Joy Ming

Prof. Nara Dillon

SS98kg

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Communicating Health Risk in the Global Sphere

At the Harvard Global Health Institute pre-departure training for the summer of 2014, one of the previous grant recipients recounted the following story:

> "I arrived home after a typical day at the Ugunja Community Resource Center office, sweating from the two-mile walk in the Kenyan heat ... I could hear someone hammering wood at the back of the house, an unfamiliar addition to the usual sounds of roosters, crying babies and laughing children, so I decided to check out the situation. When I went around to the back, my friend David called out to me with a hammer in his hand, 'Why are you home early today?' While this may seem like a simple question, I was not sure how to answer. I decided on the truth—they would find out soon anyway. 'Well,' I said, 'I'm working on a survey to assess HIV knowledge in secondary schools, and I was hoping to pilot the survey with the kids at home.' David smiled, and Raymond laughed. Both, I knew, were HIV-positive, which was why I had felt uncomfortable bringing up the topic. 'Yes,' they said jokingly, 'teach us.' They started discussing their HIV, Raymond loudly and openly, David a little less so. Raymond quickly announced 'I have stopped drugs, yes. I fear drugs. They are too Western, they smell bad. If I take drugs, everyone knows, because of the smell. Yes. I want to live an African life.' He continued, announcing, 'The world is full of suffering anyway, what is here? I am very ready to leave, there is no hope.' David nodded, and they both continued to smile." (Jain, 2014)

Tara's story raises a lot of questions, especially with regards to the way in which risk is presented. There is the original risk that Tara takes in broaching such sensitive topics in everyday conversation, as she risks offending the other party. Her conversation partners Raymond and David face risks in confirming their diagnosis and openly speaking about the topic that carries such strong stigma. But the main dilemma presented by the story is that of the risk of medical compliance: Raymond does not continue to take his medicine because he would rather take the risk of dying than living a life in stigma, a life of suffering and hopelessness.

During the training, we voiced our reactions to the scenario, under the prompt of

uncovering some of the implicit associations we had and talking about how we would respond if we were the ones in Tara's place. Most of us expressed shock in not only Raymond's decision but also the ease at which he spoke about sickness and death. But it was through what was said that we were able to get a few glimpses into the realities that David and Raymond faced. We realized that given our backgrounds of being educated at an elite, Western institution, we had the assumption of the efficacy of biomedicine—believing that taking the medicine would lead to a road of recovery—as well as our conceptions of the value of a life—that life would always be worth living. Underlying the discussion was the understanding that we would not have made the same decision that Raymond did and even with our sympathetic and academic mindsets it is difficult for us to understand why he did make the choice to not comply to his medication and live.

We talked about different ways we would have approached the situation. Having taken anthropology and sociology classes, we had learned the concepts of the *social construction of reality* and *local moral worlds*, so we knew that it would be best if we tried to understand where the two men were coming from. But the theory we learned would be hard to apply in this situation, as we talked about ways to balance being too "preachy" by imposing our own thoughts and lived experiences with being too passive and not sharing what could be life-saving insights to help those that we interact with. Of course, most of us, having signed up to go to countries in various stages of development, did have the mentality of wanting to help. As Tara shared her attempt to talk to the men about the value of medication, about the value of their lives, she told us about the blank walls she faced and her inability to change their mind. In the end, the only thing that we could conclusively say as a group was that ethical reasoning in global health is hard.

But why was it so hard? The main reason why it was so difficult for a group of Harvard students to understand and determine how to act in such a situation is because risk perception is rooted in context and in culture. For David and Raymond, the story was not as simple as a black and white decision of wanting to live by taking the medication or to die at the hand of the disease. There were other layers of complication, like the fact that there is social capital at stake because of the stigma placed around HIV/AIDS and the taking of the smelly drugs. Three main factors in

risk perception are trust, value, and time. Raymond and David have less trust in the drugs that are a product of Western medicine, rather, state that they have fear of the drugs. They place less value on following doctor's orders. And they place less value on living life in this disease state, with the side effects of the treatment, and see less potential opportunity for long-term gain. For that reason, the future that we see is not the same future that they perceive.

This story, among other similar stories in the global health sphere, open discussion about the way in which risk can be communicated. There are various boundaries in place, including the obvious boundaries of culture that are seen in this example, but the less obvious boundaries of authority—between doctor and patient, government and citizen—or individuals and the population that surround them. In order to effectively communicate health risk to change the individual's action and ability to live, the culture and the axes affected by the context have to be understood and the communication method must be adjusted accordingly. And, due to the flexibility of present software and technology, a solution can be reached feasibly, even in low-resource settings.

For my thesis project, I will be developing an adaptive computer-based user interface to help communicate information about health risk to an audience based in developing countries. This summer, I will be speaking to individuals and testing various design principles in urban and rural settings among various low-literate, low-numerate, and low-technologically-literate populations in the United Arab Emirates and Ghana. In order to do this, I will need to have some framework about how individuals or populations conceptualize risk and to what degree communication of information can alter both this conception and the planned actions that follow. This paper analyzes the factors that are important in perceiving risk, proposes design principles and interventions to adapt risk communication to these given factors, and explores some potential implications of taking these measures.

I. Defining Risk

There are many examples of what is colloquially considered *risk* and at its core, risk has many different interpretations. These can include but are not limited to sports and adventures that involve risk, the risk associated with startups and new businesses, or even simply the risk associated with asking someone on a date (Holton, 2004). Another common conception of risk is within the healthcare realm, where risk can mean the risk of contracting a communicable disease given the spread of the disease in the population and the structure of the population, the risk of contracting a disease if treatment adherence is not met, or the risk of developing chronic disease given current genes, diet, and exercise.

One example of risk that is fairly familiar in the capitalist economy is regarding investment. A risk in the financial sphere is the chance that an investment's actual return will be different than expected, including the possibility of losing some or all of the original investment (Investopedia, 2014). This demonstrates the first definition of risk, of chance or probability. Mathematically speaking, risk is the likelihood that some negative event will occur (Breakwell, 2007). For example, on any given morning, it can be said that the "risk of rain is 60%," communicating that the probability the negative outcome of rain will occur. This can be the risk that a specific event may occur, as in the rain in the previous example, or this can be a general or implied set of negative events, as in the example "this investment carries with it significant risk." This negative event is most likely prompted by some *hazard*, which is anything that could lead to *harm*, or negative consequences.

Breakwell (2007) claims there is a second definition of risk, with the interpretation of effect. Risk as an effect is the extent of the detriment associated with the adverse event, or the numerical estimate of the harm. This looks at the ramifications of a negative event as opposed to the probabilities leading up to it. And this falls more within the scope of taking risk to be the noun that embodies what will occur. An example would be "the trip didn't seem like much of a risk" or "smoking is a risk to your lungs," describing the degree of negativity in the consequences of the trip or smoking. This could also be attributing risk to be the agent which creates or suggests the

negative consequence, in the case that "he is a risk to the team," asserting that player will create a negative benefit for the group (Webster, 2014).

And of course there is the distinction between the usage of risk as a verb or a noun. Risk can also the creation of a situation that could result in a negative consequence, whether it is exposing someone to a danger or incurring the risk or danger (Webster, 2014). This puts the "risk" as defined as probability or effect already into consideration before deciding on the action, fleshing out the timeline between the abstract probability, the potential effect, and the actual action that is taken. All of these are valid descriptions of the events in the timeline associated with the concept of risk.

Though they are distinct, these definitions and examples of risk all have elements of similarity that can be used to create the definition of risk used for the remainder of this paper. All of these definitions look at "negative consequences." Even with these examples, each takes their own stance on what is considered a negative consequence, due to context or perspective. This stems from assigning a given utility to all of the possibilities. However, there is uncertainty in what out of the possibilities will occur. And risk involves the exposure of individuals to this uncertainty (Holton, 2004). Therefore, for the purposes of this paper, the definition of risk will be based on the probability definition of risk, looking at the probability of negative outcomes in situations where individuals involved are exposed to many potentially negative outcomes but at uncertain rates. And the paper will focus on how individuals will understand and evaluate this information before they take action.

II. Modelling Risk

The foundational model of risk is that of risk as interpreted by *homo economicus*, or the "economic man," a concept was originally proposed in the field of political economy by John Stuart Mill's works in the late 1830s and have been picked up and made popular by John Kells Ingram and John Neville Keynes' work (Persky, 1995). In economics, there is the assumption that individuals make decisions rationally, considering things like tradeoffs, marginal costs and benefits, or incentives (Mankiw, 2011). This theory of decision making assumes that the economic man is completely informed, infinitely sensitive, and rational in sense of making choices that maximize expected value or utility (Edwards, 1954). Therefore, in making decisions regarding situations that deal with risk, *homo economicus* will calculate and weigh the risks and benefits. Even if individuals do not have full information, they are able to make judgements of probability and their risk-taking decisions through heuristics like the availability heuristic or the representativeness heuristic (Kahneman, 1982).

However, later economists and scholars like Thaler (2000) argue that the models of rational, unemotional agents will have to accommodate innate human biases, or tendencies to stray from the most optimal course of action through the study of human cognition and emotion, transforming *homo economicus* to *homo sapiens*. This is furthered by the psychologist Slovic (2010)'s presentation of the affect heuristic, or the hypothesis that feelings serve as an important cue for risk and benefit judgements and decisions. The psychometric paradigm is described as a cognitive process in which people look to their positive and negative feelings as a guide to their evaluation of an activity's risks and benefits. A more accurate description of "feeling" is probably "intuition," the Considering risk as a feeling makes sense given some empirical evidence of individuals who respond to positive and negative imagery and theoretical foundations with affect as an important factor for explaining animal learning studies and motivating and guiding all rational human behavior (Benthin et al., 1993; Mowrer, 1960; Damasio, 1994). This successfully adds on the dimension of emotion into the decision making process.

The shift from thinking of an agent who makes decisions based on a rational calculus to

one who does so based on intuitions demonstrates individuality. For the homo economicus, there is a universal ground truth that can be achieved, a purely "rational" decision given the possibilities. This makes the agents interchangeable–whichever rational agent that is presented with a dilemma will react in the same way. However, for the affect agent, the decision is the best based on an internal, individual feeling. Therefore, there is a possibility that there is the possibility that an agent will react differently due to their individual feelings. There is also the possibility that the agent will react in the same way because their feelings match up with those of another person, but, more importantly, they are acting upon their internal, individual feelings rather than some larger, universal truth.

This brings up the question of where these "feelings" or affects originate. Breakwell (2007) acknowledges that the process for determining what is harmful through the social and psychological interpretation within and between institutions and individuals, meaning it is all socially constructed (Breakwell, 2007). From an anthropological angle, Douglas (1986) argues that risk perception is determined by social organization and culture, as the type of society and the type of accountability and focus on particular dangers associated with it (Douglas, 1986). She proposes the idea of cultural theory, a way of thinking about culture that draws the social environment systematically into the picture of individual choices (Douglas, 1986). And because of this, individuals behave neither as rational nor irrational judges, but rather as cultural evaluators of risk (Kahan, 2006).

Considering the factors on a larger scale moves from looking at just individual feelings to considering the multivalent forces of society, specifically dealing with culture. A natural extension would be to see how these forces will influence not just how agents individually react to risk, but also on a population or societal level how communities will understand and respond to risk. Douglas (1986) asserts that public perceptions of risk are not simply the sum of individual reactions to specific events, but shaped by broader social and cultural influences, extending her argument from the individual to the societal (Douglas, 1986). And from a sociological perspective, Beck presents the concept of a risk society, looking specifically at societal influences

of what he calls reflexive modernisation and scientism (Beck, 1992). Giddens (1991) also looks at modernity as a risk culture, creating a climate of risk (Giddens, 1991).

In considering modern developments such as industrial overproduction that are innately high risk in jeopardizing all forms of life on the earth, Beck (1992) considers the risk associated with globalization in the creation of a world risk society (Beck, 1992). This is still different from the economic perspective because risk is shown to be relativist rather than universalist, meaning that though context has the ability to influence the actions of many individuals at a time in a given community, it is done so on a larger scale but not necessarily with some universal truth (Caplan, 2000). Rather, it is a more interesting perspective that allows for the analysis of each of the local moral worlds and understand the potential conflicts between cultures (Douglas, 1986). And this is even more interesting from a computer science perspective, not only because the Internet has been such a major force in globalization but also because it might be interesting to understand what abstracted factors will need to be considered when creating different software designs.

However, even in this world risk society, Beck (1992) argues that different people are more affected than others by the distribution of risks or bads, enhancing extremities. This difference in levels of risks is determined by the extent of knowledge and to the uneven distribution of knowledge (Beck, 1992). This uneven distribution could be due to many factors. From a psychological perspective, this could be a failure to comprehend risk information adequately due to simple reasons such as differing levels of numeracy or more entrenched reasons, such as the inability to fully grasp all the deeper levels of understanding necessary to understand the layered process of risk (Peters, 2000; Weinstein, 1999). However, from a more anthropological perspective, this could also be due to different levels of trust for the information presented (Caplan, 2000). There is the Western notion of having much trust in science and biomedicine, but in reality, science is never autonomous or free of culture, whether this is in the discovery of what are deemed as facts or in the presentation of information that is considered correct (Nader, 1996). There is an interesting tension between this assumption and the reality of a different context (Bujra, 2000).

III. Influencing Factors

Risk and Trust.

There is, first and foremost, the trust for the information that is presented that conveys a given risk. Whether individuals are willing to act on a piece of information is determined by how much they trust that piece of information, which is a factor of what they perceive the quality of the information to be (Nicolaou and McKnight, 2006). This can also be influenced by the amount of uncertainty that the information can present. Because risk as a probability is essentially a prediction a given outcome will occur across different potential outcomes, there is a lot of uncertainty involved. However, empirical work has shown that because the general public is unfamiliar with uncertainty in risk assessments and in science, uncertainties in risk estimates will signal honesty, but also agency incompetence and less credibility (Johson and Slovic, 1995). In presenting risk information, it would be important to present the information in a way that is especially credible and trustworthy to be convincing.

Trust and credibility for a piece of information could stem not only from the information itself but also the source of the information. One way to establish legitimacy or trust is through authority. An example of traditional authority is the relationship between adolescents and parents. Though parents tend to dictate how children should act in a risky situation, it is found that in cases where adolescents have more autonomy, those who perceive a strong mutual trust with their parents are less likely to engage in high-risk behaviors such as delinquency (Borawski et al., 2003). Another dimension of implicit authority is in the governmentality of *biopower*, or the increase of political authority to exert its effects via the control of bodies and populations (Kleinman, 2010). Similar to the example of the parent-child relationship, by implementing normalization, or statistical analysis to separate the population into separate categories of risk, through a trust relationship the government primes the citizens to continue to fit into these categories and voluntarily pursue behaviors that maximize their life opportunities and minimize the risks to which they are exposed (Lupton, 1999). These concepts in political theory demonstrate that the looming influences on authority are not always quite clear but should be well

acknowledged when presenting information that can sway opinions and actions.

An example of the blurring lines of authority can be seen in Fadiman (1997), where the authority of the Hmong parents and American doctors felt challenge. Both sides wanted to assert of what they felt was best, resulting in a clash between the culture and beliefs of traditional medicine and biomedicine in the treatment of the child and patient, Lia. In Kleinman (1988), this phenomena is not a surprise. He distinguishes the definitions of *illness*, or how the sick person and members of the wider social network perceive, live with, and respond to symptoms and disability, with *disease*, or what the practitioner recasts the illness as in terms of the theoretical lens of practice, and *sickness*, or the understanding of a disorder in its generic sense across a population in relation to macrosocial forces. By separating these concepts, he asserts that local cultural orientations organize our conventional common sense about how to understand and treat illness (Kleinman, 1988). By treating biomedicine as a "culture" as opposed to a "truth," these two examples present how what would be perceived as scientific authority in the Western world also needs to gain its own legitimacy.

Cultural differences lead to different levels of trust of the authorities that present information, and therefore, to the actions taken when the information is presented. For example, Bujra (2000) looks at unsafe sex and HIV/AIDS in Tanzania. She notes that though Tanzanian men are, for the most part, well versed in the doctrine of condoms and safe sex, they are less likely to listen to Western authority because "their faith in Western medicine had been undermined by its failure to come up with a cure for AIDS." This shows that there is a different hierarchy of authority in the different context. Scientific authority does not necessarily serve as an adequate proxy to establish trust in all cases. This is also seen in Tara's story with David and Raymond, who also turned away from Western medicine for a more "African life" (Jain, 2014).

However, the Tanzanian men who face the risky decision of having unsafe sex also face another dimension of risk—what Bujra (2000) refers to as the "domestic politics of risk." The use of a condom for safe sex can help prevent the transmission of STDs brings the implication that one of the partners involved in the intimate moment may have the disease—broaching the trust

between the two individuals involved. For example, a woman asking her husband to use a condom could be implicitly accusing him of sleeping with other women or prostitutes in the city with the disease and a husband using one could be implicitly admitting to the charges (Bujra, 2000). And even so, due to the gender politics and the nature of the male condom, there is not much a woman can do to ensure her partner and husband wears one. Therefore, the home, where trust is the strongest is conversely the place where protection is the weakest. And the social and economic consequences of these risky decisions will hit the home the hardest.

Risk and Value.

The example in Bujra (2000) also demonstrates that there are social forces at play. The husband and wife's desire to maintain their relationship with one another can be analyzed through the lens of the sociological concept of *social capital*, or the value of relationships people have (Bourdieu, 1985). This can be especially important in terms of familial support, as seen in the previous example, and can be leveraged to be involved in social action and community empowerment (Portes, 1998). For example, a group of women could utilize their strong ties to create a movement around convincing their husbands to wear condoms. Conversely, a lack of social capital can result in stigma and exclusion (Sivaram et al., 2009; Portes, 1998). This could be especially important in the context of HIV/AIDS, which has a strong stigma, seen in Raymond and David's desire to avoid taking the "smelly" drugs that would make everyone know that they were HIV-positive (Jain, 2014).

Part of the reason why theses prioritizations of social capital is confusing for the Western audience is because of the anthropological concept of the *social construction of reality*, or that the world is made over into socially and culturally-legitimated ideas, practices, and things (Berger and Luckman, 1968). This context-specific construction of a value system allows for an individual evaluation of "what really matters", which can include things like status, jobs, money, family ties, sexual intimacy, sense of order and self control, health, life, among others. The valuation of each of these attributes comes from the interaction of cultural meanings, social experience, and subjectivity (Kleinman, 2006). These create the *local moral worlds* from which individual ethics

and morality arise and dictate the individual preferences (Kleinman, 2010). This is part of the reason why ethics in global health is hard—because each individual in a given context will have a different set of ethics or morals.

These valuations can translate to the economic concept of preference orders. A preference order, which is a relative or absolute ranking of an individual's options, is a prior to a choice, where individual will assess the preferences that she or he is given and act upon the best option (Sen, 1982). However, this is an extension from the original concept of the economic man because instead of global rationality, individual preference orders acknowledge that there is *approximate rationality*, which is compatible to the very real situation of limited knowledge and ability that is presented to human actors (Simon, 1955). So what would otherwise be considered "irrational behavior" of adolescents having unsafe sex can be construed as a "rational tradeoff of the desire for health against the desire for other things that entail health risk" (Gardner and Herman, 1990). The adolescents in this case have very different preference orders from what the adults perceive is rational. In this case, the altering of valuation can be seen as caused by strong desire.

Other times, the altering of value structure can be due to a different perspective of what the consequences are the weights associated with each one. An example is the concept in development economics of the *poverty trap*. As presented by Banerjee and Duflo (2011), where an individual in poverty is not given opportunity to break the vicious cycle and climb out of poverty because of mechanisms that cause poverty to persist. For example, a subsistence farmer has low crop yield this season and has to take debt in order to be able to get seed for next season. However, as more seasons pass, the farmer has to grow enough crop to cover that season as well as cover the interest, and may have to take more debt, increasing the amounts of debt and interest on that debt he has to pay, and the family falls into deeper poverty. Even if the farmer is presented with a radical new means of increasing harvest, the risk associated with it means that failing does not only lead to income poverty, but to chronic poverty. For this reason, risk aversion in the poor is due to over-weighing of probabilities associated with failure and loss (Mosley and Verschoor, 2005).

There are other factors in addition to credit that could place an individual in a poverty trap, including government, lack of education, lack of infrastructure, or war. Health could also be a factor associated with the poverty trap, because poverty breeds ill-health and ill-health keeps poor people poor (Wagstaff, 2002). This is a side effect of the idea of *structural violence*, or that socioeconomic and sociopolitical forces can at times cause disease (Kleinman, 2010). This shows that poor-health at times could also be difficult to rise from, whether it itself is its own trap or if it is simply closely tied to the poverty trap.

Risk and Time.

Time is perceived differently within the paradigm of the poverty trap. In the example of the subsistence farmer, the farmer has to constantly think in terms of seasons and cannot necessarily predict what the crop yield will be like a few seasons out. Therefore, the farmer cannot fully gauge how much risk to take outside of the given windows of time. Another perspective is the way in which the long-term is viewed. There is the dimension of the compounding of risk in the future as well as differences in long-term outlook. An extension of the weighing of consequences and benefits of a given risk is also considering the calculation with time as a factor.

Tanaka et al. (2010) presents a study that presents studies conducted in Vietnamese villages to directly measure risk and time preferences of individuals. It finds that time discounting can affect risk tolerance and that people are present-biased regardless of their wealth, but have differing degrees of present bias. This idea of *time discounting*, originally proposed by Samuelson (1937), takes interemporal choice and applies it to the idea of discounted utility—or that things are worth less in the future than they are now, highlighted by the idea of present bias (Frederick, 2002). This can be found by asking individuals a series of questions like "would you rather have $10 now or $11 in a week?" If time was not considered, $11 would have a higher utility because it is more money, but having the money now has some greater degree of usefulness than having the money later. There are many models proposed to account for this depreciation of value, including exponential, hyperbolic, and quasi-hyperbolic discounting (Benhabib et al., 2009).

There are some criticisms of time discounting is that though it psychologically makes

sense that things in the future are worth less than things now, the exact relationship presented by empirical studies has not been properly encompassed by the theoretical models presented (Frederick, 2002). And that time might not be the only factor that is affected by this change in value. However, the general idea of time discounting, whether it is ultimately economical or psychological, can still be applied in other realms.

This idea of time discounting is also put into play in a health economics and public health concept of the quality adjusted life year (QALY). This is used to determined the cost-effectiveness of an intervention by capturing gains in terms of morbidity and mortality(Vergel and Sculpher, 2008). Out of it emerged the concept of a disability adjusted life year (DALY), which is marketed as a new measure of the "burden of disease", and is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability, or early death (Murray, 1994). These were both designed for the approach of using economic or rational models of thinking for health outcomes. QALYs are different from DALYs in that they are more personalized preferences rather than population level preferences made by a panel of professionals and have other different calculation and well as conceptual differences (Sassi, 2006).

An example of the way in which QALYs are measured by a "standard gamble," which is a way of measuring cardinal preferences. This could be that a subject is presented with the option of having some disease, say losing their arm. However, there is some treatment that they could take that would allow them, with some probability p to be healthy and with the converse probability $1 - p$ to be dead. As p is adjusted, the preference for a given health state is able to be determined (Torrance, 1985). Another means of doing this is using the rating scale, such as a EuroQol questionnaire, which asks the individual to describe their own health at the current state and evaluating where it falls on between the best and worst imaginable health states (Vergel and Sculpher, 2008). Yet another method is to use a time-tradeoff, asking if the patient would want to stay in a specific state for a time t, the calculated life expectancy of an individual with that chronic condition until death or to live a healthy life for a time less than t (Torrance et al., 1972).

However, some criticisms of QALY include that though the information collected from

individuals rather than professionals, it is still an aggregation, and therefore, the context of the individuals, including starting level of health, age, or ethnicity are not taken into account directly Vergel and Sculpher (2008). And DALYs also have similar criticisms as well, failing to distinguish between socioeconomic status (Anand and Hanson, 1995). And, though it is attempting to be a more economic and rational choice model of decision making, it is still very subjective. In terms of health care, the value of a few months more of life is very different when trying to consider them a few decades later or as a question of extending lifespan right now. A challenge is to come up with a measure that is effective in rational choice as well as context-sensitive.

IV. Design Principles

One of the difficulties in presenting and distributing information to the public is the variance in the types of background and understanding individuals will have. In the field of human-computer interaction, there has been research about psychological models and design recommendations for creating visualizations for individuals who have low literacy (Kodagoda et al., 2012; Medhi et al., 2013; Theis and et. al., 2013). There has also been research done in the public health space that look at the presentation of information to those, even in the United States, who have low health literacy (Arcia et al., 2013; Baker et al., 2011; Gaissmaier et al., 2012).. In presenting statistics, there is always a sense of uncertainty, whether it is uncertainty in the statistics themselves given the confidence interval or in the concept being presented as seen in various types of "risk." This ambiguity has been seen to lead to both "ambiguity aversion" as well as heightened awareness in the effects that result from a difference in numeracy of the audience (Han et al., 2011; Spiegelhalter et al., 2011).

In the studies that span various fields about visualizing information, the factors that could inhibit an individual's understanding of visualizations include but are not limited to literacy, health literacy, graph literacy, and numeracy. And each of the studies and fields they originate from have a different definition of "literacy" in their given contexts. The conceptualizations presented are discrete, binary constraints, when in reality "literacy" in whatever form could present itself as a continuous spectrum of possibilities. It would be important to experimentally discover the context-driven "literacy" associated with visualization that are the most important determining factors to whether an individual can fully comprehend the information that is presented and convert it into knowledge. And it is also important to understand the root of these variations, which can potentially be traced to education or varying cultural backgrounds.

Additionally, these conjectures make the assumption that the only barrier to the change between information and knowledge is the presentation of information–that once individuals view information that matches their level of "literacy", they will both understand and act upon the information in a relatively predictable manner that is beneficial to themselves and to the

community. This assumes the presented information is, to some degree, correct and that it is sufficiently trustworthy to cause the individual to alter their action. It also assumes that individuals will process this information in a similar manner, resulting in one or few potential actions. However, in reality, this presentation of information may potentially result in non-action or an unintended reaction. And neither of the observed actions would necessarily shed light into whether an individual fully understands the information or even has the same conceptualization of the situation that was intended to be conveyed through the visualization.

One way to allow for the design of the information to be responsive to the information receiver's context is through adaptive user interfaces. Adaptive user interfaces (AUI) are systems that change their structure, contents, and elements according to the need and context of the user (Schneider-Hufschmidt et al., 1993; Zhuang, 2012). This is able to be achieved with the two core features of user model acquisition and user model application (Jameson, 2009). An AUI normally acquires a user model by learning and making inferences about a user's behaviour with an interface such as the start menu on Windows XP, with collaborative filtering to collect preference information explicitly given by users such as musical choices through Spotify or previous purchases made on Amazon or content-based filtering using mathematical models such as Bayesian algorithms or artificial neural networks on the content characteristics itself (Billsus and Pazzani, 2007). Different types of adaptations include split interface, moving interface, and visual popout interface (Gajos et al., 2006).

This can be adjusted to the idea that the users of software are human, and therefore incur cognitive costs and are boundedly rational. This helps ameliorate the purely *homo economicus* approach with the more flexible idea that since computer systems are carrying out tasks in mixed networks of both computer and human agents, the computer agents have to learn and adapt to social attributes that influence people's decision-making (Gal et al., 2010). The computer's position in this case is not to replace the human agent, rather, to aid the human agent by taking over tasks that are difficult for humans, such as calculating complex expected utilities or suggesting behaviors that are rational. An example of such design is the "market user interface

design" that can help study the automatic optimization of market UIs given a behavior (quantal response) model of user behavior to help users make good economic decisions (Seuken et al., 2012). This suggests personalized UI designs, with interfaces that are tailored towards each individual user's needs, capabilities, and preferences.

Healthcare is a strong potential realm for the application of AUIs because there are a wide range of actors involved in the space, from the patient to the nurses, doctors, and other specialists (Zhuang, 2012). In applying AUIs to healthcare, the important design decisions include adaptive presentation and adaptive navigation. With presentation, this means looking at the difference between the type of language used (eg. medical jargon or colloquial information). And with navigation, this means that this can be adapted to the user's interaction with the system, to make the process smoother for a given user (Ramachandran, 2009).

An example of an application of an adaptive interface to healthcare is the creation of MobiGuide, a using a shared-decisions model to help patient-centric decision support system that helps patients with chronic illnesses, such as atrial fibrillation (Sacchi et al., 2013). In the study, Sacchi et al. (2013) present a means of using a utility model (measuring QALYs through a rating scale, standard gamble, and time trade-off) and cost model (looking at out of pocket costs and opportunity cost) to collect patients preferences. Then, using the patient preferences, MobiGuide creates a decision tree and Markov Model to connect alternative decision options to their expected effects and the final outcomes of each possible scenario. This contributes to the field of artificial intelligence in computer science because it creates this shared decision framework that integrates patient preferences into the normal clinical routines to empower the patient to make better choices. Previous studies have looked mainly at static implementations of clinical guidelines (Isern and Moreno, 2008).

However, there is much future work to be done to allow this approach to be applied to healthcare. For example, it would be necessary to take the next steps of looking at usability studies or finding ways to evaluate the success of such software and its ability to help patients make these decisions about their healthcare (Sacchi et al., 2013). More importantly, this approach

has a lot of promise but more work to be done to fit to health care on a global scale. The approach needs to incorporate the three factors that affect risk, namely trust, value, and time.

The approach does take on the idea of "value" by asking the users to spell out the patient's preferences by looking at their personalized utility and cost models. However, there is a balance between having this information become so personalized that it would take a long time to test to elicit the preferences for each one of the users and integrating other population-level or categorical preferences. For example, one way to do this is in the process of trying to determine how the individuals perceive the QALY of a given chronic condition, potentially turning this into a machine learning problem of looking at how age, geography, ethnicity, socioeconomic, or education backgrounds can contribute to socially constructing a similar local moral world in the way these decisions are valued.

Though there is research looking at how poverty affects rational choice decision making in taking risks, such as in ways time discounting can be affected, there is no research looking at how some of these effects can pervade into the way QALY/DALYs are approached in developing countries. This could be due to the fact that there is not enough research looking at baselines of certain disease states in the developed world to begin with or that there is not as clear a "ground truth" as there would be in the rational choice model, but having a better anthropological and psychological basis of looking at how poverty affects perception of health outcome risks would be very interesting. This would depend strongly on the type of health risks that are being studied and what the background literature of that specific topic looks like.

Another aspect of value that is presented is looking at the way the choices are then presented. In the article, the example results display only the expected values of the payoffs in terms of life years, QALYs, and patient costs. For example, looking at the QALYs for two treatments, Warfarin and ASA, the QALYs are 15 years and 12 months and 15 years and 10 months, respectively. However, a patient would not know exactly what to do with this information—whether there is even a significant difference between those two months of time and what it would mean fifteen years later. It would be important to find a way to display this

information as informatively and as trustworthily as possible, potentially by revealing some of the calculations that were involved in a deeper level. In the end, straying from the completely rational choice model of risk taking and adopting a more cultural theory based perception of risk, having the decision process for the risk making spelled out might be more useful for the individual than the final expected utility that is a result of purely numerical cost/benefit calculations. The application designed should have more content than is presented in this example.

However, this brings up the question of how effective a QALY or a DALY would be given its limitations on generalizing valuations and discounting of time. With some conditions, specifically chronic conditions, QALYs and DALYs have been shown to be useful. But looking at some of the criticisms of the time discounting and QALYs/DALYs, it would be important to make sure that all of these concerns are addressed and ironed out. For example, looking at the concern of the idea that time discounting does not tell the full story, it would be important to measure other types of factors that could contribute to the depreciation of value of life, such as the social and cultural context, and include these variables in the calculation of the costs. Another option could be to try to use an alternative method of value calculation, but few potentials have been well highlighted and documented in that realm. Perhaps looking at the decision process of the individuals could help create a new type of risk evaluation strategy that does not fully rely on rational choice calculations. And the software would reflect this and help guide individuals who want to make choices based on this framework.

And one of the most important questions that is not to be forgotten is the trust that is place in the source of the information or the ramifications of social capital and social dynamics that are being presented. One issue to be aware of in terms of trust is the trust component in human-computer interactions. There have been mixed results in terms of human trust of computer agents, looking at the competence, benevolence, and integrity of online recommendation agents (Burgoon et al., 2000). However, it is found that having computer agents become more relational, through anthropomorphic face-to-face interfaces or social dialogue, help increase the trust that the humans have for agents with "human characteristics" (Wang and Benbasat, 2005; Bickmore and

Cassell, 2001). This can be balanced with the computer's ability to act with a sense of professionalism—dependably, securely, and reliably—allowing the human trust the information and suggestions presented by the computer (Grandison and Sloman, 2001).

Another consideration is the idea of trust and the authority from which it is presented. One possibility is to have the context in which the information is presented be one of trust. Employing community health workers as the main means of distributing information that has to do with high risk rather than doctors or hospital administrators could be a good place to start. Community health workers are individuals who are selected from their communities to serve as health liaisons, and could therefore potentially present the information in a way that would be culturally-sensitive in context and in content (1millionhealthworkers.org, 2014). It is shown that community health workers can help the patient-provider relationship by contributing respect, which could have roots in the leveraging of the social capital of their position in the community. Additionally, by exciting important members of the community, this can have the effect of collective action (Gilson et al., 2005).

V. Implementation

Through this project, I hope that the flexibility of adaptive user interface software can allow for presentation of health risk information that is more applicable for different contexts of global health and global development. The design suggestions presented above present a theoretical framework based on development and health economics, public health, human-computer interaction, anthropology, sociology, and psychology for thinking about computer-based presentation of health risk information in developing countries. However, since most of the research presented is fairly abstracted and general, before this can all be implemented in actual software design, a context-specific investigation of a few more specifics must be conducted.

By conducting a few semi-structured interviews and participant observations with health officials, doctors or other caregivers, and patients in Abu Dhabi and Accra, I hope to get a better sense of the types of health risk information that is being conveyed, the workflow in which healthcare is operated, and some of the problems that may be faced. Having a better sense of the specific health problem can help direct the specificity of the background research into the types of value measurements—whether QALYs/DALYs would be the right measurements, if there have been past studies looking different health outcome valuations, what other cultural and social influences can affect these valuations, or if there is enough data to determine the development and health economics overlap mentioned earlier. And this would help determine the exact way in which the value and time dimensions are investigated in terms of risk presentation.

Potential areas of focus include the risks associated medication compliance or antenatal care. For example, looking at medication compliance, this is an issue across many different contexts, including developed as well as developing countries. However, there could be different approaches to expressing the risk associated with it. Starting with the time in which the medication is subscribed, perhaps an interesting approach would be one similar to MobiGuide in allowing patients to choose their specific treatment or at least getting a better sense of the decision making process behind each of the choices. Or having a more educational component associated

with the onset of medication prescription so that the patient has a sense of why it is important to take the medicine and what benefits or costs are associated with it. Another option would be an educational message later on in the course of medication, such as reminder to take the medication with a warning of the risks of not taking the medication on a given day, presented in a context specific way. It would be interesting to see what types of statistics are more effective—for example looking at the effects of stopping the drug regimen on individual health in the context of getting worse health or on population health perhaps in terms of drug resistance. This would rely on the specific type of disease or disorder as well as the medication available.

And having a better sense of the context, the workflow around this information distribution can help identify some of the specific problems that are being faced in the system, even within the scope of the framework being presented for this project. In general, when working with international development and global health, knowing the workflow and working within the system can help develop a solution that is innovative and impactful, but still useful and sustainable in a constructive manner. More specifically, it would be important to know by whom health risks are being presented—whether it is by doctors, community health workers, or no one at the moment—as well as the means—by mobile phone, computer, pamphlets, or word of mouth. With regards to the means of information spread, it would be especially important to understand what resources are available—if using computers and technology would be the best way to display or convey information, or would it be more trustworthy and effective to use "low-tech" means of communication. For example, the approach would be different if there are billboards or newspapers of some sort of community-wide information distribution compared to SMS or individualized messaging system. This would be especially important to work within the system for the trust dimension of risk presentation.

The background research done up until this point show that there is a case for not only more effectively presenting health risks in developing countries, but also doing so using flexible and adaptable interfaces. There has been research in the separate domains, looking at decision making in developing countries as well as for health risks, but few do so in an integrated manner.

Additionally, most of the decision making and risk taking paradigms are based in the field of economics and rational choice theory. It would be important to include other theories associated with social sciences that truly shape the more culturally based approach to making decisions.

By increasing communication, I hope that healthcare in the future will be less about the clash of cultures, as seen in in many examples, including that of Raymond and David in Tara's story. Rather, healthcare will be more about the synergy of cultures working together to more constructively provide this human right to more individuals all over the world. With more communication, all the actors involved in a health decision and in healthcare overall can get a better sense of where the others are coming from and what basis of risk perception they have for making their choices. And I hope this can turn into educated discourse where all participants can have better understanding and feel comfortable making their choices.

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