi-Square tests.

Table 11: Number of participants in each study condition.

Study Conditions	Total	Number of Participants (N=30)		
		Limited Health Literacy	Limited Health Numeracy	High Risk
Adaptive	11	1	3	3
Non-Adaptive	10	1	4	2
Control	9	1	3	1

7.6.2 Perceived Adaptation

As a manipulation check, a Kruskal-Wallis rank sum test was conducted to examine participants' ratings for Item 12 (Table 9): "*I feel Tanya provides the same information for everyone.*" Results showed ratings significantly differed across three conditions, $p < .01$. Participants' perceived level of adaptation was computed based on their ratings on a 9-item composite scale (Table 9, Item 7-15). Results from a one-way ANOVA showed significant differences across three conditions, $p < .01$. Post hoc pairwise comparisons with Bonferroni correction were carried out to examine group differences (Table 12).

Boxplots of participants' ratings for the single-item scale "*I feel Tanya provides the same information for everyone,*" were shown in Figure 13. Specifically, participants in the adaptive condition rated significantly lower than in the non-adaptive condition (adjusted $p < .05$), and the control condition (adjusted $p < .01$). Participants' ratings for the composite scale for perceived level of adaptation were shown in Figure 14, with participants rating significantly higher in the adaptive condition, compared to the non-adaptive condition (adjusted $p < .05$) and the control

(adjusted $p < .05$). No significant group difference was found between the non-adaptive and the control conditions.

Table 12: Participants' ratings for Item 12 (Table 9), pairwise comparisons using Wilcoxon rank sum test with Bonferroni correction; participants' perceived level of adaptation, pairwise comparisons using t-test with Bonferroni correction.

Scale	Condition 1	Mean (SD)	Condition 2	Mean (SD)	p-value	Adjusted p-value
Table 9, Item 12	Adaptive	3.7 (1.3)	Non-Adaptive	5.5 (1.0)	<.01*	<.05*
	Adaptive	3.7 (1.3)	Control	5.7 (0.5)	<.01*	<.01*
	Non-Adaptive	5.5 (1.0)	Control	5.7 (0.5)	n.s.	n.s.
Perceived Adaptation	Adaptive	5.6 (0.6)	Non-Adaptive	4.7 (0.7)	<.05*	<.05*
	Adaptive	5.6 (0.6)	Control	4.3 (1.0)	<.01*	<.05*
	Non-Adaptive	4.7 (0.7)	Control	4.3 (1.0)	n.s.	n.s.

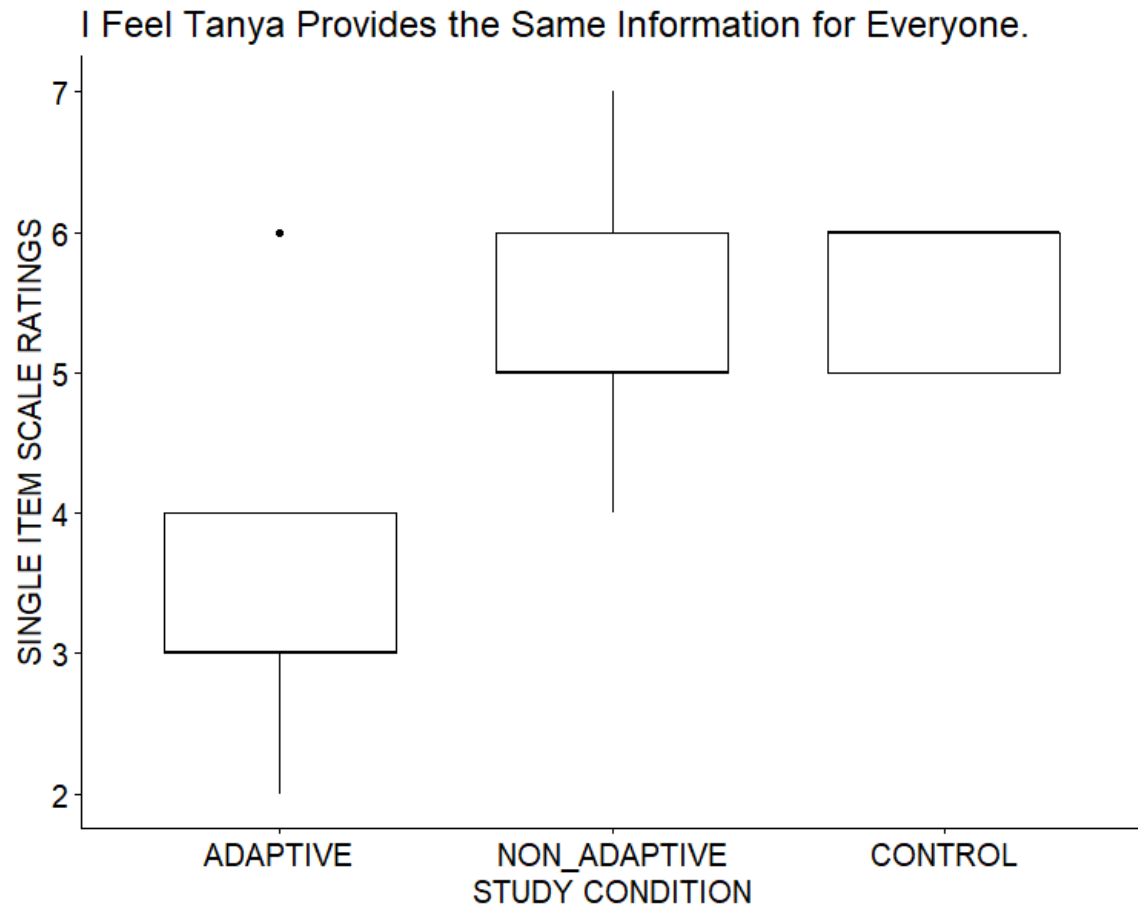


Figure 13: Participants' ratings for "I feel Tanya provides the same information for everyone" differed across three conditions, $p < .01^*$.

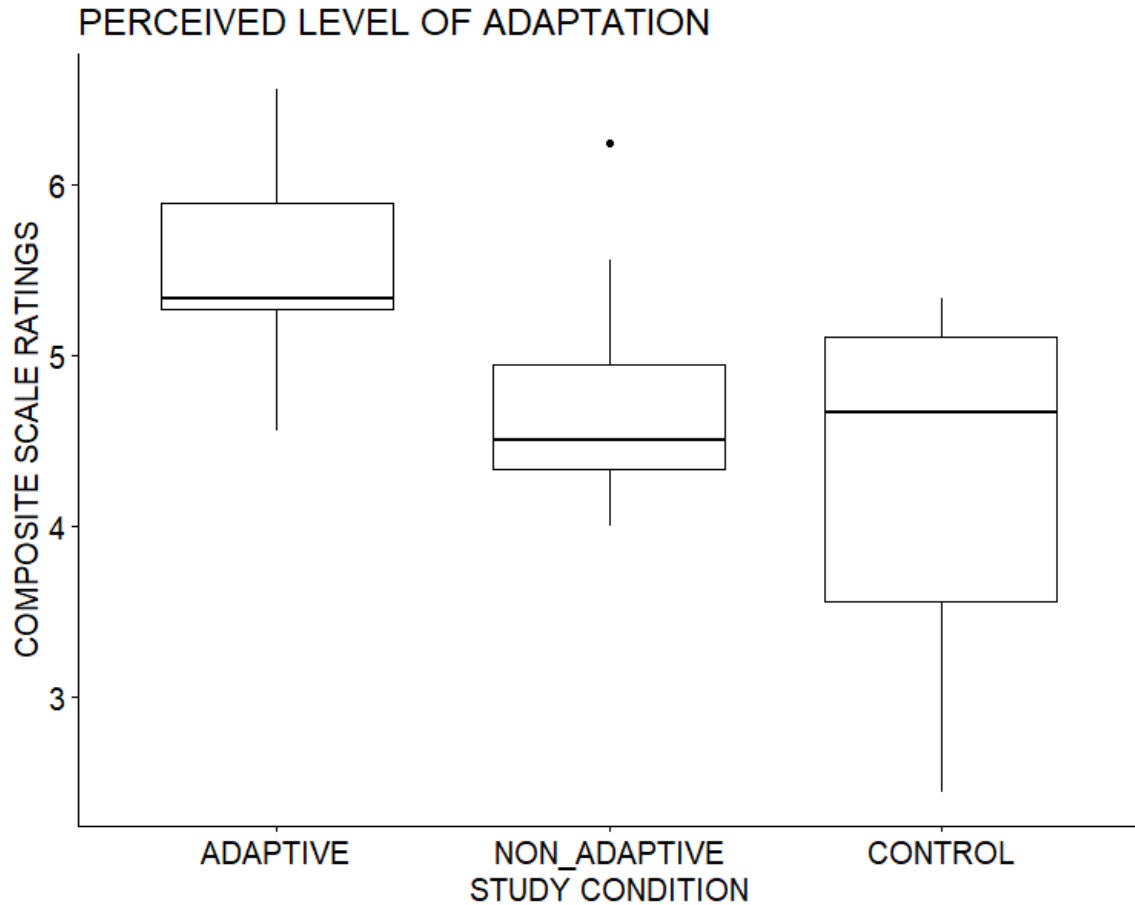


Figure 14: Participants' perceived level of adaptation differed across three conditions, $p < .01^*$.

7.6.3 Knowledge Gain

7.6.3.1 Breast Cancer Genetics Knowledge

Participants' scores for breast cancer genetics knowledge scale, as examined using Shapiro-Wilk's test, were normally distributed for each study condition both before and after interaction with Tanya, except for the adaptive condition after interaction, where a ceiling effect was observed. A repeated measure ANOVA revealed a significant interaction, $p < .01$, indicating significant differences in score changes across the three conditions (Figure 15). A

main effect of time was also found, as participants in all conditions received higher knowledge scores after their session with Tanya, $p < .001$. A one-way ANOVA using the participants' score differences between the two time points (post - pre) as the dependent variable was conducted, $p < .01$ (Figure 16), and post hoc pairwise comparisons using t-test with Bonferroni correction revealed participants in the adaptive condition (mean=6.9, sd=1.7) had significant greater knowledge gain than participants in the non-adaptive condition (mean=4, sd=2.9, adjusted $p < .05$), and the control condition (mean=3.1, sd=2.9, adjusted $p < .01$). Post hoc pairwise comparisons were carried out to examine group differences at both time points, and results showed no significant differences across all three conditions before interaction with Tanya, and significant differences across all three conditions after interaction with Tanya (Table 13). No effect of health literacy, health numeracy, and risk level on knowledge gain was found.

Table 13: Participants' breast cancer genetics knowledge scores before and after interaction with Tanya, pairwise comparisons using t-test with Bonferroni correction.

Time	Condition 1	Mean (SD)	Condition 2	Mean (SD)	p-value	Adjusted p-value
Pre	Adaptive	3.1 (1.7)	Non-Adaptive	4.4 (2.2)	n.s.	n.s.
	Adaptive	3.1 (1.7)	Control	3.7 (3.0)	n.s.	n.s.
	Non-Adaptive	4.4 (2.2)	Control	3.7 (3.0)	n.s.	n.s.
Post	Adaptive	10 (0.6)	Non-Adaptive	8.4 (1.6)	<.01*	<.05*
	Adaptive	10 (0.6)	Control	6.8 (1.2)	<.001*	<.001*
	Non-Adaptive	8.4 (1.6)	Control	6.8 (1.2)	<.01*	<.05*

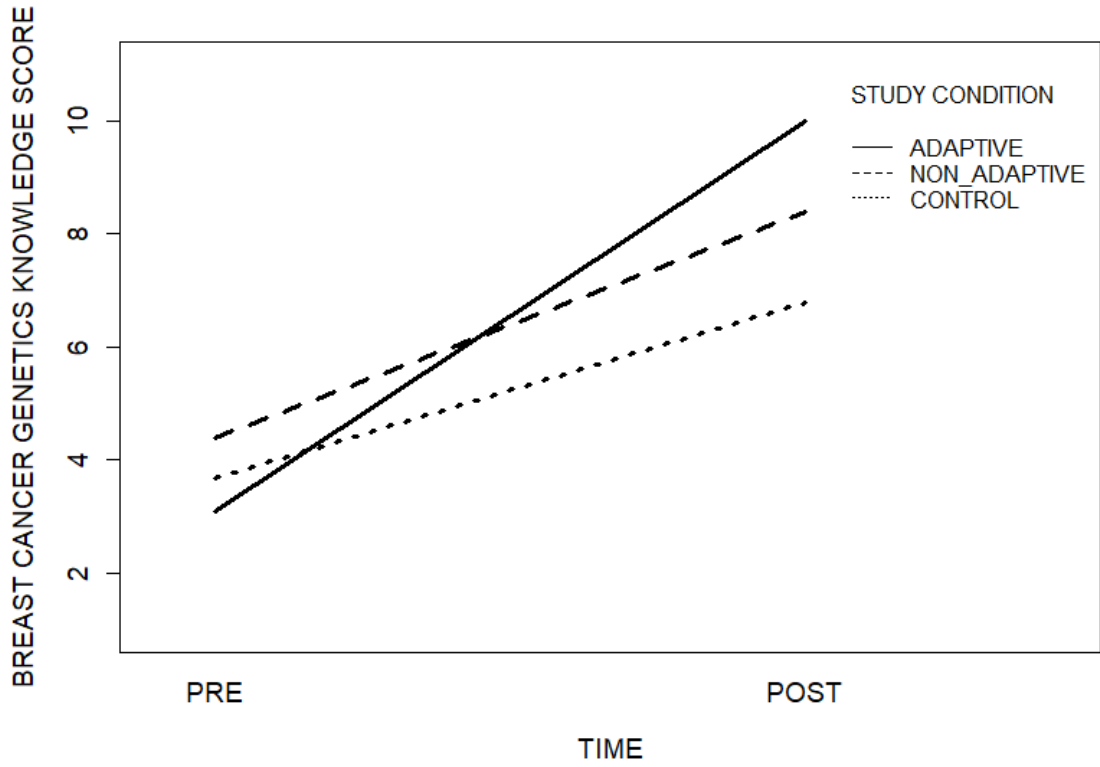


Figure 15: A significant interaction demonstrated participants had greater gain in breast cancer genetics knowledge in the adaptive condition, than in the non-adaptive and control conditions, $p < .01^*$.

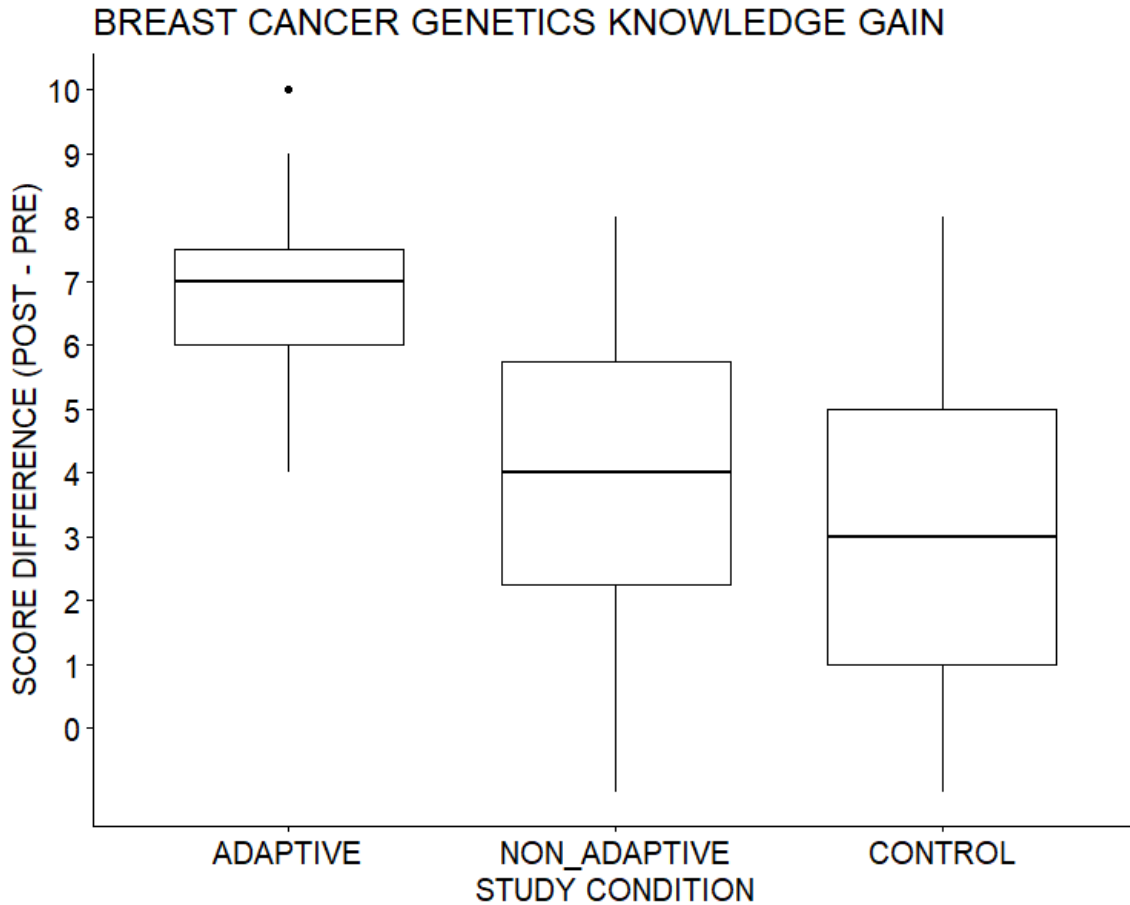


Figure 16: Participants' breast cancer genetics knowledge gain (post-pre) in adaptive (mean=6.9, sd=1.7), non-adaptive (mean=4, sd=2.9), and control (mean=3.1, sd=2.9) conditions, $p < .01^*$.

7.6.3.2 Medical Guidelines Knowledge

Participants' knowledge on breast cancer prevention and detection guidelines (Figure 17) were examined using a one-way ANOVA test, $p < .05$. Post hoc pairwise comparisons showed that participants in the adaptive condition had higher knowledge scores compared to participants in the control condition, adjusted $p < .05$, (Table 14).

Table 14: Participants' scores for the medical guidelines knowledge scale (range 1-10), pairwise comparisons using t-test with Bonferroni correction.

Condition 1	Mean (SD)	Condition 2	Mean (SD)	p-value	Adjusted p-value
Adaptive	8 (1.3)	Non-Adaptive	7.2 (2.0)	n.s.	n.s.
Adaptive	8 (1.3)	Control	5.7 (1.7)	<.01*	<.05*
Non-Adaptive	7.2 (2.0)	Control	5.7 (1.7)	n.s.	n.s.

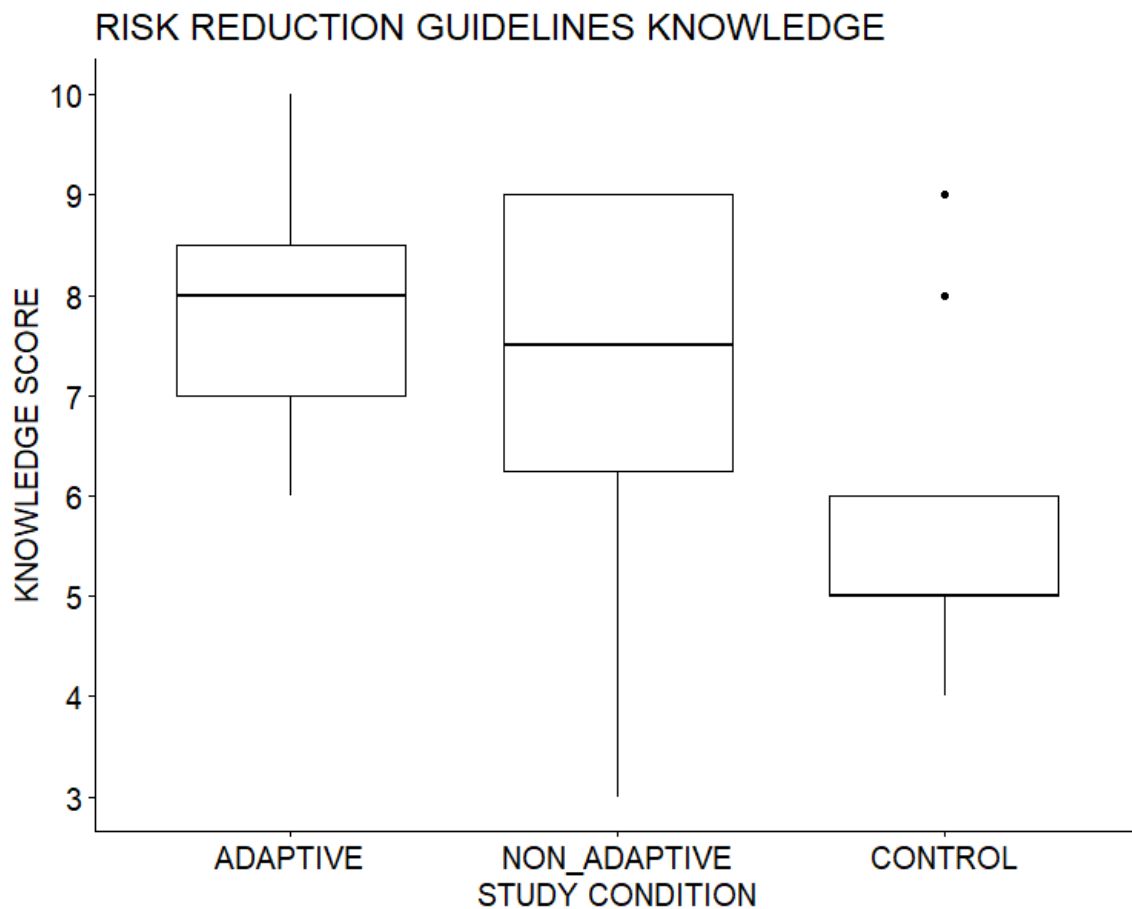


Figure 17: Participants' knowledge about breast cancer prevention and detection guidelines, across three conditions, $p < .05^*$.

7.6.4 Perceived Breast Cancer Susceptibility, Perceived Benefits of Mammogram, and Perceived Barriers of Mammogram

Participants' perceived breast cancer susceptibility was measured both before and after their interaction with the virtual counselor. A repeated measure ANOVA revealed a significant interaction, $p < .05$, indicating significantly different changes in ratings over time across the three conditions (Figure 18). Participants in the non-adaptive condition exhibited a decrease in their perceived breast cancer susceptibility after interaction with Tanya, while participants in the other two conditions showed an increase in breast cancer susceptibility. However, changes in scores were minimal. Post hoc pairwise comparisons examining group differences at both time points revealed no significant differences in ratings across all three conditions both before and after participants' interaction with Tanya.

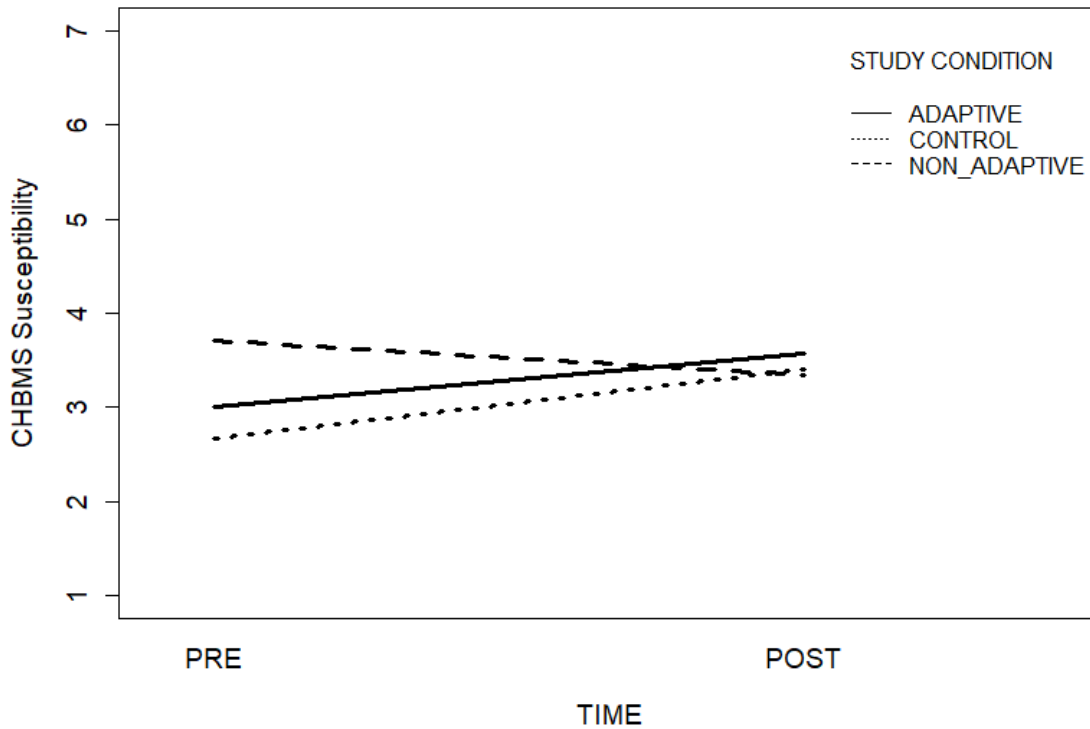


Figure 18: Participants' ratings for perceived breast cancer susceptibility before and after interaction with Tanya, in three conditions. A significant interaction demonstrated different trajectories over time, $p < .05^*$.

Participants' perceived benefits of mammogram before and after their interaction with the virtual counselor were shown in Figure 19. Perceived benefits slightly increased in the adaptive condition after the interaction, but ratings decreased in the other two conditions. A repeated measure ANOVA was carried out, and no significant interaction was found across the three conditions.

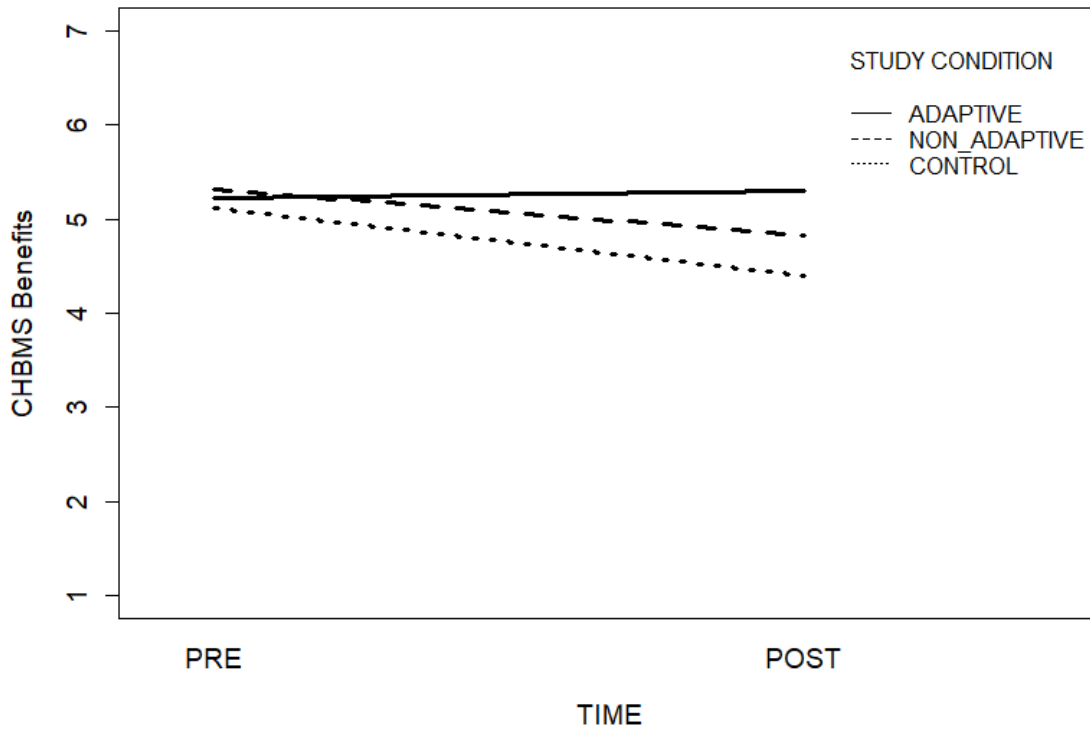


Figure 19: Participants' ratings for perceived benefits of mammogram before and after interaction with Tanya, in three conditions. No significant interaction was found.

Similarly, participants' perceived barriers of mammogram before and after their interaction were shown in Figure 20. A repeated measure ANOVA showed no significant interaction, but a significant main effect of time was found, $p < .001$. For participants in all conditions, their perceived barriers decreased after interaction with Tanya.

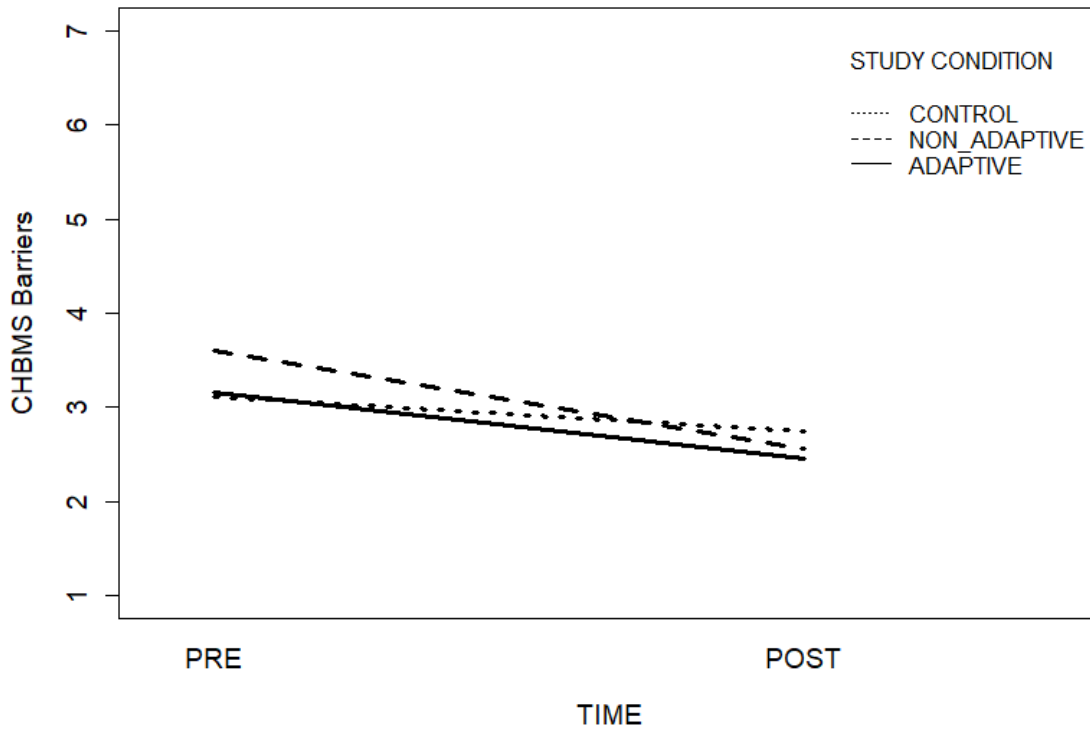


Figure 20: Participants' ratings for perceived barriers of mammogram decreased after interaction with Tanya, in three conditions. No significant interaction was found.

7.6.5 Genetic Testing Intention

Participants' intention to obtain BRCA genetic testing were assessed before and after their interaction with Tanya (Figure 21). A non-parametric paired Wilcoxon signed rank test showed that for all participants, their genetic testing intention significantly increased over time, $p < .05$, although changes were minimal. No significant interaction across three conditions was found.

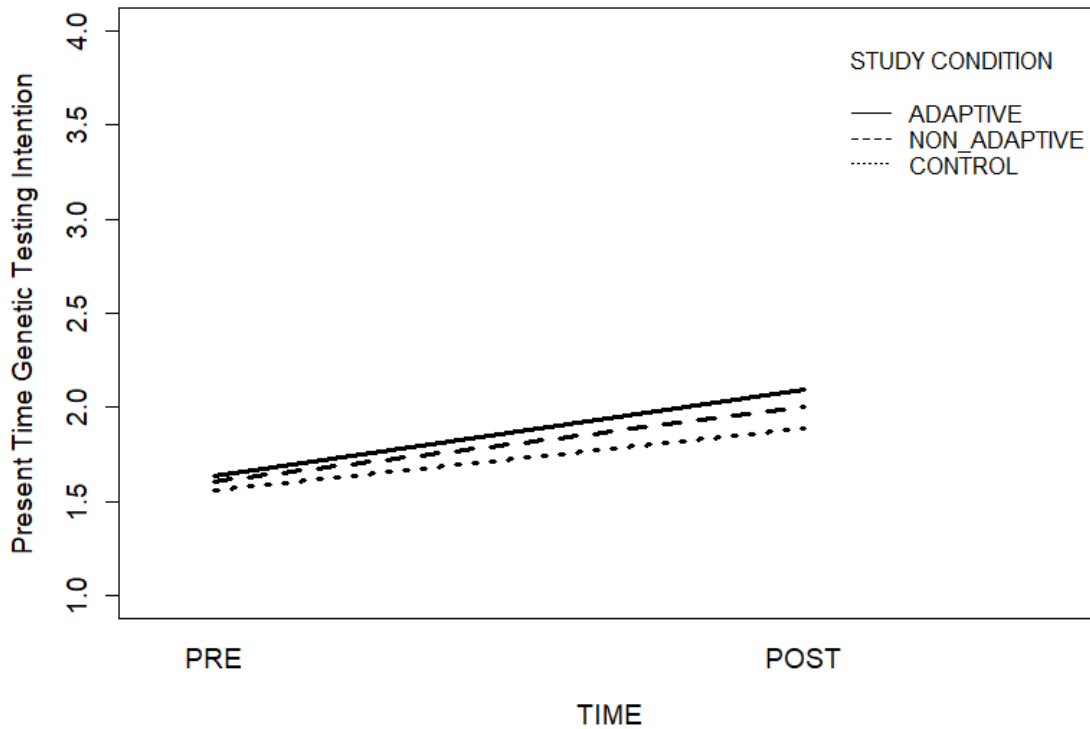


Figure 21: Participants' self-report genetic testing intention increased after interaction with Tanya, in three conditions. No significant interaction was found.

7.6.6 Familiarity with Medical Guidelines

Participants' self-report familiarity with the recommended breast cancer prevention and detection guidelines were measured both before (mean=2.9, sd=1.6) and after (mean=5.6, sd=1.0) their interaction with Tanya (Figure 22). A non-parametric paired Wilcoxon signed rank test showed that participants' self-report familiarity significantly increased after the session, $p < .001$. No significant interaction across the three conditions was found.

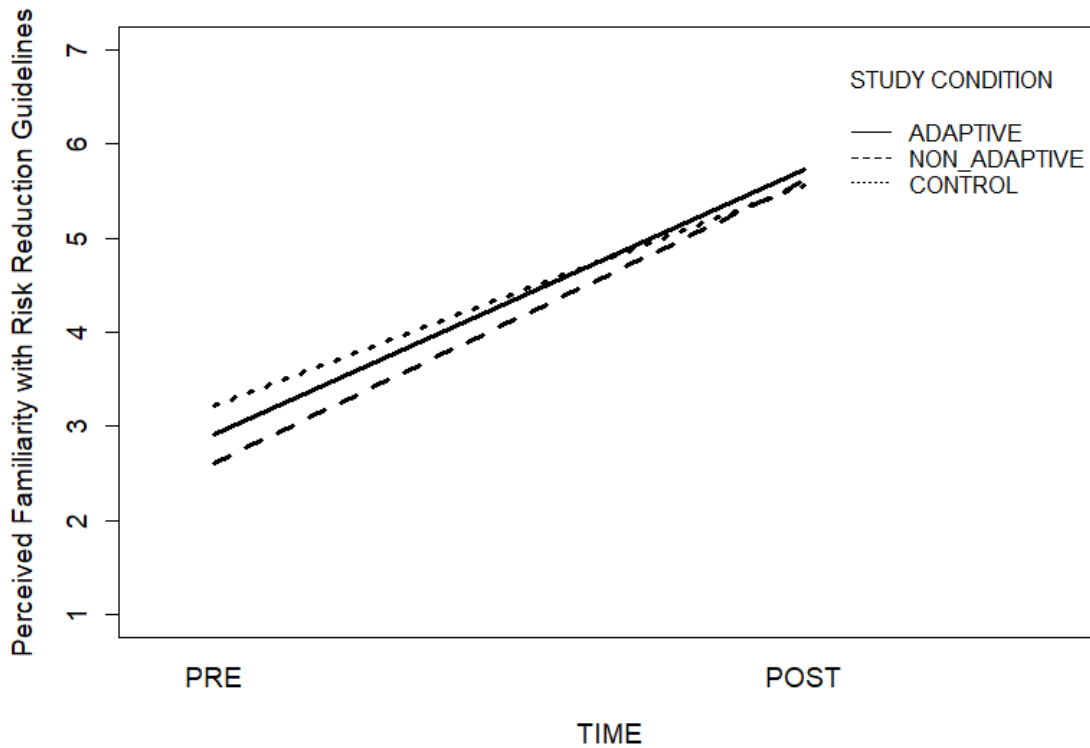


Figure 22: Participants' self-report familiarity with the recommended medical guidelines increased after interaction with Tanya, across the three study conditions. No significant interaction was found.

7.6.7 Overall Counseling Experience

Participants' satisfaction with the counseling experience, and their motivation and intention to adhere to the recommended breast cancer prevention and detection guidelines were evaluated using self-report single item scales (Table 15). Participants reported higher satisfaction with the counseling experience in the adaptive condition, although no significant difference between conditions was found (Figure 23). One-sample Wilcoxon signed rank tests demonstrated all ratings in the adaptive condition were significantly different from neutral ($=4$), $p < .01$. Across all conditions, participants found Tanya very effective in motivating them to follow the

recommended medical guidelines (Figure 25), although no significant differences across conditions were found. Participants also reported high motivation (Figure 24), and high intent (Figure 26) to follow the recommended breast cancer prevention and detection guidelines.

Table 15: Participants' ratings for self-report scales across three conditions.

Mean (SD)	Adaptive	Non-Adaptive	Control	p-value
Satisfaction with Counseling Experience (Table 9, Item 2)	6.1 (0.7)	5.6 (1.3)	4.9 (1.5)	n.s.
Motivated to Follow Guidelines (Table 9, Item 21)	6.1 (0.8)	6.2 (0.9)	6 (0.9)	n.s.
Effectiveness of Tanya (Table 9, Item 22)	6 (0.8)	5.7 (0.8)	5.6 (0.9)	n.s.
Intention to Follow Guidelines (Table 9, Item 23)	6.2 (0.8)	6 (0.8)	5.8 (0.7)	n.s.

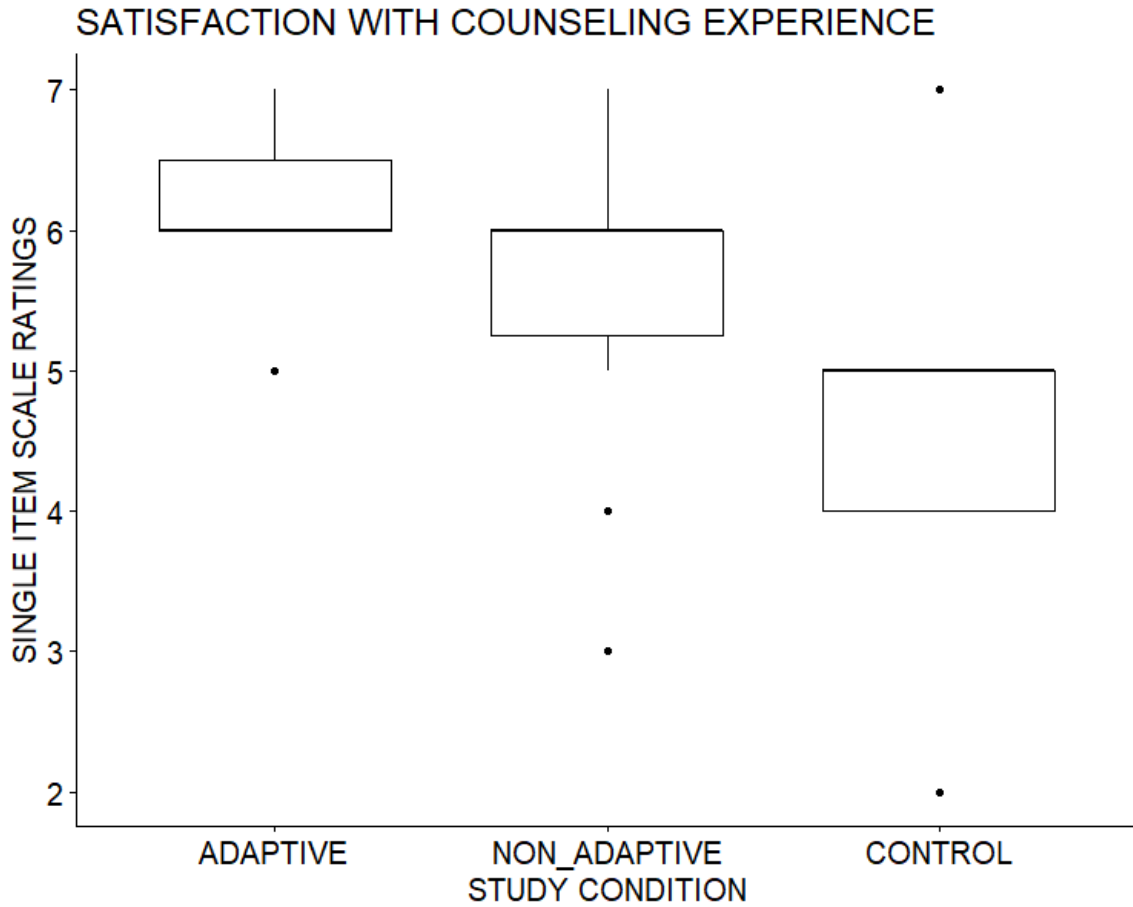


Figure 23: Participants' ratings for satisfaction with the overall counseling experience (Table 9, Item 2) across the three study conditions.

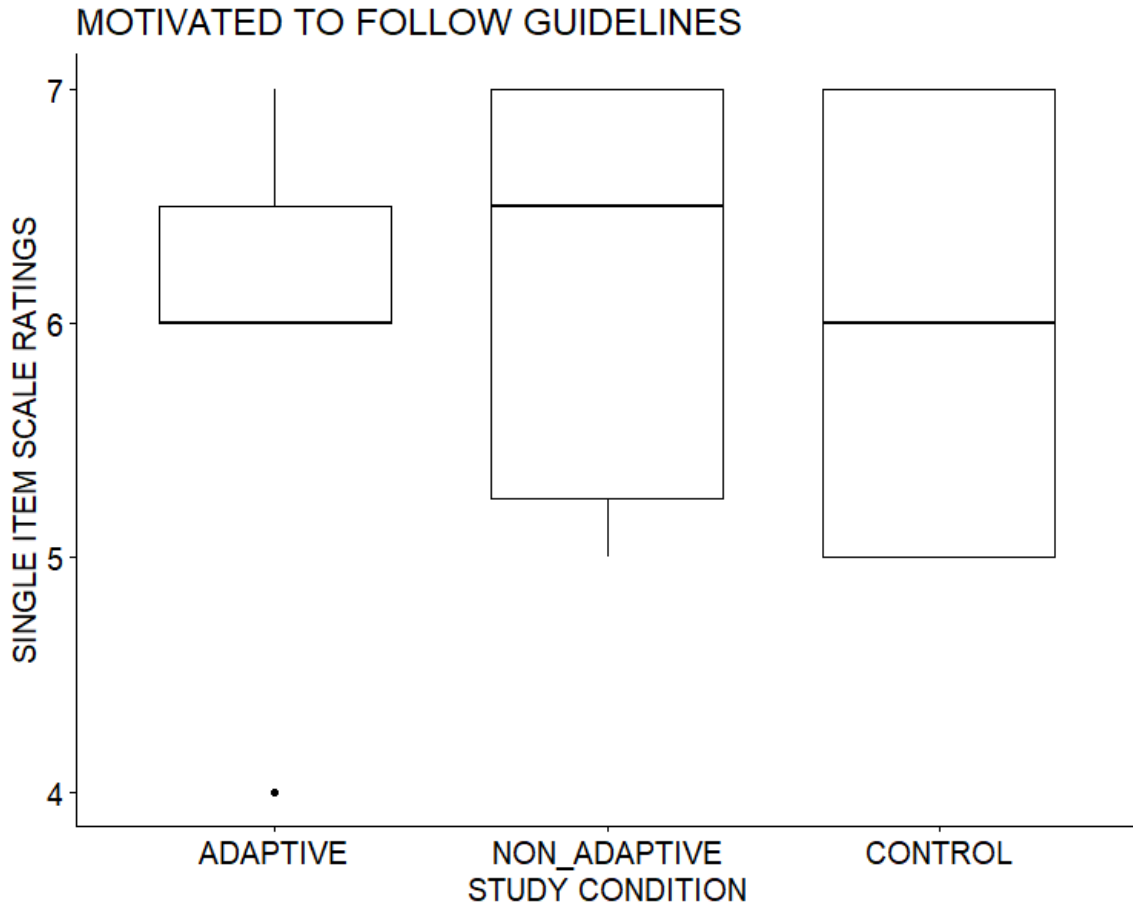


Figure 24: Participants' ratings for how motivated they were to follow the recommended medical guidelines after interaction with Tanya (Table 9, Item 21) across the three study conditions.

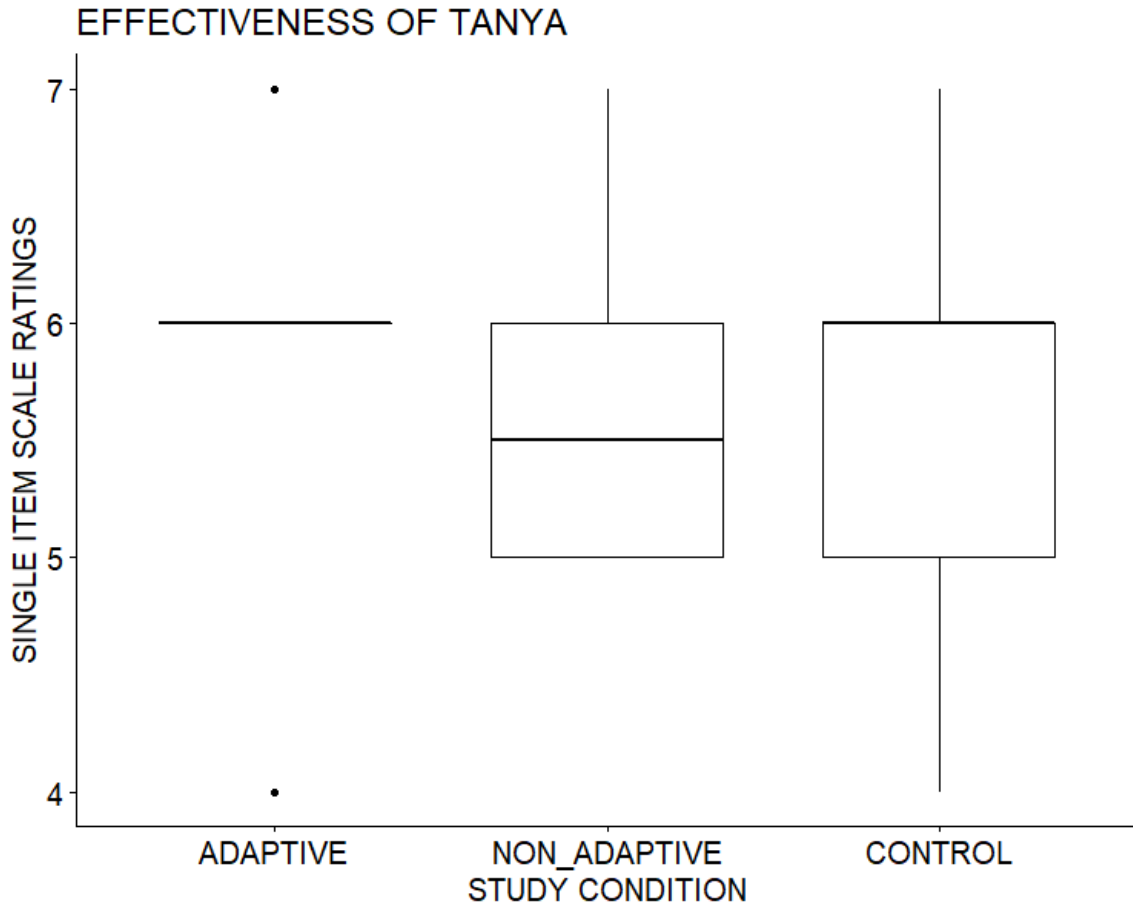


Figure 25: Participants' ratings for effectiveness of Tanya in motivating them to follow the recommended medical guidelines (Table 9, Item 22) across the three study conditions.

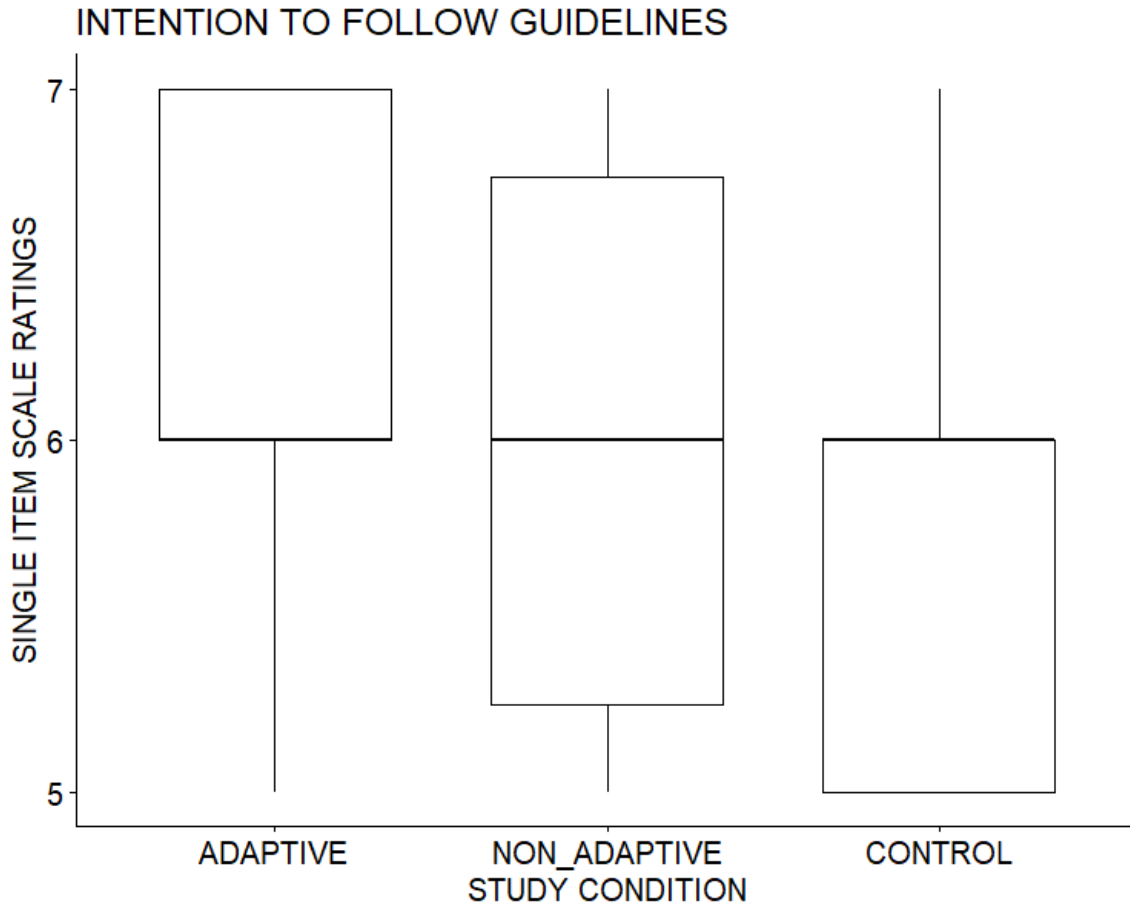


Figure 26: Participants' ratings for how likely they would make a commitment to follow the recommended medical guidelines (Table 9, Item 23) across the three study conditions.

7.6.8 Session Length

Actual session lengths in minutes were computed using session data extracted from system logs. A one-way ANOVA was conducted, and found significant differences in session length across all conditions, $p < .001$ (Figure 27). Post hoc pairwise comparisons with Bonferroni correction were carried out to examine group differences (Table 16). Participants in the non-adaptive condition had significantly shorter sessions (approximately 28 minutes) compared with the adaptive condition (adjusted $p < .01$) and the control condition (adjusted $p = .01$), while

session lengths between the adaptive condition (33 minutes) and the control (37 minutes) were not significantly different.

Table 16: Actual session length in minutes, pairwise comparisons using t-test with Bonferroni correction.

Condition 1	Mean (SD)	Condition 2	Mean (SD)	p-value	Adjusted p-value
Adaptive	32.6 (2.8)	Non-Adaptive	28.4 (2.4)	<.01*	<.01*
Adaptive	32.6 (2.8)	Control	37.1 (6.4)	n.s.	n.s.
Non-Adaptive	28.4 (2.4)	Control	37.1 (6.4)	<.01*	=.01*

After their session with Tanya, participants were asked about their perceived session length, using a single-item scale: “*How much time do you feel your interaction with Tanya took?*” (Table 9, Item 19). A Kruskal-Wallis rank sum test revealed that participants’ ratings significantly differed across three conditions, $p < .01$ (Figure 28). Post hoc pairwise comparisons with Bonferroni correction showed that participants in the control condition rated the session significantly longer than the adaptive (adjusted $p < .01$) and the non-adaptive condition (adjusted $p < .05$), while ratings for the adaptive and non-adaptive conditions were not significantly different (Table 17). These findings were consistent with the actual session lengths, as participants in the control condition had the longest sessions. Yet even though session lengths for the adaptive condition were significantly longer than the non-adaptive condition, participants in the adaptive condition did not indicate it felt longer and rated it the lowest for perceived session length (Table 17).

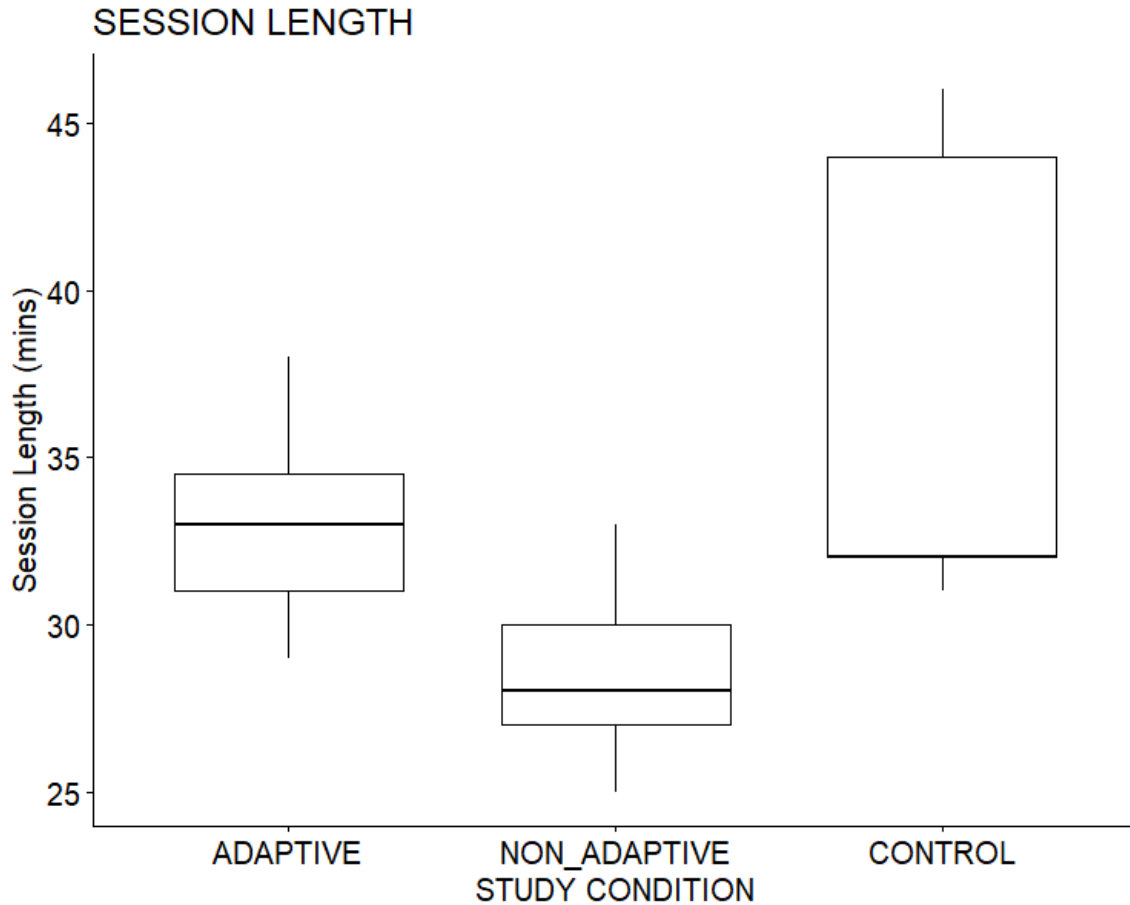


Figure 27: Actual session length in minutes differed across three conditions, $p < .001^*$.

Table 17: Participants' ratings for perceived session length (Table 9, Item 19), pairwise comparisons using Wilcoxon rank sum test with Bonferroni correction.

Condition 1	Mean (SD)	Condition 2	Mean (SD)	p-value	Adjusted p-value
Adaptive	4.9 (0.7)	Non-Adaptive	5.2 (0.8)	n.s.	n.s.
Adaptive	4.9 (0.7)	Control	6.2 (0.7)	<.01*	<.01*
Non-Adaptive	5.2 (0.8)	Control	6.2 (0.7)	<.01*	<.05*

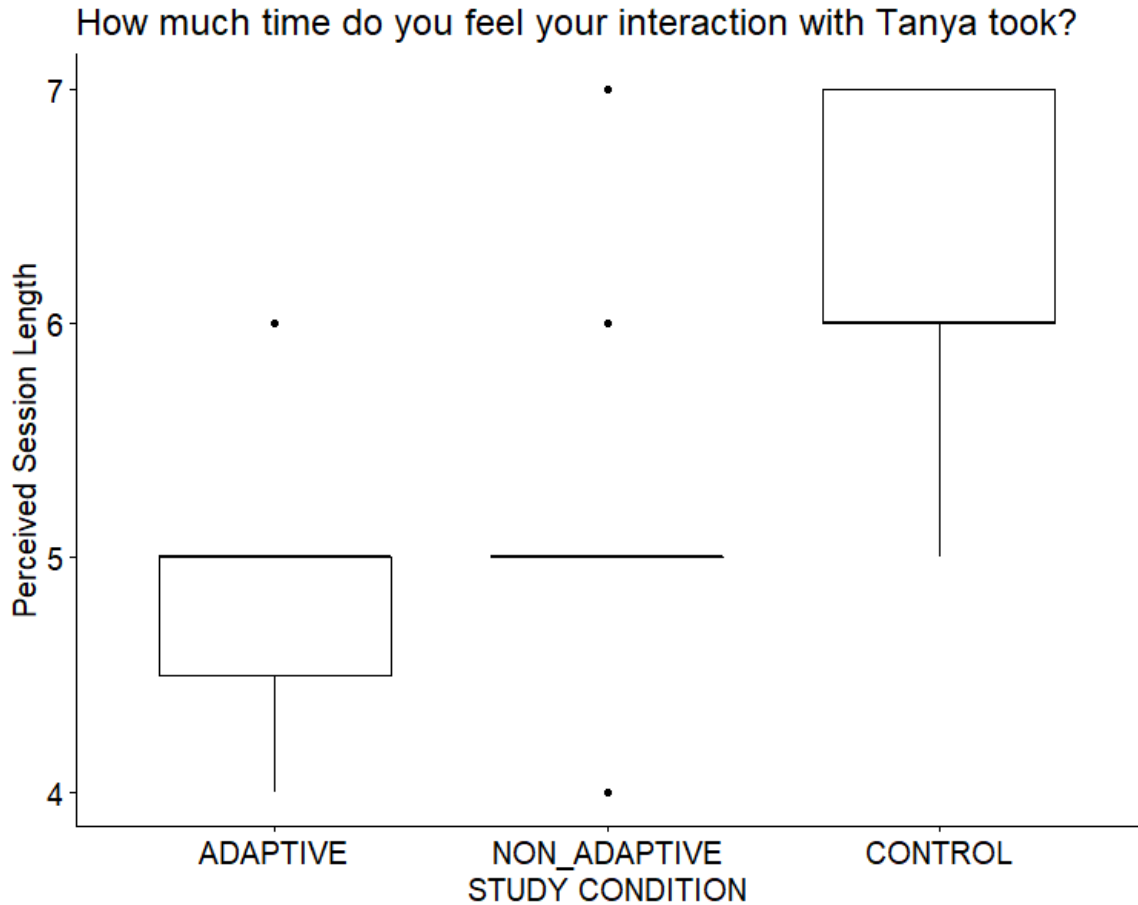


Figure 28: Participants' ratings for perceived session length (Table 9, Item 19) differed across three conditions, $p < .01^*$.

7.6.9 User Choices after Disclosure

During the semi-structured interview, the randomization process was disclosed to the participants, along with details regarding the other two study conditions they were not assigned to. Participants were then asked which version of Tanya they would prefer, if they were allowed to choose. Participants' responses were shown in Table 18. All participants in the adaptive condition chose to keep the adaptive Tanya. In the non-adaptive condition, one participant chose to keep the non-adaptive Tanya, two preferred the control condition, and the

rest preferred the adaptive Tanya. All participants in the control condition preferred the adaptive Tanya.

Table 18: User choices after disclosure about study conditions.

		User Choices after Disclosure		
		Adaptive	Non-Adaptive	Control
Study Conditions	Adaptive (N=11)	11	0	0
	Non-Adaptive (N=10)	7	1	2
	Control (N=9)	9	0	0

7.7 QUALITATIVE ANALYSIS

The semi-structured interviews conducted after participants’ interaction with Tanya were audio-recorded and transcribed, resulted in 263 minutes of audio files, 234 pages of transcription in total. The interview transcriptions were analyzed following a general inductive approach (Thomas, 2006): the transcripts were read repeatedly to obtain a general understanding of the content; initial concepts were coded, and clustered to form higher-level themes. During the interview, participants in all three conditions answered questions regarding their overall experience. Specifically, participants in the adaptive conditions were asked about their perceptions of the virtual counselor’s adaptive pedagogical strategies.

Overall, participants in the adaptive condition were highly satisfied, and described their experience with Tanya: *“felt like an interactive teaching session...almost felt like I was kind of talking to a healthcare provider”* (P4), *“way more personalized...it felt more like a conversation*

than an info dump” (P29), and *“kept me captivated”* (P10). While participants in the other conditions found the interaction *“similar to a video”* (P12, non-adaptive), *“felt like a program running its usual speech”* (P7, non-adaptive), or *“just a separate article...disconnected from Tanya...”* (P5, control), and *“wasn't tailored at all. I was just watching videos and reading something.”* (P30, high risk, control).

During the interviews, participants were comfortable sharing their personal experience with breast cancer, after their interaction with Tanya: *“I think this is something that we need to talk about really without hiding it, and I think it's a good initiative and I would continue to go on such a topic next time if there's an opportunity.”* (P31, non-adaptive).

7.7.1 Adaptive Condition

Participants in the adaptive condition acknowledged the way Tanya took their preferences and prior knowledge into account, and found the experience engaging. They also found it informative that Tanya provided information specifically tailored to their age group. P20 stated: *“As I was doing it I was thinking like, wow this feels kind of sophisticated, that it is taking into account my preferences and it's adjusting along the way when I, you know, demonstrate proficiency in one area, or what have you...I feel like a lot of the information out there that I've come across is not necessarily tailored for people in my age group, So I appreciate having the tailored aspect of it for sure.”*

One participant at high risk for breast cancer pointed out that Tanya provided risk reduction recommendations tailored to her situation which she wasn't aware before, despite actively seeking. *“I make it a point to keep myself updated, but there was a lot of new information*

regarding screening which was new to me because, uh, it was tailored to my age group, which I was not able to find before, so that was something which was very helpful.” (P3).

Participants found the visual aids provided based on their preferences helped with information recall. *“I think that the fact that Tanya tried her best to kind of accommodate what I already know, about certain aspects of, let's say genetics and like basic biology, and to be able to speed through that and also getting all the information that I don't already know, or I'm not very familiar with...I think that's very interesting...and I think that the fact that there are a lot of like graphs, since that was something that I requested...really helped me kind of remembering the information.” (P29).*

Participants also found the personalized experience motivated them to follow the recommended medical guidelines, and to take better care of themselves. *“I think that made a difference because it kind of made it personal versus something that's a little bit more obscuring, like this might not happen to you, but it seems like, well, this is tailored to your age, like what is your risk of getting breast cancer...I think that kind of motivates, well, at least for me, motivates me to pay attention and think well, what can I do to kind of take care of myself.” (P4)*

When asked for their preferences after disclosure of the randomization process, participants in the adaptive conditions expressed they were satisfied with the condition they were assigned to. One participant expressed that she usually *“would have preferred to learn information on my own,”* but found the new experience with Tanya engaging and preferable, without being lengthy: *“the experience that I had was more helpful because I think the amount of her interaction...was actually a good amount. So even though the time was uh, I think more than 30 minutes, but the entire experience...it did not feel like that I was just receiving information. I think that the tailored information that I was getting according to my age, it actually helped me*

stay, uh, you know, alert and attentive. I did not feel like the information was just being thrown at me.” (P3).

P9 also found the adaptive condition most appealing, compared to the other two conditions described to her. *“Definitely this one. I am not a fan of having to sit through an entire lecture, especially if there is information that I'm already confident about, because that's when it starts losing me. So this one (adaptive condition), it kept me on my toes...because I got to tailor it to my previous knowledge.”*

The implemented adaptation to health literacy level was found to be effective. One participant who was assessed to have limited health literacy at baseline, appreciated the visual aids Tanya provided, designed to primarily support individuals with limited health literacy, despite the fact that she indicated preference for narrative explanations during the interaction.

“That was really nice because ...I wasn't sure if I was comfortable with any kind of pictorial representation, so I just chose the verbal one. I think maybe my initial preference of not wanting to see the pictures was not right, maybe because I thought some other representation would have been shown because I don't know how comfortable I was with this to start with. But then later on I just realized that...it was very well explained, like she showed charts properly showing the statistics of how many women are getting cancer out of the general public...and I think I should have preferred this at first.” (P6).

Participants recognized that Tanya was accommodating to their preferred information processing modes, and found the experience to their liking. Heuristic processors chose to hear tailored recommendations without hearing too many statistics: *“I chose expert recommendations. I thought that it was good. I am not a super math and science person, so I would rather just kind of be told what to do, so I liked that that was an option.” (P10).* P27, on the other

hand, identified herself as a systematic processor, and found Tanya provided what she needed: “*I don't know what the other alternative would be, but I did request some scientific information, or like a high amount of scientific information. Uh, because I like to know what I'm being told is backed up by evidence. So I really like that and I noticed throughout speaking with Tanya that she like, cited her sources for some of the information...*”

7.7.2 Non-Adaptive Condition

Participants in the non-adaptive condition expressed they felt the session was too long, and less interactive. “*There was not much conversation, it was more just like uh, she was just giving information to me and like I was just consuming it and that was pretty much it.*” (P15, high risk). They wished “*it could have been a little shorter*”, and “*I don't think I could like sit down and pay attention to it for that long.*” (P7). P14 expressed that she would like to receive information more adaptive to her prior knowledge, “*I knew some of that stuff beforehand...uhm...like genes and stuff...I didn't really need a refresher on that, so it would have been nice to be able to skip that part...*”

Participants also expressed that they hoped to see more visual aids. In particular, one participant with limited health literacy stated, “*I feel like it was presented in a very good way, but it would be great if it's presented with some pictures and uh, some charts or graphs so that, uh, overall, I can understand it better.*” (P8).

7.7.3 Control Condition

Participants in the control condition also found the session took too long: “*It was helpful if I didn't know a lot of the basics, but I think it overall took a little bit too much time to keep my focus.*” (P11). Particularly, participants disliked the timer associated with reading each brochure

or watching each video, and they preferred to be able to advance to the next topic based on their own learning pace: *“I think that the articles and videos, in my opinion, took too long. Uhm, like I guess I'm a pretty fast reader, but there's like no way to click out of it once you're done until the time has passed, so there's a lot of time where I was just waiting.”* (P5). Several participants also mentioned that they were distracted while waiting to move on to the next topic, *“like during that time I would just like start doing other things and so my attention is kind of like divided...I feel like I learned something...then switched to something else while I was waiting, and so I kind of forget, like what I've learned...”* (P21).

Several participants indicated they would like to receive more educational content that was adapted to their prior knowledge, *“maybe she can quiz me first to see what I know or don't know, and then based on my responses, teach me more about the fact...like the facts that I don't know.”* (P13).

“... 'cause there's some information like I already know and like it doesn't make sense for me to spend so much time on all these topics...and (it would) make more sense to tailor it to me. And yeah, 'cause like...some information I guess is less relevant to me and like I would prefer like, oh, they know my age or like...what I do, for example, like if it asks me questions like (if I) drink alcohol and stuff like that, and tell me like about my race, I think that...I would prefer that more... 'cause more engaging too.” (P21)

7.8 DISCUSSION

7.8.1 Perception of Adaptation

Participants in the adaptive condition expressed the highest level of perceived adaptation, supported by findings derived from the post-interaction semi-structured interviews. Evidence demonstrating effectiveness of adapting to health literacy level and risk level was revealed during qualitative analysis of interviews in the adaptive condition. During the interviews, participants in the non-adaptive condition and the control condition expressed that they would like to receive information specifically tailored to their situation. After disclosure of the randomization process during the interview, 27 out of 30 participants across all three conditions expressed that they preferred the adaptive counselor, including all in the adaptive condition.

7.8.2 Knowledge Gain

Findings from our summative evaluation study supported H1, that genetic counseling with an adaptive virtual counselor led to greater gain of knowledge about both breast cancer genetics and the recommended medical guidelines, compared to a non-adaptive one and a control one, demonstrating effectiveness of the implemented adaptation mechanisms. Specifically, participants in all three conditions had similar prior knowledge regarding breast cancer genetics, yet after their interaction with the virtual counselor, participants in the adaptive condition had the highest knowledge gain, followed by the non-adaptive condition and the control (Table 13).

7.8.3 Adherence Motivation

No significant effect of adaptation on participants' self-reported motivation and intention to adhere to the recommended medical guidelines was found, so H2 was not supported.

Participants across all three conditions reported high satisfaction with the counseling experience, and high motivation and intent to follow the recommended medical guidelines, so this lack of significant differences could possibly be due to a ceiling effect. Furthermore, participants' self-report familiarity with breast cancer prevention and detection guidelines, as well as their BRCA genetic testing intention increased, in all three conditions. After interaction with Tanya, participants' self-report perceived barriers of mammogram decreased in all three conditions, while perceived benefits slightly increased only in the adaptive condition, although no significant group differences were found. Overall, the adaptive virtual counselor received high ratings of acceptance and satisfaction. In interviews, participants indicated that the personalized experience offered by the adaptive counselor, in particular, motivated them to take better care of themselves.

7.8.4 Session Length

Even though participants in the adaptive condition had significantly longer sessions compared to participants in the non-adaptive condition (Table 16, Figure 27), their self-report perception of session length indicated the opposite (Table 17, Figure 28). As supported by findings from the qualitative analysis of the interviews, while participants in both the non-adaptive and the control condition found the sessions too long, participants in the adaptive condition did not feel so. Instead, they found session with Tanya engaging, interactive, and at an appropriate length.

7.8.5 Semi-Structured Interviews

Our qualitative findings strongly supported the quantitative findings showing participants rated a significantly higher level of perceived adaptation in the adaptive condition. Participants attested the implemented adaptation mechanisms supported their comprehension and recall of genetic risks, and found the tailored recommendations motivated them to follow the recommended medical guidelines, further demonstrating the effectiveness of providing automated adaptive genetic counseling.

7.9 CONCLUSION

Findings from Evaluation Study III demonstrated interaction with the implemented adaptive virtual counselor led to the highest level of perceived adaptation, and the greatest knowledge gain. Therefore, H1 was supported. Even though evidence of effectiveness in adherence motivation was shown in qualitative findings, further investigation is needed to examine differences across study conditions. H2 was not supported. Overall, this work contributes to the field of genetic risk communication, by demonstrating automated approaches to breast cancer genetic counseling, leveraging the architecture of an intelligent tutoring system to provide dynamically adapted health education. Furthermore, this work also investigated the effect of health literacy and information processing modes on risk comprehension and adherence motivation. Qualitative findings demonstrated that adapting to these factors led to better risk comprehension and recall, higher satisfaction, and higher motivation to adhere to breast cancer screening and risk reduction guidelines.

CHAPTER EIGHT:

CONCLUSION

8.1 CONCLUSIONS

In this dissertation, I report a computational framework for automating cancer genetic counseling using embodied conversational agents. Through an iterative and incremental development process, I report the design and implementation of three prototypes based on the proposed framework. I describe three evaluation studies examining the efficacy of each prototype, and answer the three research questions as follows.

***RQ1:** Will individuals accept a pedagogical ECA as a virtual genetic counselor providing breast cancer genetic counseling?*

***RQ2:** Can an adaptive virtual genetic counselor improve individuals' comprehension of breast cancer genetic risks?*

***RQ3:** Can an adaptive virtual genetic counselor improve individuals' intent to adhere to the recommended medical guidelines?*

Evaluation Study I, a quasi-experimental study with 12 participants, demonstrated the acceptance of Prototype I. Results showed significant increase in participants' knowledge about breast cancer genetics, after their interaction with the virtual counselor. Participants reported high level of satisfaction with, and trust in the virtual counselor, and also reported high intent to follow the virtual counselor's recommendations on risk-reducing behaviors. Evidence from

Evaluation Study I answered **RQ1**, that participants accept a pedagogical ECA in the role of a virtual genetic counselor, providing automated breast cancer genetic counseling.

Based on results and user feedback collected from the first acceptance study, I developed an improved Prototype II, providing adaptive pedagogy based on real-time comprehension assessments made during the counseling session. Evaluation Study II, a quasi-experimental study with 13 participants, demonstrated that the implemented adaptive risk education of Prototype II was able to improve participants' comprehension of genetic risks. Results from this study showed that participants' knowledge about breast cancer genetics significantly increased after their interaction with the virtual counselor, compared with before. Participants also reported high levels of satisfaction with the overall counseling experience. Qualitative analysis of the semi-structured user interviews revealed that participants appreciated the implemented dynamic adaptation to their prior knowledge and current comprehension, and found the tailored experience personalized and engaging. They reported that the various pedagogical strategies employed by the virtual counselor improved their understanding and recall of the risk information being discussed, and at the same time raised their awareness about hereditary breast cancer. Results from Evaluation Study II answered **RQ2**, that an adaptive pedagogical agent acting as a virtual counselor, is able to improve individuals' comprehension of cancer genetic risks.

Based on lessons learned from the first two studies, I developed the final system Prototype III, a full implementation of the presented computational framework (Figure 29), expanding the previous prototypes to include adaptive adherence motivation, as well as additional educational modules on risk-reducing behaviors. In order to fully evaluate the efficacy of Prototype III, I conducted a randomized between-subject study with 30 participants,

Evaluation Study III, to compare the fully adaptive agent with a non-adaptive agent, and a control agent offering standard of care. Results from Evaluation Study III showed a significant interaction effect, and post hoc pairwise comparisons revealed that participants in the adaptive condition had significantly greater knowledge gain than participants in the non-adaptive and the control condition, respectively. Interacting with the adaptive virtual counselor also led to the highest knowledge about the recommended medical guidelines.

Participants in the adaptive condition also reported highest level of perceived adaptation, overall high levels of satisfaction with the counseling experience, and high levels of motivation to adhere to the recommended medical guidelines. In particular, participants in the adaptive condition reported shorter perceived session length, even though actual session lengths in the adaptive condition were significantly longer than in the non-adaptive condition. Overall, results from Evaluation Study III further demonstrated that an adaptive virtual counselor was able to improve individuals' comprehension of genetic risks, answering **RQ2**. However, more evidence is needed to answer **RQ3**. Some initial evidence showed that the adaptive virtual counselor was able to successfully motivate participants to follow the recommended medical guidelines, although a ceiling effect was found when comparing with the other two conditions.

Figure 29 illustrated the final design of the proposed computational framework for genetic risk communication. Overall, this work carefully examined how multidimensional adaptation to an individual's prior knowledge, current comprehension, health literacy, health numeracy, personal preferences, information processing mode, risk level, and other traits, led to highly effective genetic counseling. Significant gains in knowledge were found, after receipt of automated genetic counseling, demonstrating the efficacy of the implemented

multidimensional adaptation mechanisms. The fully adaptive virtual counselor was found to be more effective in improving participants' knowledge about breast cancer genetics and knowledge about the recommended medical guidelines, when compared with a non-adaptive and a control agent, and was well accepted by all participants, receiving high levels of satisfaction and trust. The adaptive agent was also successful in raising participants' awareness about hereditary breast cancer, and in motivating them to adhere to the recommended medical guidelines.

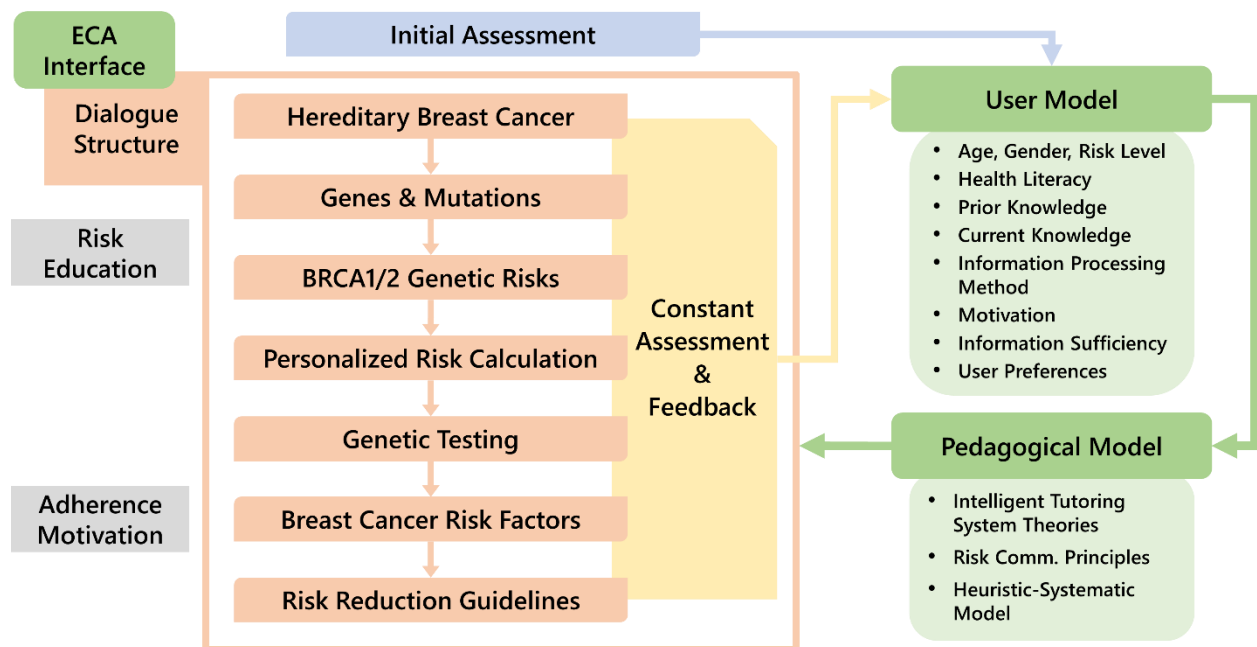


Figure 29: The presented computational framework for genetic risk communication, applied to breast cancer genetic counseling.

Furthermore, the presented framework contains a series of educational modules (Figure 29, Dialogue Structure) designed to resemble real breast cancer genetic counseling sessions previously videotaped at a comprehensive cancer treatment and research institution in the United States. Results from all three evaluation studies demonstrated that the designed

counseling dialogues were efficient and effective in conveying the pedagogical content delivered in a typical genetic counseling session.

When compared with prior work such as the BRCA Gist (Widmer et al., 2015; Wolfe et al., 2018; Wolfe et al., 2016; Wolfe et al., 2015), the presented approach provides a simulated 30-minute face-to-face genetic counseling experience, while BRCA Gist only helps users construct essay type answers to five specific questions, resembling a classroom learning experience. While BRCA Gist offers a much simpler pedagogical experience, only focusing on improving user-constructed answers, the presented virtual counselor not only improves users' knowledge regarding breast cancer genetic risks, but also teaches users about breast cancer screening and risk reduction guidelines, and motivates users to follow the recommended medical guidelines. While BRCA Gist as an intelligent tutoring system only offers adaptation based on performance assessments, the presented framework provides adaptation and tailoring based on multiple factors including comprehension assessments, a user's information processing modes, and other user traits, simulating a genuine counseling experience. In addition, the virtual counselor provides specific risk numbers and recommendations based on a user's age, gender, and breast cancer risk level, similar to what a patient would receive from a human genetic counselor. This innovative feature was not seen in prior related works.

To conclude, this dissertation presented automated approaches for cancer genetic counseling implemented using embodied conversational agents, acting in the role of a virtual genetic counselor, extending the existing options for an individual to receive genetic counseling. Overall participants rated high levels of satisfaction with the counseling experience with each of the ECA-based prototype. Findings reported in this dissertation provide strong evidence that ECA-based automated health counseling can serve as an effective alternative

when human counseling is not available. Researcher should explore the application of ECAs in other domains of health counseling and education.

In particular, being able to deliver health counseling at a distance means ECA-based approaches provide unique affordances, especially during the current COVID-19 pandemic. Recent studies already reported a significant decrease in the number of patients undergoing cancer screening during the COVID-19 pandemic (Bakouny et al., 2021). With genetic counseling being essential to cancer prevention and treatment, ensuring that at-risk individuals have access to genetic counseling and maintain adherence to cancer screening can make a life-changing difference. Given the reported national shortage of genetic counselors (Peterson et al., 2018), coupled with logistic restrictions caused by the pandemic, receiving genetic counseling through a pedagogical ECA remotely via the Internet provides a safe, easily accessible alternative. This automated approach can successfully equip at-risk individuals with the basic knowledge needed to understand their genetic risks, motivate their adherence to screening guidelines, and also prepare them for future counseling with a human counselor when available.

Research has shown that the pandemic has transformed healthcare delivery in the United States, and catalyzed rapid adoption of telehealth (Wosik et al., 2020). This means alternative formats of healthcare are becoming more acceptable to patients. While the importance of providing quality cancer genetic counseling can only increase in the future, beyond the impact of the pandemic, the need for alternative options surely remains, at the minimum as support resources in addition to human genetic counseling.

8.2 LIMITATIONS

The evaluation studies reported in this dissertation had several limitations. First, small convenience samples were used in all three studies. Even though Evaluation Study II and III were conducted remotely online, and additional efforts were taken to recruit participants online from outside of our university campus, due to requirements on equipment necessary for videoconferencing such as high-speed internet and computers with microphone and speakers, individuals from under-served populations, or who have limited computer literacy may be unintentionally excluded from our pool of study participants.

Limited numbers of individuals with low health literacy were included in all three evaluation studies. Although feedback from these participants were collected, and findings showed that the adaptive virtual counselor was well received by low health literacy participants, it would be ideal to include more participants with limited health literacy and limited health numeracy, in order to test differential effects on these groups. In addition, limited numbers of individuals at high risk for hereditary breast cancer were included only in Evaluation Study III. Even though several participants in all three studies willingly disclosed their personal experience with breast cancer during the semi-structured user interviews conducted after their interaction with the virtual counselor, participants' risk level were only collected before enrollment in Evaluation Study III, and not enough high risk participants were recruited to test any group differences.

Another limitation is that all three evaluation studies conducted in this dissertation comprised controlled single session interactions, therefore it was not possible to evaluate long-

term knowledge retention. Other longitudinal effects of adaptive counseling on adherence to risk reducing behaviors remain unknown.

8.3 FUTURE WORK

Results from Evaluation Study III revealed a ceiling effect where participants in all conditions reported high levels of satisfaction, and high intent to follow the recommended screening and risk reduction guidelines. Therefore, the effects of adaptation on adherence intention remains unclear compared with the non-adaptive and the control agent. Future research could look at alternative measures that may be more sensitive under these circumstances.

Future research should investigate the longitudinal effects of adaptive genetic counseling on knowledge retention, adherence intention, and long-term adherence behaviors. Maintaining adherence to medical guidelines are usually best evaluated in long term, instead of in controlled single-session studies. Specifically, as suggested by the HSM, systematic processing is potentially associated with more persistent long-term behavior change. Longitudinal studies looking at long term adherence behaviors may be the best way to investigate the efficacy of adaptive adherence motivation on risk reducing behaviors. It would be ideal to conduct follow-up interviews at 3 months, 6 months, and a year after the interaction. Future research may also look at expanding the current prototype into a longitudinal web-based intervention, in which the virtual counselor may have multiple counseling sessions with users over longer period of time, and continue to motivate the users to follow breast cancer screening and risk reduction guidelines after the initial interaction. A longitudinal randomized between-subject study measuring users' long term satisfaction,

knowledge retention, and adherence intention is needed to systematically evaluate the long term efficacy of the presented ECA-based automated approach.

In addition to the HSM, future research may adopt other interpersonal communication theories to maximize the persuasiveness of the presented framework, as tailoring to other constructs beyond information processing modes may improve the virtual counselor's effectiveness in adherence motivation. Furthermore, it would be beneficial to incorporate shared decision-making theories to provide additional support for the patient or family decision-making process, for example, regarding obtaining genetic testing or preventive surgeries.

Due to the limited sample size of high risk participants and low health literacy participants, it was not possible to test for group differences in Evaluation Study III. Future research should plan to use stratified sampling to include more high risk individuals, thus to further investigate the potential effects of risk level on risk comprehension and adherence behaviors. Individuals at high risk may need additional emotional support during genetic counseling, as they may have higher levels of anxiety and discomfort upon learning their elevated risks.

In this dissertation, the presented computational framework for genetic risk communication is only implemented in the field of breast cancer genetic counseling. The framework discusses genetic risks solely related to BRCA pathogenic variants, while up-to-date research recommends multi-gene panel testing to identify inherited germline mutations that may be associated with multiple cancer syndromes. Instead of considering a few most well-known cancer-related genes such as the BRCA genes in isolation, emerging evidence suggests a wide range of pathogenic variants should be considered together in order to generate more

comprehensive and accurate cancer risk profiles (Lee et al., 2021). Therefore, future research should consider incorporating multi-gene, multi-cancer risk modeling into the presented framework, in order to provide more relevant cancer prevention guidelines.

Future research may also investigate use scenarios that involve a three party interaction, with two users. The presented ECA-based approach may benefit typical dyads such as two parents or romantic couples receiving preconception genetic counseling, or a mother-daughter dyad discussing breast cancer. Researchers should analyze typical dyadic interactions to identify the specific user needs in these scenarios, and incorporate those needs into the presented framework.

And last, it is necessary to thoroughly evaluate the presented approach in a randomized controlled clinical trial, potentially with longitudinal measurements of knowledge retention and adherence behaviors.

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Appendix A: Evaluation Study I Questionnaires

Sociodemographics Questionnaire

Participant ID: _____

Date: _____

Please take a moment and answer a few questions about yourself:

Date of birth: _____

Sex: M / F

Ethnic Background (check one):

- American Indian or Alaskan Native _____
- Asian or Pacific Islander _____
- Black, Not of Hispanic Origin _____
- White, Not of Hispanic Origin _____
- Hispanic _____

Marital Status (check one):

- Single _____
- Married _____
- Divorced/Widowed _____

Last grade of school completed (check one):

- Less than high school (0-8) _____
- Some high school _____
- High school graduate or GED _____
- Technical school education _____
- Some college _____
- College graduate _____
- Advanced degree _____

Occupation: _____

How much experience do you have with computers (check one)?

- I've never used one. _____
- I've tried one a few times. _____
- I use one regularly. _____
- I'm an expert. _____

How do you feel about using computers (check one)?

- I don't like them. _____
- They're OK. _____
- They can be useful. _____
- I love playing with them. _____

REALM

Participant ID: _____

Date: _____

List 1

fat _____
flu _____
pill _____
dose _____
eye _____
stress _____
smear _____
nerves _____
germs _____
meals _____
disease _____
cancer _____
caffeine _____
attack _____
kidney _____
hormones _____
herpes _____
seizure _____
bowel _____
asthma _____
rectal _____
incest _____

List 2

fatigue _____
pelvic _____
jaundice _____
infection _____
exercise _____
behavior _____
prescription _____
notify _____
gallbladder _____
calories _____
depression _____
miscarriage _____
pregnancy _____
arthritis _____
nutrition _____
menopause _____
appendix _____
abnormal _____
syphilis _____
hemorrhoids _____
nausea _____
directed _____

List 3

allergic _____
menstrual _____
testicle _____
colitis _____
emergency _____
medication _____
occupation _____
sexually _____
alcoholism _____
irritation _____
constipation _____
gonorrhea _____
inflammatory _____
diabetes _____
hepatitis _____
antibiotics _____
diagnosis _____
potassium _____
anemia _____
obesity _____
osteoporosis _____
impetigo _____

SCORE

List 1 _____
List 2 _____
List 3 _____
Raw _____
Score _____

Newest Vital Sign

Participant ID: _____

Date: _____

Please answer the following questions based on the image on the next page. Imagine this information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?
2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have (measured by cups)?
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
6. Why or why not?

Nutrition Facts

Serving Size ½ cup
Servings per container 4

Amount per serving

Calories 250 Fat Cal 120

%DV

Total Fat 13g 20%

Sat Fat 9g 40%

Cholesterol 28mg 12%

Sodium 55mg 2%

Total Carbohydrate 30g 12%

Dietary Fiber 2g

Sugars 23g

Protein 4g 8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Numeracy Scale

Participant ID: _____

Date: _____

Please answer the following questions:

1. Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even (2, 4, or 6)?
2. In the BIG BUCKS LOTTERY, the chances of winning a \$10.00 prize is 1%. What is your best guess about how many people would win a \$10.00 prize if 1,000 people each buy a single ticket to BIG BUCKS?
3. In the ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percentage of tickets to ACME PUBLISHING SWEEPSTAKES win a car?
4. Which of the following numbers represent the biggest risk of getting a disease?

_____ 1 in 100, _____ 1 in 1000, _____ 1 in 10
5. Which of the following numbers represents the biggest risk of getting a disease?

_____ 1%, _____ 10%, _____ 5%
6. If person A's risk of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk?
7. If person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?

8. If the chance of getting a disease is 10%, how many people would be expected to get the disease?

A: Out of 100?

B: Out of 1000?

9. If the chance of getting a disease is 20 out of 100, this would be the same as having a _____% chance of getting the disease.

10. The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected?

Breast Cancer Genetics Knowledge Questionnaire (Pre)

Participant ID# _____ Date: _____

Please circle either **True** or **False** for each of the following statements.

- | | | |
|---|------|-------|
| 1. One in 10 women have an altered breast cancer gene. | True | False |
| 2. One half of all breast cancer cases occur in women who have an altered breast cancer gene. | True | False |
| 3. A father can pass down an altered breast cancer gene to his children. | True | False |
| 4. The sister of a woman with an altered breast cancer gene has a 50% risk of having inherited the same altered gene. | True | False |
| 5. A woman who does not have an altered breast cancer gene can still get breast or ovarian cancer. | True | False |
| 6. Early onset breast cancer is less likely due to an altered breast cancer gene than late onset breast cancer. | True | False |
| 7. A woman who has an altered breast cancer gene has a higher ovarian cancer risk. | True | False |
| 8. All women who have an altered breast cancer gene get cancer. | True | False |
| 9. A woman who has had her breasts removed can still get breast cancer. | True | False |
| 10. Women who have BRCA1/2 testing will always get positive or negative results. | True | False |
| 11. Breast cancer patients with an altered BRCA1 or BRCA2 gene are more likely to develop a second breast cancer. | True | False |
| 12. The best candidate for BRCA1/2 genetic testing is someone who has had breast or ovarian cancer. | True | False |

Breast Cancer Genetics Knowledge Questionnaire (Post)

Participant ID# _____ Date: _____

Please circle either **True** or **False** for each of the following statements.

- | | | | |
|-----|--|------|-------|
| 1. | One in 10 women have an altered breast cancer gene. | True | False |
| 2. | One half of all breast cancer cases occur in women who have an altered breast cancer gene. | True | False |
| 3. | A father can pass down an altered breast cancer gene to his children. | True | False |
| 4. | The sister of a woman with an altered breast cancer gene has a 50% risk of having inherited the same altered gene. | True | False |
| 5. | A woman who does not have an altered breast cancer gene can still get breast or ovarian cancer. | True | False |
| 6. | Early onset breast cancer is less likely due to an altered breast cancer gene than late onset breast cancer. | True | False |
| 7. | A woman who has an altered breast cancer gene has a higher ovarian cancer risk. | True | False |
| 8. | All women who have an altered breast cancer gene get cancer. | True | False |
| 9. | A woman who has had her breasts removed can still get breast cancer. | True | False |
| 10. | Women who have BRCA1/2 testing will always get positive or negative results. | True | False |
| 11. | Breast cancer patients with an altered BRCA1 or BRCA2 gene are more likely to develop a second breast cancer. | True | False |
| 12. | The best candidate for BRCA1/2 genetic testing is someone who has had breast or ovarian cancer. | True | False |

Instructor Evaluation Questionnaire

Participant ID# _____ Date: _____

1. How satisfied were you with Tanya?

not at all			neutral			very satisfied
1	2	3	4	5	6	7

2. How satisfied were you with the entire experience?

not at all			neutral			very satisfied
1	2	3	4	5	6	7

3. How much would you like to continue working with Tanya?

not at all			neutral			very much
1	2	3	4	5	6	7

4. How much do you like Tanya?

not at all			neutral			very much
1	2	3	4	5	6	7

5. How much do you trust Tanya?

not at all			neutral			very much
1	2	3	4	5	6	7

6. How knowledgeable was Tanya?

not at all			neutral			very knowledgeable
1	2	3	4	5	6	7

Please state your opinion of the character on each of the scales below.

1. I think Tanya is dependable.

disagree completely			neutral			agree completely
1	2	3	4	5	6	7

2. I feel Tanya is dishonest.

disagree completely			neutral			agree completely
1	2	3	4	5	6	7

3. I think Tanya is unreliable.

disagree completely			neutral			agree completely
1	2	3	4	5	6	7

4. I feel Tanya is sincere.

disagree completely			neutral			agree completely
1	2	3	4	5	6	7

5. I think Tanya is trustworthy.

disagree completely			neutral			agree completely
1	2	3	4	5	6	7

Breast Cancer Counseling Experience Questionnaire

Participant ID# _____ Date: _____

The following questions are about the entire counseling experience you just had with the agent.

1. How much information did you get? (With 1 being too little information, 4 being just right, and 7 being too much information.)

too little			just right			too much
1	2	3	4	5	6	7

2. How likely would you make a commitment to follow the recommended guidelines for breast cancer screening?

not at all			neutral			very likely
1	2	3	4	5	6	7

3. How likely would you be willing to talk more about your breast cancer risks with your primary care doctor or a genetic counselor?

not at all			neutral			very likely
1	2	3	4	5	6	7

4. In your opinion, how likely is it that you have an altered breast cancer gene?

not at all			neutral			very likely
1	2	3	4	5	6	7

5. At the present time, which of the following statements describes you best?

- 1 Not considering genetic testing. / Haven't thought about it.
- 2 Considering genetic testing.
- 3 Probably will have genetic testing.
- 4 Definitely will have genetic testing.

Appendix B: Evaluation Study II Questionnaires

Demographics

Q1 Please enter your study ID.

Q2 What is your age?

Q3 What sex were you assigned at birth?

- Male
- Female
- Intersex
- Prefer not to disclose

Q4 What is your ethnic background?

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black, Not of Hispanic Origin
- White, Not of Hispanic Origin
- Hispanic

Q5 What is your marital status?

- Single
- Married
- Divorced/Widowed

Q6 What was the last grade of school that you completed?

- Less than high school (0-8)
- Some high school
- High school graduate or GED
- Technical school education
- Some college
- College graduate
- Advanced degree

Q7 What is your occupation? If you are retired or otherwise not working please let us know.

Q8 How much experience do you have with computers?

- I've never used one
- I've tried one a few times
- I use one regularly
- I'm an expert

Q9 How do you feel about using computers?

- I don't like them
- They are OK
- They can be useful
- I love playing with them

REALM

Q1 Please enter your study ID.

Q2 Please read this list of words out loud in order, starting with column 1.
If you're having trouble with a particular word, you can just skip it.

List 1

fat _____
flu _____
pill _____
dose _____
eye _____
stress _____
smear _____
nerves _____
germs _____
meals _____
disease _____
cancer _____
caffeine _____
attack _____
kidney _____
hormones _____
herpes _____
seizure _____
bowel _____
asthma _____
rectal _____
incest _____

List 2

fatigue _____
pelvic _____
jaundice _____
infection _____
exercise _____
behavior _____
prescription _____
notify _____
gallbladder _____
calories _____
depression _____
miscarriage _____
pregnancy _____
arthritis _____
nutrition _____
menopause _____
appendix _____
abnormal _____
syphilis _____
hemorrhoids _____
nausea _____
directed _____

List 3

allergic _____
menstrual _____
testicle _____
colitis _____
emergency _____
medication _____
occupation _____
sexually _____
alcoholism _____
irritation _____
constipation _____
gonorrhea _____
inflammatory _____
diabetes _____
hepatitis _____
antibiotics _____
diagnosis _____
potassium _____
anemia _____
obesity _____
osteoporosis _____
impetigo _____

Newest Vital Sign

Q1 Please enter your study ID.

Q2 Please answer the following questions based on the image below.
If you are not sure of a question, you can leave it blank.

Imagine this information is on the back of a container of a pint of ice cream.



The image shows a Nutrition Facts label for ice cream. The label is enclosed in a blue border. It lists the serving size as 1/2 cup and 4 servings per container. The amount per serving is 250 calories and 120 fat calories. The label also lists Total Fat (13g, 20% DV), Saturated Fat (9g, 40% DV), Cholesterol (28mg, 12% DV), Sodium (55mg, 2% DV), Total Carbohydrate (30g, 12% DV), Dietary Fiber (2g), and Sugars (23g). Protein is listed as 4g (8% DV). A disclaimer states that the percentage daily values are based on a 2,000 calorie diet. The ingredients list includes Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, and Vanilla Extract.

Nutrition Facts	
Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
%DV	
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Q3 If you eat the entire container, how many calories will you eat?

Q4 If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have (measured by cups)?

Q5 Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Q6 If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Q7 Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

Q8 Is it safe for you to eat this ice cream?

Q9 Why or why not?

Numeracy

Q1 Please enter your study ID.

Q2 Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even (showing 2, 4, or 6)?

Q3 In the BIG BUCKS LOTTERY, the chances of winning a \$10.00 prize is 1%. What is your best guess about how many people would win a \$10.00 prize if 1,000 people each buy a single ticket to BIG BUCKS?

Q4 In the ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percentage of tickets to ACME PUBLISHING SWEEPSTAKES win a car?

Q5 Which of the following numbers represent the biggest risk of getting a disease?

- 1 in 100
- 1 in 1000
- 1 in 10

Q6 Which of the following numbers represents the biggest risk of getting a disease?

- 1%
- 10%
- 5%

Q7 If person A's risk of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk?

Q8 If person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?

Q9 If the chance of getting a disease is 10%, how many people would be expected to get the disease?

A: Out of 100? _____

B: Out of 1000? _____

Q10 If the chance of getting a disease is 20 out of 100, this would be the same as having a _____% chance of getting the disease.

Q11 The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected?

Breast Cancer Genetics Knowledge (Pre)

Q1 Please enter your study ID.

Q2 One in 10 women have an altered breast cancer gene.

- True
- False
- Not sure

Q3 One half of all breast cancer cases occur in women who have an altered breast cancer gene.

- True
- False
- Not sure

Q4 A father can pass down an altered breast cancer gene to his children.

- True
- False
- Not sure

Q5 The sister of a woman with an altered breast cancer gene has a 25% risk of having inherited the same altered gene.

- True
- False
- Not sure

Q6 A woman who does not have an altered breast cancer gene will not get breast or ovarian cancer.

- True
- False
- Not sure

Q7 Early onset breast cancer is less likely due to an altered breast cancer gene than late onset breast cancer.

- True
- False
- Not sure

Q8 A woman who has an altered breast cancer gene has a higher ovarian cancer risk.

- True
- False
- Not sure

Q9 All women who have an altered breast cancer gene get cancer.

- True
- False
- Not sure

Q10 A woman who has had her breasts removed can still get breast cancer.

- True
- False
- Not sure

Q11 Women who have BRCA1/2 testing will always get positive or negative results.

- True
- False
- Not sure

Q12 Breast cancer patients with an altered BRCA1 or BRCA2 gene are more likely to develop a second breast cancer.

- True
- False
- Not sure

Q13 In your opinion, how likely is it that you have an altered breast cancer gene?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q14 At the present time, which of the following statements describes you best?

- Not considering genetic testing. / Haven't thought about it.
- Considering genetic testing.
- Probably will have genetic testing.
- Definitely will have genetic testing.

Breast Cancer Genetics Knowledge (Post)

Q1 Please enter your study ID.

Q2 One in 10 women have an altered breast cancer gene.

- True
- False
- Not sure

Q3 One half of all breast cancer cases occur in women who have an altered breast cancer gene.

- True
- False
- Not sure

Q4 A father can pass down an altered breast cancer gene to his children.

- True
- False
- Not sure

Q5 The sister of a woman with an altered breast cancer gene has a 25% risk of having inherited the same altered gene.

- True
- False
- Not sure

Q6 A woman who does not have an altered breast cancer gene will not get breast or ovarian cancer.

- True
- False
- Not sure

Q7 Early onset breast cancer is less likely due to an altered breast cancer gene than late onset breast cancer.

- True
- False
- Not sure

Q8 A woman who has an altered breast cancer gene has a higher ovarian cancer risk.

- True
- False
- Not sure

Q9 All women who have an altered breast cancer gene get cancer.

- True
- False
- Not sure

Q10 A woman who has had her breasts removed can still get breast cancer.

- True
- False
- Not sure

Q11 Women who have BRCA1/2 testing will always get positive or negative results.

- True
- False
- Not sure

Q12 Breast cancer patients with an altered BRCA1 or BRCA2 gene are more likely to develop a second breast cancer.

- True
- False
- Not sure

Instructor Evaluation

Q1 Please enter your study ID.

Q2 How satisfied were you with Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very satisfied 7

Q3 How satisfied were you with the entire experience?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very satisfied 7

Q4 How much would you like to continue working with Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very much 7

Q5 How much do you like Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Much 7

Q6 How much do you trust Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Much 7

Q7 How knowledgeable was Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Knowledgeable 7

Q8 Please state your opinion of the character on each of the scales below.

Q9 I think Tanya is dependable.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q10 I feel Tanya is dishonest.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q11 I think Tanya is unreliable.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q12 I feel Tanya is sincere.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q13 I think Tanya is trustworthy.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Breast Cancer Counseling Experience

Q1 Please enter your study ID.

Q2 The following questions are about the entire counseling experience you just had with the character.

Q3 How much information did you get? (With 1 being too little information, 4 being just right, and 7 being too much information.)

- Too little 1
- 2
- 3
- Just right 4
- 5
- 6
- Too much 7

Q4 How likely would you make a commitment to follow the recommended guidelines for breast cancer screening?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q5 How likely would you be willing to talk more about your breast cancer risks with your primary care doctor or a genetic counselor?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q6 In your opinion, how likely is it that you have an altered breast cancer gene?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q7 At the present time, which of the following statements describes you best?

- Not considering genetic testing. / Haven't thought about it.
- Considering genetic testing.
- Probably will have genetic testing.
- Definitely will have genetic testing.

Appendix C: Evaluation Study III Questionnaires

Pre-Screening Questionnaire

Q1 Do you have a first-degree relative who has been diagnosed with breast cancer?

Q2 Do you have a family member who tested positive for a BRCA1 or BRCA2 mutation?

Q3 Have you ever been diagnosed with breast cancer?

Q4 Have you ever been tested for BRCA mutations?

Demographics

Q1 Please enter your study ID.

Q2 What is your age?

Q3 What sex were you assigned at birth?

- Male
- Female
- Prefer not to disclose

Q4 What is your ethnic background?

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black, Not of Hispanic Origin
- White, Not of Hispanic Origin
- Hispanic

Q5 What is your marital status?

- Single
- Married
- Divorced/Widowed

Q6 What was the last grade of school that you completed?

- Less than high school (0-8)
- Some high school
- High school graduate or GED
- Technical school education
- Some college
- College graduate
- Advanced degree

Q7 What is your occupation? If you are retired or otherwise not working please let us know.

Q8 How much experience do you have with computers?

- I've never used one
- I've tried one a few times
- I use one regularly
- I'm an expert

Q9 How do you feel about using computers?

- I don't like them
- They are OK
- They can be useful
- I love playing with them

Newest Vital Sign

Q1 Please enter your study ID.

Q2 Please answer the following questions based on the image below.
If you are not sure of a question, you can leave it blank.

Imagine this information is on the back of a container of a pint of ice cream.



The image shows a Nutrition Facts label for ice cream. The label is enclosed in a blue border. It lists the serving size as 1/2 cup and 4 servings per container. The amount per serving is 250 calories and 120 fat calories. The label also lists Total Fat (13g, 20% DV), Saturated Fat (9g, 40% DV), Cholesterol (28mg, 12% DV), Sodium (55mg, 2% DV), Total Carbohydrate (30g, 12% DV), Dietary Fiber (2g), and Sugars (23g). Protein is listed as 4g (8% DV). A disclaimer states that the percentage daily values are based on a 2,000 calorie diet. The ingredients list includes Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, and Vanilla Extract.

Nutrition Facts	
Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
%DV	
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Q3 If you eat the entire container, how many calories will you eat?

Q4 If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have (measured by cups)?

Q5 Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Q6 If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Q7 Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

Q8 Is it safe for you to eat this ice cream?

Q9 Why or why not?

Numeracy

Q1 Please enter your study ID.

Q2 Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even (showing 2, 4, or 6)?

Q3 In the BIG BUCKS LOTTERY, the chances of winning a \$10.00 prize is 1%. What is your best guess about how many people would win a \$10.00 prize if 1,000 people each buy a single ticket to BIG BUCKS?

Q4 In the ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percentage of tickets to ACME PUBLISHING SWEEPSTAKES win a car?

Q5 Which of the following numbers represent the biggest risk of getting a disease?

- 1 in 100
- 1 in 1000
- 1 in 10

Q6 Which of the following numbers represents the biggest risk of getting a disease?

- 1%
- 10%
- 5%

Q7 If person A's risk of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk?

Q8 If person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?

Q9 If the chance of getting a disease is 10%, how many people would be expected to get the disease?

A: Out of 100? _____

B: Out of 1000? _____

Q10 If the chance of getting a disease is 20 out of 100, this would be the same as having a _____% chance of getting the disease.

Q11 The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected?

Breast Cancer Genetics Knowledge (Pre)
Champion's Health Belief Model Scale (Pre)

Q1 Please enter your study ID.

Q2 One in 10 women have a mutated breast cancer gene.

- True
- False
- Not sure

Q3 One half of all breast cancer cases occur in women who have a mutated breast cancer gene.

- True
- False
- Not sure

Q4 A father can pass down a mutated breast cancer gene to his children.

- True
- False
- Not sure

Q5 The sister of a woman with a mutated breast cancer gene has a 25% risk of having inherited the same mutated gene.

- True
- False
- Not sure

Q6 A woman who does not have a mutated breast cancer gene will not get breast or ovarian cancer.

- True
- False
- Not sure

Q7 Early onset breast cancer is less likely due to a mutated breast cancer gene than late onset breast cancer.

- True
- False
- Not sure

Q8 A woman who has a mutated breast cancer gene has a higher ovarian cancer risk.

- True
- False
- Not sure

Q9 All women who have a mutated breast cancer gene get cancer.

- True
- False
- Not sure

Q10 A woman who has had her breasts removed can still get breast cancer.

- True
- False
- Not sure

Q11 Women who have BRCA1/2 testing will always get positive or negative results.

- True
- False
- Not sure

Q12 Breast cancer patients with a mutated BRCA1 or BRCA2 gene are more likely to develop a second breast cancer.

- True
- False
- Not sure

Q13 For the following statements, please rate from "Strongly Disagree" to "Strongly Agree" based on your current feelings.

Q14 It is likely that I will get breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q15 My chances of getting breast cancer in the next few years are great.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q16 I feel I will get breast cancer sometime during my life.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q17 If I get a mammogram and nothing is found, I do not worry as much about breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q18 Having a mammogram will help me find breast tumors early.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q19 If I find a tumor through a mammogram, my treatment for breast cancer may not be as bad.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q20 Having a mammogram is the best way for me to find a very small tumor.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q21 Having a mammogram will decrease my chances of dying from breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q22 I am afraid to have a mammogram because I might find out something is wrong.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q23 I am afraid to have a mammogram because I don't understand what will be done.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q24 I don't know how to go about getting a mammogram.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q25 In your opinion, how likely is it that you have a mutated breast cancer gene?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q26 At the present time, which of the following statements describes you best?

- Not considering genetic testing. / Haven't thought about it.
- Considering genetic testing.
- Probably will have genetic testing.
- Definitely will have genetic testing.

Q27 How familiar are you with the recommended medical guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very familiar 7

Display Q28 If Q27 = 5 OR 6 OR 7

Q28 Do you intend to follow the recommended medical guidelines for breast cancer prevention and detection?

- No, I definitely will not 1
- 2
- 3
- Neutral 4
- 5
- 6
- Yes, I definitely will 7

Display Q29 If Q27 = 5 OR 6 OR 7

Q29 At this moment, how motivated are you to follow the recommended medical guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very motivated 7

Breast Cancer Genetics Knowledge (Post)
Medical Guidelines Knowledge (Post)

Q1 Please enter your study ID.

Q2 One in 10 women have a mutated breast cancer gene.

- True
- False
- Not sure

Q3 One half of all breast cancer cases occur in women who have a mutated breast cancer gene.

- True
- False
- Not sure

Q4 A father can pass down a mutated breast cancer gene to his children.

- True
- False
- Not sure

Q5 The sister of a woman with a mutated breast cancer gene has a 25% risk of having inherited the same mutated gene.

- True
- False
- Not sure

Q6 A woman who does not have a mutated breast cancer gene will not get breast or ovarian cancer.

- True
- False
- Not sure

Q7 Early onset breast cancer is less likely due to a mutated breast cancer gene than late onset breast cancer.

- True
- False
- Not sure

Q8 A woman who has a mutated breast cancer gene has a higher ovarian cancer risk.

- True
- False
- Not sure

Q9 All women who have a mutated breast cancer gene get cancer.

- True
- False
- Not sure

Q10 A woman who has had her breasts removed can still get breast cancer.

- True
- False
- Not sure

Q11 Women who have BRCA1/2 testing will always get positive or negative results.

- True
- False
- Not sure

Q12 Breast cancer patients with a mutated BRCA1 or BRCA2 gene are more likely to develop a second breast cancer.

- True
- False
- Not sure

Q13 Never having given birth to a child will not affect your risk of getting breast cancer.

- True
- False
- Not sure

Q14 Getting older will raise your breast cancer risk.

- True
- False
- Not sure

Q15 Women with dense breasts are less likely to get breast cancer.

- True
- False
- Not sure

Q16 If you have a BRCA mutation, medical guidelines recommend getting annual breast MRI screening, starting at age 40.

- True
- False
- Not sure

Q17 The intake of a light or moderate amount of alcohol (1 drink per day) will not increase your breast cancer risk.

- True
- False
- Not sure

Q18 Overweight or obese women have a lower risk for postmenopausal breast cancer.

- True
- False
- Not sure

Q19 Women with a BRCA mutation are sometimes recommended risk-reducing surgeries to remove both ovaries, upon completion of child bearing.

- True
- False
- Not sure

Q20 Women who do not have a BRCA mutation are recommended to have annual mammogram screening starting at age 30.

- True
- False
- Not sure

Q21 Having first childbirth after age 30, may reduce your risk of getting breast cancer.

- True
- False
- Not sure

Q22 Mammogram has **not** been scientifically proven to reduce breast cancer mortality rate.

- True
- False
- Not sure

Instructor Evaluation Perceived Adaptation

Q1 Please enter your study ID.

Q2 How satisfied were you with Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very satisfied 7

Q3 How satisfied were you with the entire experience?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very satisfied 7

Q4 How much would you like to continue working with Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very much 7

Q5 How much do you like Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Much 7

Q6 How much do you trust Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Much 7

Q7 How knowledgeable was Tanya?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very Knowledgeable 7

Q8 Please state your opinion of the character on each of the scales below.

Q9 I think Tanya is dependable.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q10 I feel Tanya is dishonest.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q11 I think Tanya is unreliable.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q12 I feel Tanya is sincere.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q13 I think Tanya is trustworthy.

- Disagree completely 1
- 2
- 3
- Neutral 4
- 5
- 6
- Agree Completely 7

Q14 Please answer the following questions based on the entire counseling experience you just had with the character.

Q15 How **accommodating / tailored** do you feel Tanya was to your preferences?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very accommodating 7

Q16 The information I received regarding breast cancer was **tailored** to my needs.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q17 I feel Tanya provided the information **based on what I knew**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q18 Tanya understood my preferences and explained the risk information **the way I wanted**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q19 The information on breast cancer risks was **tailored to my understanding and knowledge**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q20 I feel Tanya provides the **same** information for **everyone**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q21 I think Tanya really tried to understand what I wanted and provided information **just to my liking**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q22 The information on the recommended medical guidelines to reduce breast cancer risk was provided in a way that was **most appropriate for my situation**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q23 The information on breast cancer was communicated in a way that was **tailored to my preferences**.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Champion's Health Belief Model Scale (Post) Breast Cancer Counseling Experience

Q1 Please enter your study ID.

Q2 For the following statements, please rate from "Strongly Disagree" to "Strongly Agree" based on your current feelings.

Q3 It is likely that I will get breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q4 My chances of getting breast cancer in the next few years are great.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q5 I feel I will get breast cancer sometime during my life.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q6 If I get a mammogram and nothing is found, I do not worry as much about breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q7 Having a mammogram will help me find breast tumors early.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q8 If I find a tumor through a mammogram, my treatment for breast cancer may not be as bad.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q9 Having a mammogram is the best way for me to find a very small tumor.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q10 Having a mammogram will decrease my chances of dying from breast cancer.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q11 I am afraid to have a mammogram because I might find out something is wrong.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q12 I am afraid to have a mammogram because I don't understand what will be done.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q13 I don't know how to go about getting a mammogram.

- Strongly disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

Q14 For the following questions, please answer based on your current feelings.

Q15 How **familiar** are you with the recommended medical guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very familiar 7

Q16 Do you **intend to follow** the recommended medical guidelines for breast cancer prevention and detection?

- No, I definitely will not 1
- 2
- 3
- Neutral 4
- 5
- 6
- Yes, I definitely will 7

Q17 At this moment, how **motivated** are you to follow the recommended medical guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very motivated 7

Q18 How **effective** do you feel **Tanya** was in motivating you to follow the recommended medical guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very effective 7

Q19 How likely would you **make a commitment** to follow the recommended guidelines for breast cancer prevention and detection?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q20 The following questions are about the entire counseling experience you just had with the character.

Q21 How much information did you get? (With 1 being too little information, 4 being just right, and 7 being too much information.)

- Too little 1
- 2
- 3
- Just right 4
- 5
- 6
- Too much 7

Q22 How much time do you feel your interaction with Tanya took?

- Too short 1
- 2
- 3
- Just right 4
- 5
- 6
- Too long 7

Q23 How likely would you be willing to talk more about your breast cancer risks with your primary care doctor or a genetic counselor?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q24 In your opinion, how likely is it that you have a mutated breast cancer gene?

- Not at all 1
- 2
- 3
- Neutral 4
- 5
- 6
- Very likely 7

Q25 At the present time, which of the following statements describes you best?

- Not considering genetic testing. / Haven't thought about it.
- Considering genetic testing.
- Probably will have genetic testing.
- Definitely will have genetic testing.

Appendix D: Evaluation Study I Protocol and Interview Questions

Evaluation Study I Protocol

(07/31/19)

1. Thank you for coming in today to help us out with our research study. Are you at least 18 years old? And able to speak and read English? **[If no thank and dismiss, if yes continue]**

Let me tell you a bit about what we will be doing in this study. We're designing a system that explains genetic risks related to breast cancer. The goal of this study is to explore methods that our system can use to effectively explain genetic risks.

During this study we are also interested in tracking your eyes to better understand human behaviors. You will be interacting with an animated character, answering questionnaires, and taking some short quizzes. The entire study should take about one hour and you will be paid \$15 for completing the study.

Are you still interested in participating in the study? **[If no, thank and dismiss, if yes continue]**

2. Now I need you to sign a consent form. I will explain it to you and then you can take as much time as you need to read it and ask any questions you might have. **[Hand subject consent forms, explain, sign]**

3. Now I would like you to fill out this questionnaire providing some information about yourself. [**Administer socio-demographics questionnaire**]

4. Now I am going to give you this list of words, and I just want you to read these words out loud in order. I want to hear you read as many words as you can, starting with column 1. But if you're having trouble with a particular word, you can just skip it. [**Administer REALM questionnaire**]

Now I'm going to ask you to read this nutrition label and answer some questions. Please imagine this information is on the back of a pint of ice cream. [**Administer Newest Vital Sign questionnaire**]

Now please fill out this questionnaire. [**Administer health numeracy questionnaire**]

5. Great. Before we start, I'll need you to fill out this quiz. Don't worry if you don't know the answer to any of the questions, you can leave it blank if you're not sure. [**Administer pre knowledge test**]

6. Now we can get started. As I mentioned before, the animated character you are going to interact with will be talking to you about genetic risks related to breast cancer. After your interaction with the animated character, I will ask you to fill out some more quizzes and questionnaires.

7. **[After interaction with Tanya]** Great. Now this is the end of your interaction with Tanya. I'm going to ask you to complete this quiz again. And you can leave it blank if you don't know the answer. **[Administer post knowledge test]**

8. Please fill out these questionnaires about your experience with Tanya in general.
[Administer instructor evaluation questionnaire & counseling experience questionnaire]

9. Thank you. Now, I would like to ask you a few questions about your experience with Tanya. Is it okay if I record our conversation, so that I don't need to take notes? **[Record conversation]**

- Can you describe the conversation you just had with Tanya?
- What was your overall impression of Tanya, and your interaction with her?
- Was Tanya helpful? Can you tell me more?
 - What was the most helpful or important thing that Tanya told you today?
 - Was there anything she talked about that you don't like or you feel unnecessary?
 - Is there anything else you want to learn from Tanya?
- Tell me more about the way Tanya explained some of the numerical or statistical information.
 - Would you prefer visual explanation, or verbal explanation?
 - How did you feel about the different graphs and images Tanya showed you during the session? (Stadium charts, pie charts, line graphs, & bar charts, etc.)
 - Were they helpful? Any particular one you found helpful, or not helpful?

- How can Tanya explain it better?
- Could you give me an example?
- How did you feel about the quiz questions Tanya asked you?
 - Were they helpful, or not?
 - In what way?
- How did you feel about the length of the session?
 - Was it too long? Too short? Just right?
 - Did you get enough information? Was it too much? Too little?
- How did you feel about talking to Tanya about genetics, and breast cancer?
 - Did the conversation make you feel anxious, stressed, or uncomfortable?
 - Would you rather talk to a doctor or nurse about this?
- What did you like most about your interaction with Tanya?
 - How come?
 - Can you give me an example?
- What did you like the least?
 - How come?
 - Can you tell me a bit more about that?
- Anything else you want to mention about your experience with Tanya?

10. Great. That would be all for today. Thank you for participating in this study. Do you have any other questions? Now if you can just sign this payment receipt you can be on your way.

Thanks again. **[Pay subject, hand payment receipt]**

Appendix E: Evaluation Study II Protocol and Interview Questions

Evaluation Study II Protocol

(09/22/20)

1. Thank you for volunteering to participate in our research study. Are you between 18 and 45 years old? And able to speak and read English? **[If no thank and dismiss, if yes continue]**

Let me explain what we will be doing in this study. We're designing a system that explains genetic risks related to breast cancer. The goal of this study is to explore methods that our system can use to effectively explain genetic risks.

During this study, you will be interacting with an animated character, answering questionnaires, and taking some short quizzes. The entire study should take about one hour and you will be paid \$20 in Amazon gift card for completing the study.

Are you still interested in participating in the study? **[If no, thank and dismiss, if yes continue]**

2. Now I need to obtain your verbal consent to participate in this study.

Go through the consent form that you have emailed them. Explain and obtain verbal consent for study participation, contact for future studies, and session recording.

Once they give consent, make a new Word doc. The doc should be the only documentation that **has participant's identifying information (full name and email)**. The document **should also list who administered consent, the date and time it was obtained, and what consent was obtained. The doc should be titled with the participant ID and then encrypted.**

3. Now I would like you to fill out this questionnaire providing some information about yourself. **[Send link to demographics questionnaire]**

4. Now I am going to give you this list of words, and I just want you to read these words out loud in order. I want to hear you read as many words as you can, starting with column 1. But if you're having trouble with a particular word, you can just skip it. **[Send link to REALM questionnaire]**

Now I'm going to send you another questionnaire, please read this nutrition label and answer some questions. Please imagine this information is on the back of a pint of ice cream. **[Send link to Newest Vital Sign questionnaire]**

Now please fill out this questionnaire. **[Send link to health numeracy questionnaire]**

5. Great. Before we start, I'll need you to fill out this quiz. Don't worry if you don't know the answer to any of the questions, you can leave it blank, or select not sure, if you're not sure about the answer. **[Send link to pre knowledge test]**

6. [Send system link to participants]

Now we can get started. As I mentioned before, the animated character you are going to interact with will be talking to you about genetic risks related to breast cancer. After your interaction with the animated character, I will ask you to fill out some more quizzes and questionnaires.

7. [After interaction with Tanya] Great. Now this is the end of your interaction with Tanya. I'm going to ask you to complete this quiz again. And you can leave it blank or select not sure if you don't know the answer. **[Send link to post knowledge test]**

8. Please fill out these questionnaires about your experience with Tanya in general. **[Send link to instructor evaluation questionnaire, & counseling experience questionnaire]**

9. Thank you. Now, I would like to ask you a few questions about your experience with Tanya. Is it okay if I record our session, so that I don't need to take notes? **[Record session in TEAMS]** Interview questions see attached.

10. Great. That would be all for today. Thank you for participating in this study. Do you have any other questions? **[Our project manager will send a \$20 Amazon gift card within 24 hours. Let me confirm your email address.]**

Evaluation Study II Semi-Structured Interview Questions

General Questions

- What were your overall impressions of the technology system you interacted with today?
 - Probes: Tell me more about that? How did that make you feel? I'm not sure I understand, can you explain what you mean?
- What was your overall impression of the computer character Tanya?
- Imagine going home and telling someone about your conversation with Tanya today. What would you say?
- How do you feel about talking to Tanya?
 - Probes: Tell me more about that? How did that make you feel? I'm not sure I understand, can you explain what you mean?
- Did you learn anything new from Tanya today?
 - What was the most helpful thing that Tanya told you about today? How was it helpful to you?
 - What was the most important thing Tanya told you about today? Why was it important to you?
- Now, let's talk about the other side of things. Can you give me an example of what you didn't like about the session?

About Assessments & Quizzes

- How did you feel about answering the questions about genes and breast cancer at the beginning of the session?
 - Do you still remember some of the questions?
 - How did answering these questions make you feel?
 - Did it make you uncomfortable? Tell me about that.
 - Why do you think Tanya asked you these questions? Tell me more about that.

- During your conversation with Tanya, she sometimes asked you questions like [example question]. Tell me your thoughts about that? How did you feel about the quiz questions Tanya asked you after she talked about each topic?
 - Were they helpful, or not?
 - In what way?
 - How do you feel about answering these questions?
 - Did answering these questions impact you negatively?
 - Would you have preferred to not have these questions? How come?

About Numbers & Adaptive Teaching

- Tell me more about the way Tanya explained some of the numerical or statistical information.
 - Would you prefer visual explanation, or verbal explanation?
 - Did you remember that Tanya asked for your preference earlier during the session?

- You told me earlier that you prefer information about numbers presented as a picture/said out loud to you? Is that right?
- Do you feel that the information Tanya told you today was mostly presented this way?
 - How did that make you feel?
 - How did that impact the rest of the conversation with Tanya?
 - What would you have preferred?
 - Why or why not?
- How did you feel about the different graphs and images Tanya showed you during the session? (Stadium charts, pie charts, line graphs, & bar charts, etc.)
 - Were they helpful? Any particular one you found helpful, or not helpful?
 - How can Tanya explain it better?
 - Could you give me an example?
- How accommodating do you feel Tanya was to you?
 - In what ways was she accommodating?
 - Can you give me an example?
 - Can you give me a rating, about how accommodating or how tailored do you feel Tanya was to your preference, **(1-7, with 7 being the most accommodating, and 1 the least)?**

About Health Background & Family History

- The topic of breast cancer is a sensitive subject and can be upsetting. But, I'd like to hear from you.

- How did you feel about talking to Tanya about genetics, and breast cancer?
 - Did the conversation make you feel anxious, stressed, or uncomfortable? How come? Tell me more about that? Why do you think that is?
 - Would you rather talk to a doctor or nurse about this?
How come? Tell me more about that? Why do you think that is?
 - Is there any content that you think should not be included? Tell me about that?
 - Prior experiences? How does that experience impact using the system today?

Other Questions & Wrap-Up

- How did you feel about the length of the session?
 - Was it too long? Too short? Just right?
 - Did anything seem unnecessary? Or not relevant to the conversation?
 - Did you get enough information to learn about your risk for breast cancer? Was it too much? Too little?

- Is there anything else you want to learn from Tanya?

- Anything else you want to mention about your experience with Tanya?

Appendix F: Evaluation Study III Protocol and Interview Questions

Evaluation Study III Protocol

(08/06/21)

1. Thank you for participating in our research study. Are you between 18 and 45 years old?

And able to speak and read English? And do you have a desktop computer? **[If no thank and dismiss, if yes continue]**

Let me explain what we will be doing in this study. We're designing a system that explains genetic risk related to breast cancer. And we'd like you to evaluate our system.

During the study, you will first answer some questionnaires, interact with an animated character, and then answer some more questionnaires. We will have a brief interview at the very end, about your experience using the system. And I would like to audio record our interview, so that I don't need to take notes.

The entire study should take about one hour and you will be paid \$20 in Amazon gift card for completing the study.

Are you still interested? **[If no, thank and dismiss, if yes continue]**

2. Now I need to obtain your verbal consent.

Go through the consent form sent via Email. Explain and obtain verbal consent for study participation, contact for future studies, and session recording.

Once they give consent, make a new Word doc. The doc should be the only documentation that **has participant's identifying information (full name and email)**. The document **should also list who administered consent, the date and time it was obtained, and what consent was obtained. The doc should be titled with the participant ID and then encrypted.**

3. Now let's start. First, I would like you to fill out this questionnaire providing some basic information. **[Send link to Demographics]**

4. Now I'm going to send you this questionnaire. When you open it you will see a nutrition label. I want you to imagine this information is on a pint of ice cream, and please answer the questions based on this nutrition label. **[Send link to Newest Vital Sign]**

Now please fill out this questionnaire. **[Send link to Health Numeracy]**

5. Now this questionnaire contains some quiz questions. Don't worry if you don't know the answer to any of the questions, you can leave it blank, or select not sure, if you're not sure about the answer. **[Send link to Pre Knowledge]**

6. **[Randomize participant to one of the three conditions, set up basic info in database, and send system link to participants]**

Now let me set up the system for you. Could you tell me your age?

Great, thank you. As I mentioned before, the animated character you are going to interact with will talk to you about genetic risk related to breast cancer. After your session with the character, I will ask you to fill out some more questionnaires.

Here is the link to the system. You can start when you're ready.

7. [After interaction with Tanya] Great. Now I'm going to ask you to fill out some more questionnaires. Some of the questions you've answered earlier, but I would like you to answer them again. And same as before, you can leave it blank or select not sure if you don't know the answer. **[Send link to Post Knowledge]**

8. Please fill out these questionnaires about your experience with Tanya in general. **[Send link to Instructor Evaluation, Counseling Experience]**

9. Thank you. Now, I would like to ask you a few questions about your experience with Tanya. Is it okay if I record our interview, so that I don't need to take notes? **[Record session in Zoom]** Interview questions see attached.

10. Great. That would be all for today. Thank you for participating in this study. Do you have any other questions? **[Our project manager will send a \$20 Amazon gift card within one business day. Let me confirm your email address.]**

Evaluation Study III Semi-Structured Interview Questions

General Questions

- What was your overall impression of your session with Tanya today?
When I say “session”, I mean when you logged into the website and started your conversation with Tanya.
- Imagine going home and telling someone about your session with Tanya. What would you say?
 - How do you feel about talking to Tanya?
 - How come? Could you tell me more?

ALL CONDITIONS: Risk Education

- During your session, you were presented information regarding a woman’s risk for breast and ovarian cancer. How do you feel about the way the information was communicated to you?
 - How Come? Could you tell me more?

IF ADAPTIVE CONDITION: Assessments & Quizzes

- At the beginning of the session, Tanya asked whether you would like to answer a few questions about genes and breast cancer.
Did you choose to answer those questions, or did you choose to skip this part? An example question would be: genes are inside of cells, select true or false.
 - **IF CHOSE TO ANSWER:** Do you still remember some of the questions?
 - What were they?

- How did answering these questions at the beginning of the session make you feel? How come? Tell me more.
- Why do you think Tanya asked you these questions? Tell me more about that.
- During your conversation with Tanya, she sometimes quizzed you after she covered a specific topic. For example, she asked you, “what would be your chance of having a BRCA mutation, if your father, or one of your siblings carries this mutation?”
 - Do you remember some of these questions?
 - How did you feel about answering these questions?
 - How come? Tell me more.
 - Would you have preferred to not answer these quiz questions?
 - How come? Tell me more.

IF ADAPTIVE CONDITION: Numerical Info & Adaptive Teaching

- At the beginning of your session with Tanya, she asked you if you would prefer information about numbers to be presented as images and charts, or just said out loud to you.
 - Do you remember this?
 - Which one did you choose? Visual or Verbal explanations?
 - Do you feel that the information Tanya told you today was mostly presented this way? How did that make you feel?
 - **IF CHOSE VISUAL CONDITION:** Regarding the different graphs and images Tanya showed you during the session (Pictographs, pie charts, line graphs, & bar charts, etc.) -

- How did the graphs and images impact your session?
 - How did they make you feel?
 - Any particular one you found helpful, or not helpful?
- During the session, Tanya asked whether you would prefer to hear your personal risk numbers for breast and ovarian cancer. How did you respond?
 - How did that make you feel?
 - Would you rather change your response now, if you could go back? How come?

ALL CONDITIONS: Adherence Motivation & Medical Guidelines

- During your session, you were presented information regarding the recommended medical guidelines for breast cancer screening, and other things you can do to lower your risk. How do you feel about the way this kind of information was communicated to you?
 - How Come? Could you tell me more?

IF ADAPTIVE CONDITION: Adaptive Adherence Motivation

- During your session with Tanya, she asked you these following questions, such as “do you prefer scientific evidence, or expert opinions?” “how important is learning about breast cancer to you?” “how much information have you already received?”
 - How did answering these questions make you feel?
 - Did you feel answering these questions affected the information you received in any way? How come? Tell me more.

Health Background & Family History (OPTIONAL)

- The topic of breast cancer is a sensitive subject and can be upsetting. But, I'd like to hear from you. How did you feel about talking to Tanya about genetics, and breast cancer?
 - **IF HIGH RISK:** You mentioned before you joined this study, that you have a family member who had breast cancer/tested positive for a BRCA mutation.
 - Would you like to talk more about this?
 - How did that experience affect your conversation with Tanya today?

Session Length

- How did you feel about the length of the session?
 - Was it too long? Too short? Just right?
 - Did you get enough information to learn about your personal risk for breast cancer, and what you can do to lower your risk? Was it too much? Too little?

Debriefing & Wrap-Up:

- You were actually randomly assigned to interact with one of three systems. (Explain the other two conditions.) If you could choose, which system would you choose to interact with? And why?
 - Could you tell me more?
- Anything else you want to mention about your experience today?