

# **Topics on the Implementation of Health Technology**

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## **ABSTRACT**

In this thesis I include work that addresses three different stages of health technology implementation and policy.

In chapter 2, I analyze policy implementation limitations that hinder the adoption of Electronic Health Records (EHR). As more hospitals adopt EHR, focus has shifted to how these records can be used to improve patient care. One barrier to this improvement is limited information exchange between providers. In this work I examine the role of EHR vendors, hypothesizing that vendors strategically control the exchange of clinical care summaries. My findings show that the likelihood of a hospital exchanging clinical summaries with hospitals outside its health system increases as the percentage of hospitals with the same EHR vendor in the region increases. When reviewing the relationship of vendor market concentration at the state level I find a positive significant relationship with the percentage of hospitals that share clinical care summaries within a state. However, I find no significant impact from state policies designed to incentivize information exchange through the State Health Information Exchange Cooperative Program. In order to avoid closed networks that foreclose some hospitals, it is important that future regulation attempt to be more inclusive of hospitals that do not use large vendors and are therefore unable to use proprietary methods for exchange.

Chapter 3 explores the mental models of patients and how it may affect the implementation of tools to enhance adherence to Antiretroviral Therapy (ART). High levels of adherence to ART are necessary to prevent the emergence of drug-resistant HIV virus and delay disease progression. For this reason, a number of interventions have been designed to support adherence for people living with HIV (PLWH). However, widely used adherence interventions, though successful for some populations, still fail certain vulnerable groups. The mental model approach allows us to go beyond current decision-making models to understand context specific aspects of behavior most relevant to this group. I interview nine high-risk non-adherents and compare their mental models to non-adherence models as seen by experts. In this study I identified how scarcity conditions and the several ways in which adhering to ARVs induces negative



affect can influence the cost-benefit analysis that decision makers engage in when deciding to take their medication. Further work needs to be done to understand the prevalence of this decision-making biases in order to design more inclusive interventions.

Chapter 4 explores the use of future self interventions (FSI) and the possible unintended consequences of their use in health decision making due to negative perceptions of aging. Many leading causes of mortality and morbidity in developed countries stem from health risk factors that are influenced by individual choices. Improving decision makers' understanding of how benefits will accrue to themselves in the future could inform health choices over their lifespan. However, negative attitudes toward aging related to the view of declining health or illness during this period could be uniquely relevant when the decision maker determines the utility of future health. The goal of this study is to examine how the relationships between future self connection generated by FSI along with expectations of aging and aging anxiety influence the anticipated valuation of future health. Participants between the ages of 18 and 45 were recruited via Amazon's Mechanical Turk. They were then assigned to participate in one of three groups of letter-writing exercises, a control, one to the self 20 years in the future and another to the 68-year-old version of the self. Our results suggest that a connection with the future aged self interacts with aging anxiety in ways that decrease the value a decision maker assesses to future quality of life. As we expected, we found that a positive effect of expectations regarding aging, however, this effect is lower for those in the intervention group who were tasked with writing a letter to a far-off future self. Furthermore, we find that anticipated health utility has a negative effect on the health discount rate. This study provides evidence that there are unique characteristics of aging that may impact future health valuation which should be considered before using FSI to incentivize future oriented health behavior.

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## **LIST OF ABBREVIATIONS**

### **CHAPTER TWO**

EHR	Electronic Health Record
HRR	Hospital Referral Region
HITECH	Health Information Technology for Economic and Clinical Health
MU	Meaningful Use
CCR	Continuity of Care Record
CCD	Continuity of Care Document
HHI	Herfindahl-Hirschman Index
AHA	American Hospital Association
HIMSS	Healthcare Information and Management Systems Society
IDS	Integrated Delivery System
CMS	Centers for Medicare and Medicaid Services
ONC	Office of the National Coordinator for Health Information Technology
IE	Information Exchange
VMS	Vendor Market Share
RHIO	Regional Health Information Organizations

### **CHAPTER 3**

ART	Antiretroviral Therapy
MM	Mental Models
HIV	Human Immunodeficiency Virus
PLWH	People Living with HIV
PrEP	Pre-Exposure Prophylaxis

PHV            Positive Health Clinic

#### **CHAPTER 4**

FSI            Future Self Interventions

FSC            Future Self Connection

AHU           Anticipated Health Utility

BHU           Baseline Health Utility

PROMIS      Patient-Reported Outcomes Measurement Information System

PROPr        PROMIS-Preference

HDR           Health Discount Rate

MDR           Monetary Discount Rate

ERA           Expectations Regarding Aging

ANX           Aging Anxiety/Anxiety about Aging

LOC           Locus of Control

PREV          Preventive Health Measure



## **1. Introduction**

The rapid increase of information technology and technological devices has been seen as a great opportunity for substantial improvements in healthcare provision and health outcomes. In fact, healthcare providers are increasingly incorporating these tools in their practices and policy makers are developing policies to incentivize their use. However, as our health system becomes progressively digitized (1) and novel persuasive technology tools are incorporated in patient treatment (2), it has become evident that there several limitations which we must overcome in order to fulfill the promise of technological innovation and health (3).

First, it is important to understand the existing incentives in place for the current healthcare market and how technology adoption can be hindered by these incentives. Additionally, although the goal of several of these tools is behavioral change, their success may be limited for specific populations or by contextual circumstances. Finally, while some information and technological tools have been successfully used for other areas of human behavior, it is important to understand the nuances of health behavior in order to be able to effectively use and incorporate these in healthcare provision.

The papers included in this thesis use three different methods to further inform these issues. For the first paper, I examine policy incentives for the adoption of Electronic Health Records and how the existing vendor market impacts the successful implementation of interoperable systems. Interoperable systems ensure that electronic health information can be used and exchanged without any special effort from the sender or receiver through the use of a common language. Without interoperable

systems, the full potential benefits of adopting Electronic Health Records cannot be achieved. Furthermore, interoperability is an intended policy objective of the Federal Government's monetary incentives assigned to hospitals and medical practices (4). I use statistical analysis of the reported interoperability outcomes of hospitals and determine market factors that impede complete interoperability.

In my second paper, I study a specific population, ART non-adherent HIV+ patients, and how their mental models affect the successful implementation of adherence aids currently used in clinical practice. Several types of interventions have been used to try to address the problem of non-adherence among HIV+ patients, and some have produced small but significant effects. However, these tools are unable to help certain vulnerable populations who are often facing unique psychosocial challenges. For this purpose, I use qualitative methods to determine the mental models of this population. The goal of this work is to identify different issues that are specific to this group so that they may be better addressed by current and new adherence interventions.

For the final paper, I review how future self interventions, used previously to incentivize future oriented behavior in savings for retirement and procrastination, may impact health choices differently. I use experimental methods to examine how perceptions of aging affect health valuation, and how this interacts with interventions that may bring the decision maker closer to the aged version of the self, such as virtual reality representations used in future self interventions. I then use statistical methods to determine the significance of this interactions.

Hence, the methods used in this thesis address the implementation of health technology tools in three phases. I examine policy incentives for the use of a tool with a stated goal and how existing market conditions may limit the achievement of this goal. Next, I review how patients' existing mental models impact why a technology might not be incorporated successfully, proposing new areas that could be addressed in the design of these tools. Finally, I analyze how a tool that has proved useful in other areas of behavioral change may have different outcomes when used for healthcare.

## **2. Vendor of Choice and the Effectiveness of Policies to Promote Health Information Exchange**

### **2.1. Abstract**

As more hospitals adopt Electronic Health Records (EHR), focus has shifted to how these records can be used to improve patient care. One barrier to this improvement is limited information exchange between providers. In this work we examine the role of EHR vendors, hypothesizing that vendors strategically control the exchange of clinical care summaries. Their strategy may involve the creation of networks that easily exchange information between providers with the same vendor but frustrate exchange between providers with different vendors, even as both Federal and State policies attempt to incentivize exchange through a common format.

Using data from the 2013 American Hospital Association's Information Technology Supplement, we examine the relationship between a hospital's decision to share clinical care summaries outside of their network and EHR vendor market share, measured by the percentage of hospitals that have the same vendor in a Hospital Referral Region. Our findings show that the likelihood of a hospital exchanging clinical summaries with hospitals outside its health system increases as the percentage of hospitals with the same EHR vendor in the region increases. The estimated odds of a hospital sharing clinical care summaries outside their system is 5.4 (95% CI, 3.29-8.80) times greater if all hospitals in the Hospital Referral Region use the same EHR Vendor than the corresponding odds for a hospital in an area with no hospitals using the same EHR Vendor.

When reviewing the relationship of vendor market concentration at the state level we find a positive significant relationship with the percentage of hospitals that share clinical care summaries within a state. We find no significant impact from state policies designed to incentivize information exchange through the State Health Information Exchange Cooperative Program. There are benefits to exchanging using proprietary methods that are strengthened when the vendors are more concentrated. In order to avoid closed networks that foreclose some hospitals, it is important that future regulation attempt to be more inclusive of hospitals that do not use large vendors and are therefore unable to use proprietary methods for exchange.

## **2.2. Background**

Exchange of health information through interoperable systems is an essential goal as providers transition from hard to digital copies of medical records (4). Interoperable systems ensure that electronic health information can be used and exchanged without any special effort from the sender or receiver through the use of a common language (5). Without interoperable systems, the full potential benefits of adopting Electronic Health Records cannot be achieved (6).

The Health Information Technology for Economic and Clinical Health (HITECH) Act enacted in 2009 (7), and the associated State Health Information Exchange Cooperative Program (8), provide monetary incentives to eligible providers and hospitals to support the adoption of EHRs and health information exchange. To receive these incentives, hospitals and physicians must meet usability criteria also known as meaningful use (MU) objectives (core and menu) that ensure EHRs are used to support

health policy priorities (9). EHR products that are purchased through the Meaningful Use incentives are certified by the Department of Health and Human Services (10). While certification criteria changed the supply side of the EHR market, the stated incentives allowed for a greater demand for EHR certified products (11).

A core objective of Meaningful Use's second stage is the exchange of clinical summaries when patients transition between providers. Until the year 2014, certification requirements stated that both the Continuity of Care Record (CCR) and the Continuity of Care Document (CCD) standardized formats could be used for said exchange (12). Current regulation, published in 2015, requires that vendors demonstrate that they are able to use the second version of the Consolidated Clinical Document Architecture (C-CDA 2.1) markup standard. Aside from the format standard, MU incentives foster an open approach to health information exchange, allowing for direct exchange among EHR vendors as well as enterprise and community solutions (13).

Despite these efforts to promote interoperability and meaningful use, information exchange has remained below expectations set by HITECH (4, 14, 15). Qualitative and quantitative studies identify several operational and economic barriers to health information exchange. Qualitative studies have found that operational barriers include the use of information as a competitive advantage, lack of cost-efficiency, limited incentives for staff and diminished trust of other providers (16–18). Quantitative studies have shown that certain hospital characteristics are related to the probability that hospitals exchange health information with other hospitals. For example, Adler-Milstein and Jha (19) found that hospitals with a larger market share within a region were more

likely to participate in information exchange but that hospitals in competitive markets were less likely to share information. Furthermore, Miller and Tucker (20) found that hospitals that are part of larger health systems are less likely to exchange information with hospitals outside their system. In sum, several studies find that information exchange is a function of a hospital's strategic reasons for sharing (19–23).

Although most research has looked at the characteristics of hospitals associated with information exchange, recently more focus has been directed toward vendors and how they may also use information exchange strategically (24). While EHR products must be capable of transforming from proprietary architectures to the semantics and structure used in CCR or CCD formats at least once during the certification process, there are still reports of both cost and technical barriers for the process of exchanging clinical care summaries (25, 26). Hence, EHR vendors could knowingly and unjustifiably interfere with health information exchange by engaging in what is known as information blocking (24).

We hypothesize that vendors can leverage proprietary software to make it easier for hospitals to share clinical care summaries with other hospitals that have the same software while making it challenging to share with hospitals that use a different EHR vendor. This imposes costs on hospitals that need to share information and creates an incentive for them to adopt the dominant vendor. Specifically, research has shown that hospitals that use dominant vendors likely face fewer technical obstacles and engage in a higher number of HIE activities (27).

Empirical work in other domains supports this. For example, Shapiro and Varian find that there are network externality benefits to being connected to a larger communication network (28). The value of connecting to a network depends on the number of others that are already connected, which means that from the perspective of a user, being connected to a bigger network is better (28). When an EHR vendor has a large closed network, in this case a large number of hospitals that use its product, a user will have an easier time sharing information. This creates a competitive advantage for the EHR vendor that provides the closed network.

Even if policy incentivizes the exchange of clinical care summaries, there is significant variation in the use of HIE across EHR vendors. Some vendors have been at the forefront by facilitating exchange through private proprietary networks. The most prominent of these networks is Care Everywhere, a system incorporated into EPIC EHR products since 2005 (29). Although Care Everywhere is meant to be able to connect to EHR systems from other vendors, it is most successfully used to connect with other EPIC users (30). Additionally, connection even within the Care Everywhere network may require additional customization (31).

The present study aims to identify the effect of vendor choice and vendor network size on whether a hospital reports participating in the exchange of clinical care summaries. As a measure of the size of an EHR vendor's network we will use EHR vendor market share and market concentration. We hypothesize that *the probability of a hospital engaging in the exchange of clinical care summaries with another hospital*



*outside its health systems is associated with the market share of the EHR vendor in the immediate region where exchanges are more likely to occur.*

To determine this association, we use a logistic regression model at the hospital level using the response from each provider about whether they exchange clinical care summaries outside of their system as a dependent variable. EHR vendor market share is measured by the percentage of hospitals that have the same vendor in the hospital referral region (HRR) where a hospital operates. These regions, or markets for tertiary medical care, consolidate zip codes where the majority of patients are referred to a specific hospital for cardiovascular surgery and neurosurgery (32). We expect that in HRRs where intra-vendor sharing occurs the probability of a hospital engaging in information exchange increases as the market share of this hospital's EHR vendor increases. This effect is due to the increase of the number of opportunities to engage in intra-vendor exchange. We also test for differences that might be unique to large EHR vendors that have established proprietary information networks, such as EPIC, by testing the different interactions in logistic regressions for the three largest EHR vendors.

A second analysis is done at the state level. The aim of this second model is to further analyze the propensity to share in the context of state level policies that incentivize health information exchange. Our hypothesis is that a higher EHR vendor market concentration, measured by the Herfindahl-Hirschman Index (HHI), is associated with a positive change in the percentage of hospitals that participate in information exchange within each state. We also expect to find differences in the

propensity of this exchange depending on the strategies adopted by each state to incentivize HIE.

## **2.3. Methods**

### **2.3.1. Data**

We use data from the 2013 American Hospital Association (AHA) Annual Survey Information Technology Supplement. The survey was distributed between November 2013 and February 2014 to the Chief Executive Officers of U.S. Hospitals, who in turn may delegate the responsibility of completion to the institution's qualified IT personnel. The survey had a response rate for non-federal acute care hospitals of 61% (2,737/4,451 hospitals). For our first model we drop 311 hospitals that are not able to generate summary of care records for transitions of care. We also remove the hospitals for which we have no information relevant to our main variables of analysis (electronically exchange clinical care summaries, EHR vendor, use of common format and ability to exchange with other EHR vendors). Finally, we drop regions with less than three hospitals and are left with a sample of 1871 acute care hospitals. Detailed characteristics of our final sample are included in the Additional Files used in the logistic regression. At the state level we aggregate the data from this survey to create indicators for the percentage of hospitals that participate in HIE exchange and the prevalence of EHR vendors in each state.

Additionally, we use data from the Healthcare Information and Management Systems Society (HIMSS) Analytics Database for the year 2012, which compiles data

on the Information Technology capabilities for 5,467 hospitals. From this database we extracted each hospital's affiliation to an Integrated Delivery System (IDS). An IDS is a healthcare organization that owns at least two medical/surgical hospitals. In this analysis we will refer to an IDS as a health system. We also use reports from the Centers for Medicare and Medicaid Services (CMS) that detail the EHR Products used for meaningful use attestation by eligible hospitals. Finally, we use reports from the Office of the National Coordinator for Health Information Technology (ONC) on the status of the State HIE Cooperative Agreement Programs in 2013.

### **2.3.2. Measures**

#### **Dependent Variables**

##### *Information Exchange (IE) and Percent of Hospitals that Exchange Information (%IE)*

We use information exchange as our dependent variable, operationalized as the yes/no answers found in the AHA IT supplement database to questions about whether each hospital electronically exchanges/shares patient information such as laboratory results, medication history, radiology reports, and clinical care summaries with providers outside their health system. We use the exchange of clinical summaries during transitions of care, which is the requirement for Stage 2 meaningful use compliance, coded as one or zero for yes and no, respectively. According to the ONC, a clinical care summary includes basic clinical information regarding the care provided, such as medications, upcoming appointments, or other instructions. It is shared with patients and clinicians in order to increase awareness of what occurred during office visits and can be used to

assist care coordination. This variable was used to determine a hospital's indication of health information exchange (*IE*) and was also aggregated to determine the percentage of hospitals that answered positively to sharing within a state (*%IE*), using as a denominator the number of hospitals on the final sample (a total of 2,296 hospitals).

#### *Vendor Market Share (VMS)*

To operationalize vendor market share, we used data from the AHA IT supplement database that requested the name of the hospital's primary outpatient EHR/EMR tool. This data was checked and complemented with data from the CMS Meaningful Use Attestation database, which has information on the outpatient EHR product used by eligible hospitals that participate in the MU program. The indicator for EHR vendor market share (*VMS*) for each hospital was calculated by determining the percentage of hospitals within a Hospital Referral Region that use the same EHR vendor as the subject hospital.

#### *State EHR Vendor HHI (VendorHHI)*

To determine the EHR vendor market concentration in a state we use the Herfindahl-Hirschman Index (HHI), the standard measure used by the U.S. Department of Justice to determine market concentration (33). This indicator measures market concentration using the relative size of the market share and distribution of the firms in a market (33). For our analysis we define market share as the number of final users (patients) that will use a specific EHR Vendor. As a proxy for the number of patients we use the number of beds in each hospital, giving more weight to larger hospitals. We then calculate the

HHI index by squaring the percentage share of beds for each EHR Vendor at the state level (**VendorHHI**).

### **Hospital-Level Variables**

Other potential explanatory variables are extracted from the AHA IT Supplement database. We use an indicator for a hospital's capability to send clinical summary of care records in one of three formats (**CL**): Continuous Care Record (CCR), Clinical Document Architecture (CDA) or Continuous Care Documentation (CCD). Also included is a variable that asks if the hospital's EHR allows sending clinical care summaries to unaffiliated hospitals using a different EHR vendor (**CS**).

Other hospital descriptive indicators, which have been found significant in the literature, such as hospital size (**Size**) (20), ownership (**Ownership**), rural or urban location (**Rural**) and hospital HHI (19), are also included. Hospital HHI (**HospitalHHI**) at the regional level is calculated by weighting hospital market participation in an HRR with hospital size, using total beds as a proxy. To determine health system affiliation, we used the IDS indicator from the HIMSS analytics database and included a dummy variable that indicates if there is more than one hospital from the same health system in the HRR (**System Hospital**). The aim of this last indicator is to account for different sharing policies between hospitals that are part of the same system and are in the same region. Finally, we used dummy variables for the largest three EHR Vendors: Epic, Meditech and Cerner. We test the efficacy of state programs to encourage HIE by adding dummy variables indicating the availability (**RHIO**) and use (**RHIO<sub>PART</sub>**) of Regional Health Information Organizations (RHIO), organizations that bring together

health care stakeholders within a defined geographic area and govern health information exchange among them (34).

### **State-level Variables**

Information on the models used by states for information exchange was extracted from the ONC progress report on the State HIE Cooperative Agreement Program (35). We coded variables on the availability of Direct and Query exchange if the state reported that each type of exchange was “broadly available”. Broadly available types of exchange include Directed Exchange (point-to-point secure communication) and Query-based Exchange (pull transactions through a request) (36). We also coded variables for the strategic approaches each state used to encourage information exchange, including four categories Elevator (rapid facilitator of Directed Exchange), Capacity Builder (assists regional exchanges through financial and technical support), Orchestrator (state level network to connect regional exchanges) and Public Utility (provides HIE services directly) (37).

Using the IDS indicator from the HIMSS analytics database we calculated an HHI index for Health Systems in a State (***SystemHHI***) also weighted by hospital beds. We also included a variable for the number of beds in a State (***HospitalsState***).

### **2.3.3. Analyses**

To determine the relationship between the probability of a hospital engaging in information exchange and EHR Vendor market share we used a logistic regression model. The basic bivariate model between the dependent variable Information

Exchange (**IE**) and our variable of interest Vendor Market Share (**VMS**) Concentration is represented by **Equation 2.1**.

$$\text{logit}(IE|VMS) = \log\left(\frac{P(IE|VMS)}{1-P(IE|VMS)}\right) = \beta_0 + \beta_1 * VMS \quad (\text{Equation 2.1})$$

$$p(IE|VMS) = \text{logistic equation}$$

We then added other explanatory variables found in the literature to reduce possible omitted variable bias **Equation 2.2**.

$$\log\left(\frac{\hat{p}(x)}{1-\hat{p}(x)}\right) = \hat{\eta}(IE) \quad (\text{Equation 2.2})$$

$$\begin{aligned} \hat{\eta}(IE) = & \hat{\beta}_0 + \hat{\beta}_1 * VMS + \hat{\beta}_2 * CL + \hat{\beta}_3 * CS + \hat{\beta}_4 * RHIO + \hat{\beta}_5 * RHIO_{PART} + \hat{\beta}_6 \\ & * Ownership + \hat{\beta}_7 * Rural + \hat{\beta}_8 * Size + \hat{\beta}_9 * System Hospital + \hat{\beta}_{10} \\ & * HospitalHHI + \varepsilon \end{aligned}$$

We also include state fixed effects to control for local characteristics that might impact information exchange and analyzed the characteristics for the largest market players by including dummy variables.

For our second analysis we looked for an association between vendor concentration and the percentage of hospitals that exchange clinical care summaries within a state. To test this association, we used a multivariate linear regression model represented by **Equation 2.3**.

$$\%IE = \hat{\beta}_0 + \hat{\beta}_1 VendorHHI + \hat{\beta}_2 SystemHHI + \hat{\beta}_3 HospitalsState + \varepsilon \quad (\text{Equation 2.3})$$

To this model we added dummy variable indicators for state level policies to incentivize health information exchange.

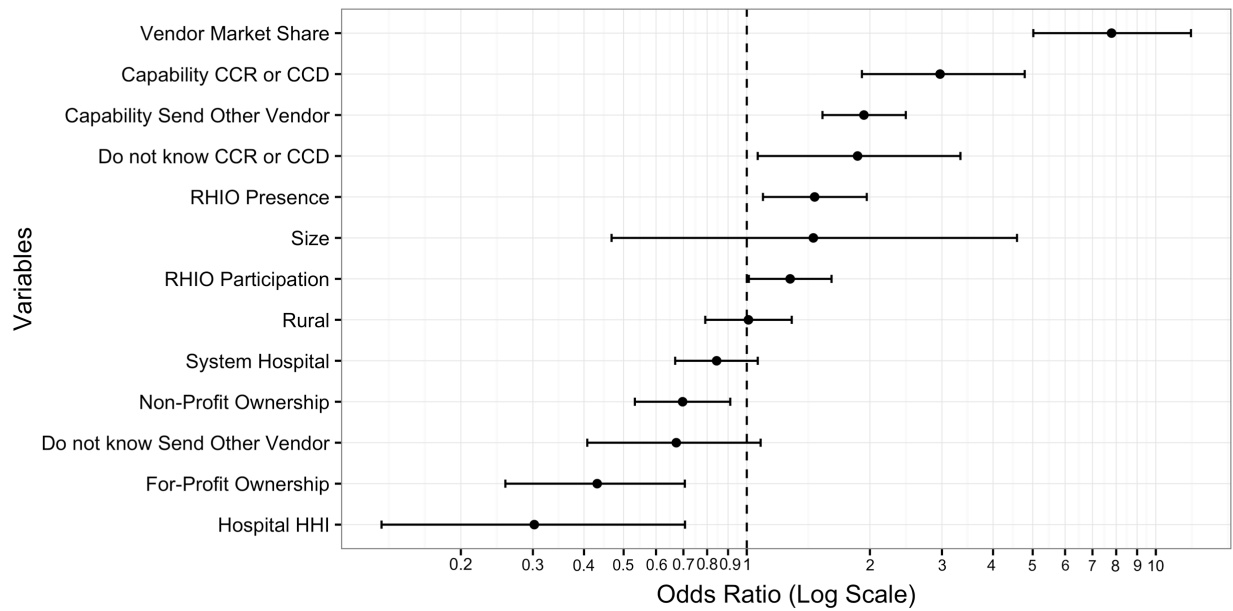
## 2.4. Results

### 2.4.1. Vendor Market Share and Hospital Information Exchange

#### Logistic Hospital Level Regression

We find that for our 2013 dataset there was a positive relationship between the likelihood of sharing and a hospital's EHR vendor market share within an HRR. A graphic representation of the logistic regression results can be seen in **Figure 2.1**, which presents the odds ratio results of the logistic regression with error bars representing a 95% confidence interval. Additionally, in an effort to control for the different state level characteristics that might influence the likelihood of hospital sharing we used a state fixed effects (**Table 2.1**) again finding the same positive relationship between VMS and information exchange. The location of the hospital was determined by the provided zip code address as HRRs are regions of service provision and therefore are not always within state boundaries.





**Figure 2.1** Odds Ratio for Independent Variables Predicting Probability that a Hospital “Shares Clinical Care Summary Outside their Health System” with error bars for a 95% interval

When we control for State fixed effects, the estimated odds of a hospital sharing clinical care summaries outside their system is 5.4 times greater if all hospitals in the HRR use the same EHR Vendor than the corresponding odds for a hospital in an area with no hospitals using the same EHR Vendor. We include dummy variables for the ability to send documents in CCR or CCD format, if an EHR system allows for sending summary of care records to another EHR vendor and the availability of RHIOs. These three variables are significant in increasing the likelihood of sharing clinical summaries; nevertheless, the effect of Vendor Concentration remains large in comparison.

The results remain stable as we include other control variables that have been found relevant in the literature such as ownership (non-profit versus for-profit), rural versus urban location, normalized hospital size, hospital market concentration, and

system affiliation. Of these only rural status and system affiliation were not statistically significant.

For-profit hospitals are found to be less likely to share information, which is consistent with the results found by Adler-Milstein and Jha (19) who hypothesize that a hospital's strategic decision not to participate in information exchange is an effort to minimize costs. We also find that the measure of hospital market concentration is negatively related to the probability of participating in the exchange of clinical care summaries, which suggests that hospitals in more concentrated markets are less likely to exchange information.

**Table 2.1** Adjusted Odds Ratio for Hospitals with Dependent Variable “Shares Clinical Care Summary Outside their Health System” with State Fixed Effects

Variables	Hospital Shares Clinical Summary	
	Odds Ratio	95% Confidence Interval
Vendor Market Share	5.37***	(3.29, 8.80)
CCR or CCD (YES)	3.19***	(2.00, 5.27)
Allow other EHR Vendor (YES)	1.90***	(1.47, 2.45)
RHIO	1.23	(0.90, 1.67)
RHIO Participation	1.56***	(1.19, 2.04)
Non-Profit Ownership	0.69**	(0.51, 0.94)
For-Profit Ownership	0.57**	(0.33, 0.96)
Rural	0.84	(0.63, 1.11)
Number of Beds	3.28*	(0.94, 11.6)
System Hospital	0.87	(0.68, 1.11)
Hospital HHI	0.62	(0.23, 1.67)
<i>Note:</i>		
*p<0.1; **p<0.05; ***p<0.01		

#### 2.4.2. Differences Between Specific Vendors

Three EHR vendors, Epic, Meditech and Cerner, together control 58% of the hospital market in our sample data. Of the pool of non-federal acute hospitals that responded to the survey question, 39% had shared clinical care summaries with outside hospitals. We find that hospitals that use Epic exchange clinical care summaries significantly more than the total average, while hospitals that use Meditech or Cerner do so significantly less (**Table 2.2**). The type of hospitals that chose a specific vendor also varies between the different EHR vendors. Our results from the logistic regression show that hospital size is positively related to information exchange while being a For-Profit hospital is negatively related to this variable. In **table 2.3** we see that hospitals that use Epic as their EHR vendor are significantly larger and less likely to have a For-Profit ownership model. This is consistent with being more likely to share information. The opposite is true for hospitals that use Meditech, which are significantly less likely to be large and more likely to be For-Profit.

**Table 2.2** Percent of Hospitals that Share Clinical Care Summaries Outside their Health System for the Seven Largest Vendors

Vendor	% Share Clinical Care Summary	n(N)	p value* (two-tailed)
EPIC	73%	296(407)	p<0.01
Meditech	27%	97(360)	p<0.01
Cerner Corporation	32%	109(338)	p<0.01
McKesson	30%	58(191)	p<0.01
CPSI	30%	48(160)	p<0.05
Siemens	40%	41(102)	
Allscripts	26%	19(74)	p<0.05

*Note:*

\* Using t-test for equality of means

n = Number of hospitals that share clinical care summaries with hospitals outside their system

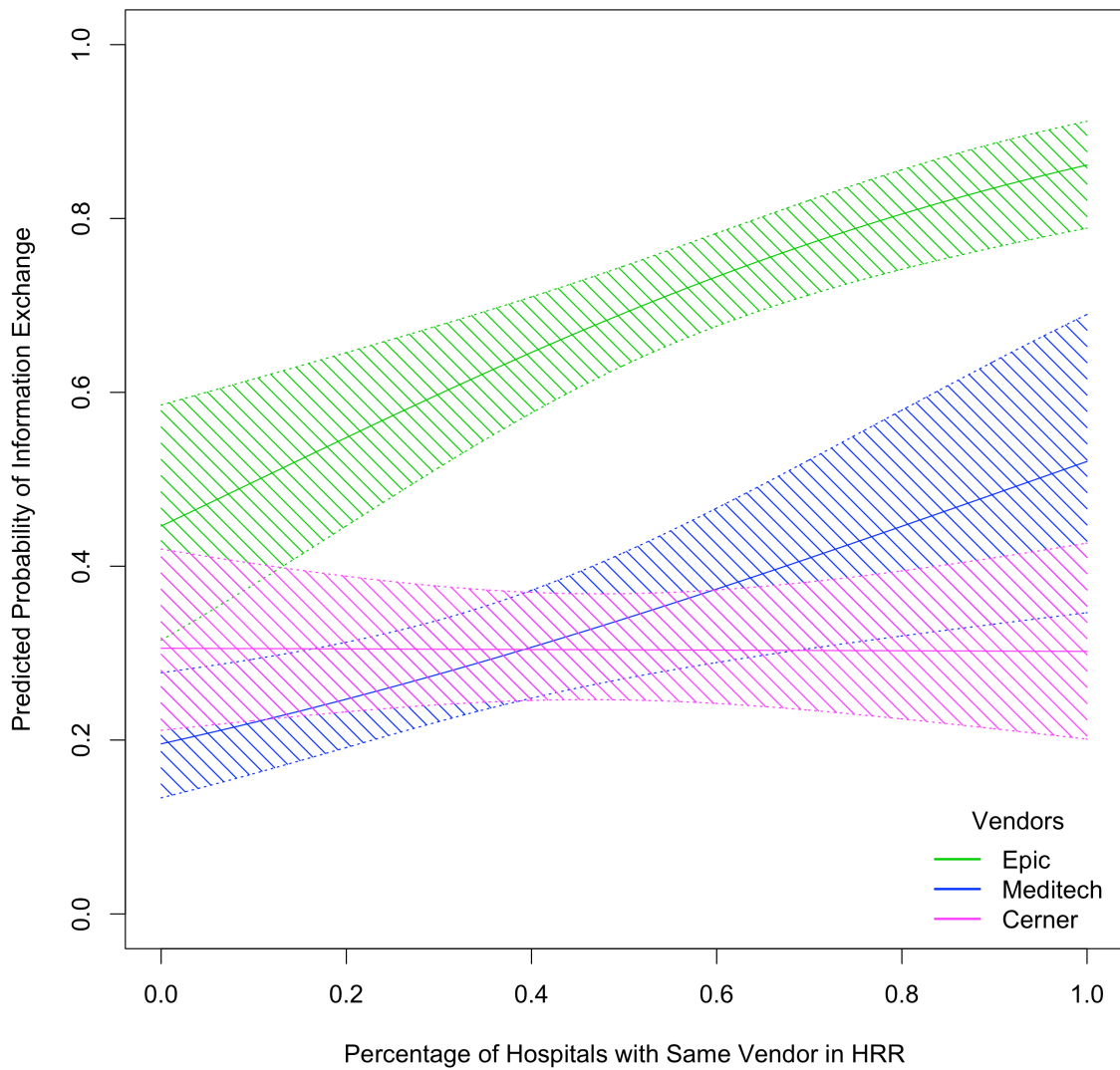
N = Total number of hospitals that use each EHR Vendor included in the database and that responded to the variable of analysis

**Table 2.3** Differences in Hospital Characteristics of Hospitals for Epic, Meditech and Cerner

		All EHR Vendors N=1871	EPIC N=407	Meditech N=360	Cerner N=338
Hospital Size	Small (<100 beds)	47%	33% <sup>***</sup>	44%	33% <sup>***</sup>
	Medium (100-399 beds)	40%	44% <sup>*</sup>	51% <sup>***</sup>	49% <sup>***</sup>
	Large (>=400 beds)	13%	23% <sup>***</sup>	5% <sup>***</sup>	18% <sup>***</sup>
Ownership	Non-Profit	71%	88% <sup>***</sup>	69%	78% <sup>***</sup>
	For-Profit	8%	1% <sup>***</sup>	14% <sup>***</sup>	7%
	Public	21%	11% <sup>***</sup>	17% <sup>**</sup>	15% <sup>***</sup>

Note: Using t-test for equality of means the significance levels for two-tailed tests are \*p<0.1; \*\*p<0.05; \*\*\*p<0.01

We expect that these three vendors have the potential of exploiting the network effects of market concentration because of their large number of users. We ran separate regressions to test the interactions between the main EHR vendors and the variable of interest. From **Figure 2.2** we find that there are important differences in the coefficient of the key independent variable Vendor Market Share for each of the different EHR vendors. Although hospitals using Epic start with a higher predicted probability of sharing, the increase of market share in the HRR has an important positive effect. A similarly positive effect is found for hospitals using Meditech as their EHR Vendor. However, for hospitals that use Cerner find there are negative effects of having other hospitals with the same vendor in the HRR. This suggests additional non-measured difficulties in information exchange for Cerner users.



**Figure 2.2** Predicted Probability that a Hospital “Shares Clinical Care Summary Outside their Health System” for Each of the Three Largest Vendors with 95% confidence interval

### 2.4.3. Vendor Concentration at the State Level

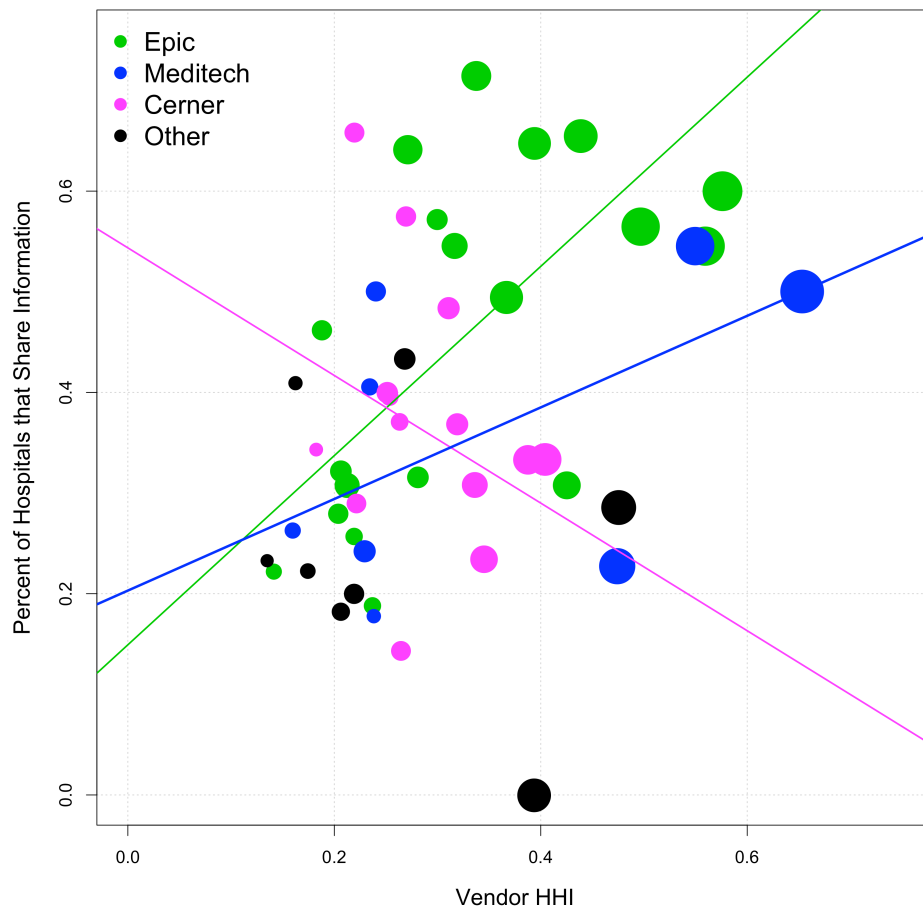
#### Percent Sharing within State and EHR Vendor Concentration

Our second analysis examines at the market dynamics of EHR vendors at the state level and state policies to incentivize information exchange. The percentage of sharing

varies widely across states, with Florida, Illinois, Missouri, New Mexico, Oklahoma, Tennessee and Texas sharing significantly less than the global mean of 37% (see Additional File). The differences across states have been attributed to factors such as state-level privacy regulation and information security practices (20, 38). Another possible explanation is the different strategic approaches for information exchange prompted by the incentives received through the State Health Information Exchange Cooperative Agreement Program. We find no support for different strategies accounting for different levels of sharing. However, this study does find that these differences could also be explained in part by differences in the market concentration of EHR Vendors across states. **Figure 2.3** shows the relationship between Vendor HHI and the total sharing within a state with different colors for the dominant vendor in each state. In this figure, the size of the point is proportional to percent market share of dominant vendor and trend lines indicate linear relationship between Vendor HHI and Percent of Hospitals that Share Information. We find that the three trend lines for each vendor mirror the relationship found at the hospital level. However, because of the smaller sample at the state level for each vendor this relationship is only statistically significant for states in which the dominant vendor is Epic.

Our results show that there is a relationship between EHR vendor concentration in a state and the percentage of hospitals that participate in the exchange of clinical care summaries within a state, **Table 2.4** column 1 shows the result of the base bivariate linear regression model. Our independent variable of interest, Vendor HHI, is positively related to the percent of hospitals that participate in information exchange

within a state. In our sample, as the market concentration of EHR Vendors in a state increases there is also an increase in the percent of hospitals that exchange clinical care summaries. This value remains significant as we include control variables such as the market concentration of hospitals within a system (column 2), the availability of Directed Exchange or Query Exchange within a state (column 3), and, the strategies used by the state as part of the State Health Information Exchange Cooperative Agreement Program (column 4).



**Figure 2.3** State Sharing versus Vendor HHI with dominant EHR vendor



**Table 2.4** State level Linear Regression with Dependent Variable “Percentage of Hospitals in State that Share Clinical Care Summaries”

	Dependent variable:			
	Percentage that Share Clinical Summary			
	(1)	(2)	(3)	(4)
Vendor HHI	0.349** (0.168)	0.657*** (0.188)	0.636*** (0.193)	0.639*** (0.202)
System HHI		-0.714** (0.242)	-0.900** (0.292)	-0.948*** (0.366)
No. of Hospitals			-0.209 (0.145)	-0.347* (0.172)
QE Statewide			-0.045 (0.048)	
DE Statewide			-0.016 (0.065)	
Elevator				0.073 (0.073)
Public Utility				0.042 (0.083)
Capacity Builder				0.116 (0.091)
Orchestrator				0.081 (0.065)
Constant	0.280*** (0.061)	0.289*** (0.058)	0.410*** (0.099)	0.308*** (0.099)
Observations	49	49	49	49
R <sup>2</sup>	0.08	0.23	0.27	0.30
Adjusted R <sup>2</sup>	0.06	0.20	0.19	0.19
Residual Std. Error	0.17 (df = 47)	0.15 (df = 46)	0.16 (df = 43)	0.16 (df = 41)
F Statistic	4.3** (df = 1; 47)	6.9*** (df = 2; 46)	3.3** (df = 5; 43)	2.6** (df = 7; 41)
Note:				*p<0.1; **p<0.05; ***p<0.01

In column 2 we see that including the System HHI variable has an effect on the marginal value of our key variable of interest. This result is consistent with the fact that hospitals within a health system are likely to use a unique vendor and that the initial

Vendor HHI effect might be related to health system concentration. Nevertheless, even correcting for this possible omitted variable bias, the Vendor HHI remains positive and significant. The negative nature of the coefficient on System HHI is consistent with previous research (20) which showed that states with larger networks dominating the market have a lower percentage of hospitals that participate in information exchange outside their health system.

## **2.5. Discussion**

Through this analysis we have found empirical evidence that, among other factors, vendor market share and concentration are related to the likelihood of a hospital sharing clinical care summaries and the percentage of hospitals within a state that exchange such information. These factors remain important even when we take into account policies that incentivize information exchange such as the requirement for the use of standardized formats (CCR, CDA and CCD) and State level programs. While the capability to use a common format to send clinical care summaries is significant in increasing the likelihood of participating in the exchange of these documents, this ability is not enough to guarantee exchange outside a hospital's network. In fact, 72% of hospitals that do not share clinical care summaries with other vendors are capable of using these common formats.

Furthermore, almost 30% of hospitals that can use CCD and CDA continue to claim that they are not capable of exchanging clinical care summaries with hospitals using a different certified EHR vendor. This supports the notion that even when EHR

systems are certified to comply with this MU requirement, exchange with outside vendors remains a challenge.

In this context, EHR vendor market share and concentration become relevant topics of analysis. Of the hospitals that exchange clinical care summaries with hospitals outside their system 23% assert that they cannot exchange with hospitals using a different EHR vendor (despite the fact that only 10% of hospital EHR systems don't support CCD or CDA exchange standards), suggesting that exchange in this subgroup is happening directly between hospitals using the same EHR vendor. Although we cannot conclude from the available data if exchange for the rest of the sample is taking place through proprietary or standards-based methods, we can presume that there are benefits to exchanging using proprietary methods that are strengthened when the vendors are more concentrated. These benefits may include reduced technical difficulty and ease of access to specific interfaces, which might remain influential even if a hospital is technically able to exchange using standard formats.

When we control for each of the three largest EHR Vendors in the market we find relevant differences in the propensity for information exchange. We analyze the interactions with these EHR vendors in our sample and find that the positive relationship between HIE and market share is very strong for hospitals that use Epic. Hospitals using EHR vendor Epic are much more likely to exchange clinical care summaries than the rest of the hospitals in our sample. Conversely, hospitals that use Meditech and Cerner are less likely to exchange this type of information. By promoting proprietary sharing, larger players strengthen the network externality benefit of choosing an EHR

from a large player. From these results we can infer that the availability of Epic's Care Everywhere has important implications for hospitals looking to participate in information exchange. In fact, Epic becomes an interesting case study for the effects of having a proprietary network for health information exchange. Our analysis shows that Epic users might overcome some of the barriers for information exchange when other hospitals in the same region use Epic. However, when there are no users nearby that use this same EHR vendor the net benefits for exchange are diminished. This suggests that when removing the incentive of a geographically close Epic user for exchange, additional customization could act as a deterrent for developing further HIE capabilities (30, 31).

Due to the competitive nature of the EHR market, a larger player such as Epic could leverage its network size by facilitating intra-vendor sharing in an effort to enlist new users interested in sharing within its existing network. Smaller practices and hospitals interested in exchanging clinical care summaries with larger hospitals that use said EHR vendor would need to join the network. The decision to choose a specific EHR product involves a lock-in factor because of the sizeable costs of implementation. Not only does this make it unlikely that smaller hospitals could then change to a different vendor, it may involve additional unforeseen costs that could discourage them from implementing usable exchange capabilities (13, 39).

We have similar results at the state level. We find that higher Vendor HHI is positively correlated with the percentage of hospitals within the state that share information, even when controlling for different policies that incentivize or hinder

information exchange. The different strategies applied through the State Health Information Exchange Cooperative Agreement Program (State HIE) do not show a significant effect on the percentage of hospitals that exchange clinical care summaries within a state. Hence, in states with highly concentrated markets measured by the Herfindahl-Hirschman Index (where one or two EHR vendors are used by the majority of the hospitals) there are more hospitals engaging in information exchange.

Part of the objective of the State HIE program was to fill HIE service gaps and build capacity for every eligible provider (8). The fulfillment of this goal could be an important contribution toward overcoming some of the limitations of vendor facilitated exchange and the possible failures of closed proprietary networks. Unfortunately, our current research shows that none of the state level strategies seem to be successful in reducing this effect. In states where there are less concentrated markets, none of the different implementations were significant in incentivizing exchange. This might be a symptom of misaligned incentives, as there have been reports of current regulation undermining the role of community health information exchanges supported by State HIE by allowing EHR vendor mediated exchange that cuts out public exchanges (13).

As more hospitals transition to the second stage of meaningful use, data from recent years shows that similar challenges for HIE persist. While the percentage of hospitals that report that they have the capability to send clinical care summaries has increased, the percentage of hospitals that send them during transitions of care remains low. Data from Meaningful Use attestations between 2014-2016 shows that a median hospital sends clinical care summaries electronically for 33 percent of transitions, while

the use of Epic as an EHR provider positively increases this probability (40).

Furthermore, qualitative work evidences that the number of EHR providers in the market, and the need for different interfaces to exchange clinical information between them, is still reported as an important barrier for HIE (13). A recent survey of third party HIE organizations supports the issues of vendor information blocking, with half of those surveyed reporting that they had experienced information blocking by an EHR vendor (41). Finally, vendor choice remains an important determinant in the successful implementation of MU objectives (14, 42).

## **2.6. Limitations**

There are some important limitations to our results. First, data from the AHA IT Supplement is self-reported and has limited representativeness with a self-selected sample of 61% of the population. While this database has been validated for reliability against other sources, it does show some bias toward over reporting (43). It also includes some responses that are inconsistent and were removed from the dataset. Both of these issues would likely result in an overestimate of our measure of interoperability. Additionally, although we aimed to include most variables relevant to our analysis, there are other factors related to health information exchange that we were not able to quantify for this analysis. For example, we are not able to measure different security or privacy policies for different vendors that might facilitate or deter information exchange. Similarly, although research has found a relationship between state privacy policies and state information exchange practices, we were not able to include a measurement of privacy legislation in this study. It is possible that including indicators

for state privacy regulation would have accounted for lower levels of information exchange. Third, we were only able to infer that EHR vendors in our analysis use proprietary methods for exchange because we do not have detailed information on the methods of information exchange for each hospital. Therefore, if a large percentage of hospitals are exchanging information through non-vendor mediated methods or regional health information exchanges, it is possible that some vendors offer an advantage for this type of sharing. Finally, all of our results show association and not causality because of the nature of the sample and the method.

## **2.7. Conclusions**

Identifying the barriers for information exchange is a necessary step to achieve the goals of the HITECH Act in creating a more efficient and effective healthcare system. Our research finds a relationship between the existence of dominant EHR networks and the exchange of clinical care summaries, which has important policy implications as the meaningful use program continues to transition to future stages. In fact, there is some evidence that information blocking could be partly the result of vague policies that undermine public exchanges.

Even though the current certification process for EHR products requires the use of a common language, there are several gaps that permit variability in its implementation. These gaps allow EHR vendors to implement information exchange capabilities in different ways. A clear example is the implementation of Care Everywhere, which has been successful in increasing sharing among Epic users. Nevertheless, the existence of isolated networks means that many hospitals are left out.

In the case of Epic, this affects smaller and rural hospitals disproportionately (only 21% of hospitals that use EHR vendor Epic are rural which is significantly less than the sample mean).

In order to avoid proprietary exchange networks that foreclose some hospitals, it is important for the current regulation attempt to be more inclusive of hospitals that do not use large vendors and are therefore unable to use proprietary methods for exchange. Incentives could be tied to open exchange using previously defined standards rather than metrics that just measure if HIE occurs. For state level incentives, it might be necessary that state programs identify hospitals that are being left out of the exchange networks and offer technical and financial support. In our analysis at the state level we find no significant relationship between the percentage of hospitals that participate in health information exchange and the policies implemented through the State Health Information Exchange Cooperative Agreement Program. Our research suggest that future state level policies should take into account the different market conditions of EHR vendors in order to accommodate hospitals that may be left out of large proprietary networks.

Finally, although our findings suggest the importance of a network where information is exchanged only among hospitals that use a specific EHR vendor within a region and a state, further research is necessary to validate this relationship. Current information collection efforts only ask if information exchange occurs. More work needs to be done to determine the methods of exchange, including interviews with hospital



staff that might give us some insight on if and why proprietary methods of exchange are being used.

### **3. Mental Models of High-Risk Non-Adherent HIV+ Patients**

#### **3.1. Abstract**

High levels of adherence to ART are necessary to prevent the emergence of drug-resistant HIV virus and delay disease progression. For this reason, a number of interventions have been designed to support adherence for people living with HIV (PLWH). However, widely used adherence interventions, though successful for some populations, still seem to fail certain vulnerable groups. The mental model approach allows us to go beyond current decision-making models to understand context specific aspects of behavior most relevant to these groups. We interview nine high-risk non-adherents and compare their mental models to non-adherence models as seen by experts. In our interviews, participants reported being in a constant state of instability and stress which resemble “scarcity” environments that have recently garnered great attention in psychology. Additionally, in defining what was important in their cost and benefit calculus, participants discussed interactions with other PLWH, family members and friends, as contributing to their understanding of the disease, using available lay information to inform their decisions. Finally, this study also identified several ways in which adhering to ARVs induces negative affect which manifests as a sense of alienation, which can have its own power and influence over a cost-benefit analysis. We suggest that the decision-making process for high-risk non-adherents may belong in its own category of study, and that the biases and heuristics identified here should be further assessed for prevalence and, if born out, addressed in future interventions.

### 3.2. Introduction

The development of antiretroviral therapy (ART) and its widespread use has led to improvements in the quality of life for people living with HIV (PLWH). Indeed, because of ART, HIV can now be managed as a chronic rather than an acute condition (44).

However, high levels of adherence are necessary to prevent the emergence of drug-resistant HIV virus and delay disease progression. Existing estimates suggest that adherence levels below 90% have clinically significant negative effects (45).

Nevertheless, for HIV+ patients in the United States, the average rate of suboptimal adherence to ART remains high (46, 47). Furthermore, a meta-analysis of several observational studies done in different settings determined that optimum adherence to ART may be as low as 62% (48). This dichotomy implies that investments on tools to improve ART adherence are a necessary and cost-efficient way to improve care for PLWH (49).

Several types of interventions have been used to try to address the problem of non-adherence among PLWH, and some have produced small but significant effects (50–52). The most widely used behavioral interventions—directly observed therapy, dosage reminder devices and cognitive therapy—have been shown to significantly increase adherence in randomized controlled trials (52–54). However, this and other interventions tend to be most effective in controlled settings (e.g., hospitals and prisons) and are often labor intensive (53–55). Moreover, and similar to the intervention limitations being recognized in the domain of HIV prevention (56), due to their application as a one-size-fits-all solution, many behavioral ART interventions do not

address the contextual, psychological and social factors (57, 58) that are critical to adherence-related behavior for PLWH. Below, we review the factors previously identified in the literature on (non) adherence, and then introduce the mental models methodology as a tool for identifying previously unexplored contextual and behavioral barriers and motivations for ART adherence.

### **3.2.1. Review of Previously Identified Barriers and Supporters of Adherence**

More than two decades of research has been conducted both nationally and internationally to identify the numerous factors associated with non-adherence to daily ART. These factors, identified mainly through observational or descriptive studies, are the basis for the design of current behavioral interventions (59). Below we review several of the most prominent ones.

To start, patient-related factors are a major category of influence (60). These include patients' medication-related beliefs and concerns, such as: doubts about the efficacy of the medication, uncertainty about its safety in the long term, and assumptions about or interpretations of how medication is affecting one's quality of life and body image (61). Similarly, self-efficacy, a patient's belief in their ability to successfully accomplish a task (62), is independently associated with ART adherence (63–65). It may also act as a mediator to other variables, such as: depression (66), lack of social support (67) and health literacy skills (68). Patient perceived stigma has also and repeatedly been correlated with medication adherence, using a variety of measures (69). Stigma is defined as the labeling of an individual as a deviation from some ideal or expectation, with this type of discredit changing the way individuals view themselves or

are viewed by others (70). Perceived stigma may affect social support (71), which itself correlates positively with ART adherence (64). Additionally, one's living conditions predict adherence. Social and medical services appear necessary for HIV positive patients who lack stability or are homeless. Indeed, controlling for other factors, one's housing situation independently correlates to ART adherence (72).

Multiple studies have demonstrated that mental health and substance abuse disorders play a role in adherence. Heavy drinking has been shown to hinder adherence, but the evidence is less conclusive for moderate levels of alcohol consumption (73). Both clinical and non-clinical depression have been found to be significantly correlated with low medication adherence (74). Patients who are cognitively impaired also have difficulty adhering to medications. Importantly, non-adherence might also cause decreases in cognitive function (75).

Patients who experience side effects or adverse clinical events often exhibit lower medication adherence (63, 76). Specifically, patients who report suffering from symptoms such as nausea, anxiety, confusion, vision problems, anorexia, insomnia, taste perversion, and abnormal fat distribution are more likely to become non-adherent (77).

Lastly, several aspects of the patient-provider relationship, such as general communication (78) and participatory decision-making (79), are correlated with adherence (80).

### 3.2.2. Goals of the Study

Two issues stood out to us as we reviewed the literature on ART adherence. First, the most widely used adherence interventions appear unable to help certain vulnerable populations facing unique psychosocial challenges. For example, for low-SES PLWH, HIV may be the least of their stressors. Instead, they may be dealing with socioeconomic scarcity, instability and mental health issues (81, 82). Additionally, or alternatively, the perceived cost-benefit calculus of adherence may be different for patients who have lived with the disease for a long period of time, since ART side effects become more prominent while HIV symptomology decreases (82).

Behavioral adherence interventions often target specific populations at higher risk of non-adherence, such as PLWH who suffer from depression, have mental impairments or are substance abusers. However, some patients may not fall neatly into one of these categories, despite being persistently low adherers or experiencing repeated episodes of non-adherence. We label these individuals as “high risk non-adherents” (59, 83), and argue that identifying the judgment and decision-making processes of people who repeatedly struggle with adherence yet continually fall between the cracks of current interventions is an important step toward creating more inclusive treatment options. Thus, in this study, the participants we identified as “high risk” non-adherents were defined by high viral load values at the time of recruitment, alongside low success rates with clinic adherence interventions.

Second, while the intervention literature recognizes a need for interventions that address or interact with “context-driven” influences on (non)adherence, we found few in-

depth studies that focused on contextually-informed behavioral factors. For instance, there is a paucity of research examining the role that scarcity- and affect-related concepts (beyond stigma) may play in the cost-benefit calculation of ART medication adherence. Given these two lacunae in the literature, our goal was to apply a behaviorally-informed qualitative approach to identifying and understanding context-driven ARV motivations and constraints facing high risk, repeatedly non-adherent PLWH.

### **3.2.3. The Mental Models Approach**

To do this, we employed the mental models methodology, a method of schema analysis from decision science often used to gather information on cognitive simplifications used for decision making, specifically context-specific decision making around risk behavior (84, 85). The aim of the method is to identify people's perception of the risks and benefits related to an issue – in this case to uncover the beliefs, attitudes, motivations and constraints related to ART and HIV associated decisions and actions (86). These ART-patient “mental models” are then compared to more formal adherence representations, also called “expert models,” which are based on scientific evidence and technical expertise, with the aim of identifying gaps that will inform future interventions. The mental model approach is characterized by systems thinking and its ability to draw from diverse social and behavioral disciplines. In the field of health, the MM method has been used to elucidate context specific adolescent sexual behavior (85), risk beliefs about mammography (87), cancer risk communication (88) and risk beliefs and attitudes

about taking a daily dosage of an HIV prevention pill called pre-exposure prophylaxis (PrEP) (89).

### **3.3. Methods**

Using the mental models (MM) approach, our goal was to identify individual and contextual barriers to adherence as well as factors that could influence motivation, such as implicit cognitions triggered by situational contexts, affective associations and heuristic biases.

#### **3.3.1. Expert Model**

We first generated a draft expert model (see Appendix 2), derived from the existing literature, to summarize current knowledge on barriers to ART adherence. The expert model was presented to and reviewed by medical staff at a nationally recognized HIV/AIDS treatment center and a Ryan White Part C provider located in Pittsburgh, PA. The clinic, which uses a harm-reduction approach to care, serves patients with demographics that match those of the national HIV epidemic in terms of substance abuse and persistent mental health disorders as well as other social determinants of health.

#### **3.3.2. High-Risk Non-Adherent Model**

To create the lay mental model, we conducted nine interviews with persistently non-adherent PLWH. Nine is a small sample size even by qualitative standards, yet this type of work offers advantages, as a relatively small sample can yield much of the value due



to the open-ended nature of the interviews (86). We thus deemed it appropriate for exploratory research meant to establish if previously unrecognized contextual and behavioral factors might influence adherence (versus demonstrating prevalence of beliefs or cognitive or psychological mechanisms). Specifically, the clinic identified and recruited HIV+ women and men in treatment, age 18-65, who had a viral load of >1000 copies at the time of recruitment and who had proven resistant to the clinic's behavioral interventions. The clinic provides a range of supportive services for PLWH, including social work support, directly-observed therapy, dosage reminders, cognitive and mental health therapy, an in-house pharmacy involved in teaching and reinforcing the importance of medication adherence, an HIV+ peer advocate, and direct supports such as transportation assistance.

### **3.3.3. Interviews**

Interviews took place between the months of March – August 2017 at the clinic. The project was approved by the Allegheny Singer Research Institute Ethics Board. Participants participated in a one-hour, semi-structured interview in which they discussed issues specific to their daily routine, important relationships, and, their beliefs and attitudes related to HIV and ART and adherence. The interviews began with open-ended questions, so that participants could use their own intuitive framing and language. Questions then became increasingly focused, to the extent that risk scenarios were posed as probability estimates (to address potential numeracy challenges, we used a spatial response format).

### **3.3.4. Coding and Analysis**

A codebook was derived from the expert model diagram and, in keeping with the mental model method, thematic nodes are coded as links (i.e., “Financial challenges —> Access”). Interviews with high risk PLWH were transcribed verbatim and coded by Carnegie Mellon University research assistants. When a text did not fit to links within the expert model, the team had to agree upon the creation of novel codes (indicated in the influence diagram by a dotted line). Two independent judges were responsible for coding each interview, with the possibility of revising the codes until an inter-coder reliability of 0.8 was reached. Upon coding completion, the team surveyed the transcripts for instances where a link was repeated multiple times within a single question; these mentions were collapsed into a single count so as not to overweight the theme due to protocol suggestion. Lastly, we computed the percentage of codes that mention each model link. These percentages represent respondents’ relative emphasis on each link overall, irrespective of their total number of comments.

## **3.4. Results**

### **3.4.1. Participant Attributes**

Nine patients completed the interview (3 female, 6 male). The average age of the participants was 45 years old (Range: 27 - 58). On average, the participants had lived with HIV for 19 years (Range: 9 – 33 years for eight participants, one patient reported not remembering the number of years). Seven participants described themselves as African-American or Black, two as “Other”. The majority of the sample had completed

high school but not college. Two of the participants were married, one was living with a partner and the rest were single. Six had one or more children. Half of the participants were not working at the time of the interviews and all but two had an income below USD 25,000, likely to be living under the US poverty line. Five participants reported having at least one previous period of long-term non-adherence, however, all nine professed to consistently struggling with adherence, e.g., often not keeping up with daily doses.

### **3.4.2. Mental Model Narrative**

The integrated assessment diagram of ART Adherence in **figure 3.1** incorporates all topics mentioned by the participants. In line with previous risk and health decision models (88, 90, 91), the diagram is broadly organized such that major themes run through perceived risks, costs and benefits. We note that risk decisions, such as whether to take one's ART medication or not, are not about risks alone (e.g., developing immunity to ART, developing AIDS, or passing HIV to another) (92). Large risks might be acceptable to patients if there are no good ways to reduce them or if they bring large benefits (for instance, the possibility for long-term toxicity might be acceptable in exchange for being able to "live a normal life"; or, in contrast, the possibility of developing AIDS due to non-adherence might be acceptable in exchange for "feeling normal"). Similarly, small risks that bring small benefits, or could be easily mitigated, may be deemed unacceptable. Patients make their adherence decisions by comparing the expected risks, costs, and benefits of the available options. However, that comparison may or may not be well-informed; it might be influenced by environmental stressors, affective responses, or judgment and decision biases; and critically, much of

it can occur implicitly (93). In the following section we focus only on the “gaps” between expert and high-risk non-adherent patient models of ART adherence. That is, we discuss the new themes identified in our interviews or new interpretations of previously identified themes in the literature.

### ***Perceptions of Non-Adherence Risks***

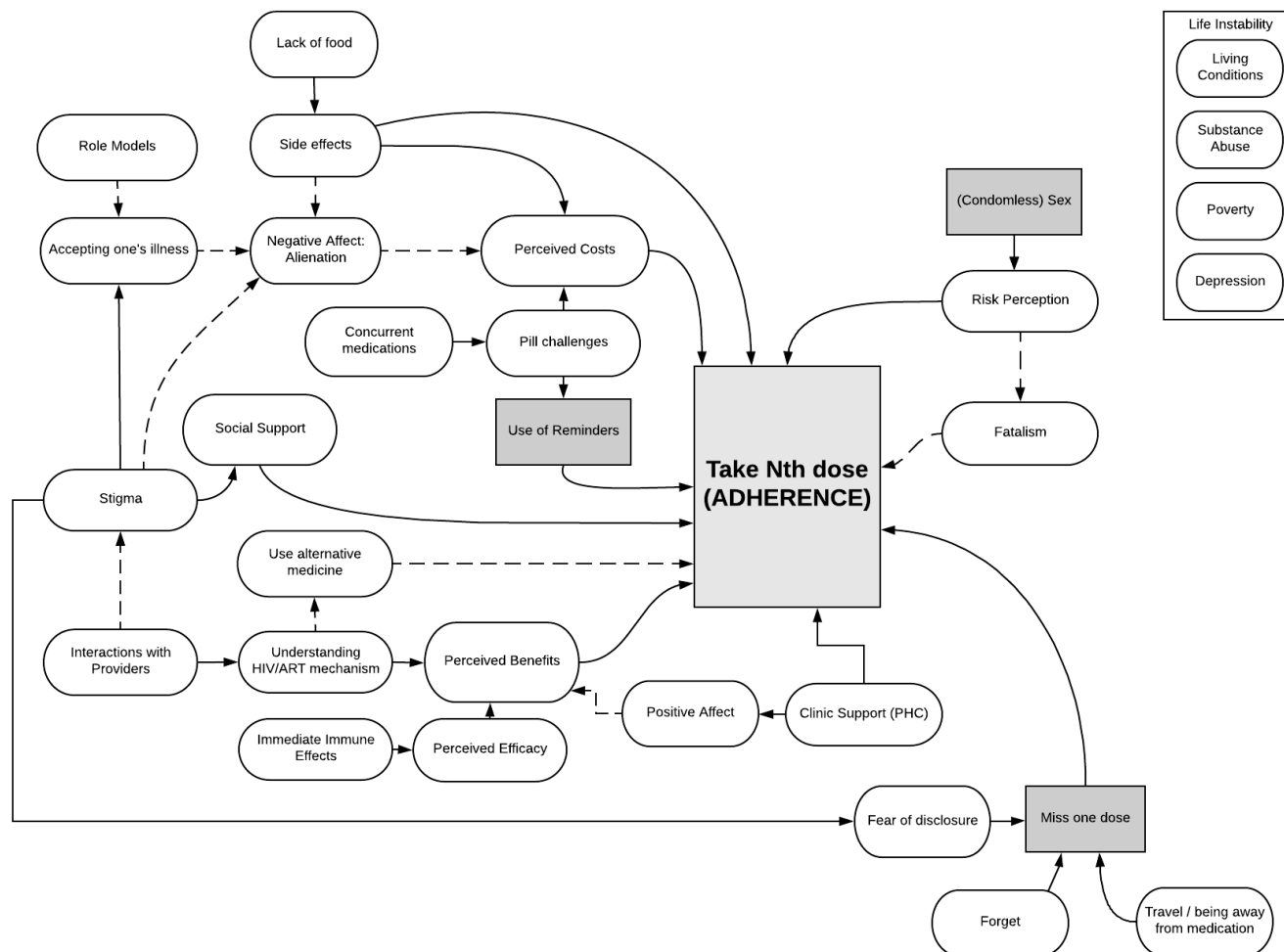
This research revolved around the judgment and decision-making processes involved in the daily act of ART dosing. We thus begin by establishing how patients understood the risks involved with *not* dosing. Interviews asked participants to identify the risks of non-adherence, then had them rank the risks they mentioned according to how much they worried about them. When asked if the physical effect of missing medication or the possibility of infecting someone was more concerning, three participants placed worries of harming someone else as their top-ranked concern, while for others both were equally important. As relayed by participant P-7:

*I: OK. What do you worry more about, the physical consequences of missing your medication for a while, or the prospect of infecting someone else with HIV?*

*S: The prospect of infecting someone — actually both, but more the prospect of infecting someone else.*

*I: OK. Why is that?*

*S: I just don't want to be responsible for messing up nobody's child.*



**Figure 3.1** Integrated Assessment Diagram of ART Adherence

When asked to estimate the chance someone would have of contracting HIV if that person had unprotected sex with them *one time* while they had a viral count of >1000, versus one that was undetectable, the average response was 56 (median 51) per cent and 44 (median 49.5) per cent, respectively. The actual risk of transmitting HIV while unsuppressed is 1.5 per cent or lower depending on type of sexual act (94), thus participants greatly overestimated their risk of transmitting HIV. Perhaps more importantly, since every participant in this sample worried about infecting others, and since messaging about lack of transmissibility while suppressed has been a priority at the clinic in recent years, it is troubling that most didn't seem understand that transmission highly improbable if not impossible while being adherent to ART (95–99).<sup>1</sup>

Six of nine participants cited the possibility of developing complications from AIDS as a risk of non-adherence, each of them ranking it highest for worry. Throughout their interviews, three out of those six participants relayed vivid and emotional stories of how they had witnessed the death of close friends or family members who had developed full-blown AIDS through non-adherence. In those cases, the salience of the concept was due to an *availability heuristic* whereby personal memories made the link between AIDS and non-adherence more easily accessible. Importantly, the mere accessibility of that link could amplify it as a risk for one's self (100). Indeed, fatalistic references were made by four participants in our sample. "Fatalism" refers to the belief of the inevitability of some events, including death. In some cases, having seen a loved one die to AIDS seemed to cause an automatic association for participants with regards

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<sup>1</sup> The results of the PARTNERS 2 study were recently unveiled at CROI, confirming that suppressed individuals effectively cannot transmit HIV to HIV- partners (99).

to their own death. In the excerpt below, a participant discusses this thinking process, which was triggered by learning of her viral load results:

*[...] If I don't take my medication, I might end up getting HIV. I mean, the AIDS. And it's like, it's really bad for me. But I don't-- I mean, I don't know. It's just, I don't know. I never mess with-- I said, 'If God wants me to go fast, he would want me-- He would want me to go.' I'll go. Like, my niece. I lost my niece to [AIDS].*  
(P-2)

It seems possible that having lost a close loved one to AIDS could be associated with fatalism in the same way that being close to or even just identifying with individuals who've committed suicide increases one's chance of committing suicide in a phenomenon known as "suicide contagion," (101, 102), an idea worthy of future research.

Lastly, only three out of nine participants raised the possibility of developing resistance to ART as a risk of non-adherence. While the sample size in this study was very small, this number was surprising since ART resistance is a communications priority at this particular clinic. Patients receive instruction on the link between (non)adherence and ART resistance (which would lead to having to take more meds and experience more side effects) at their initial visit, as well as every follow-up visit where any level of non-adherence is noted.

In summary, all participants held a salient concept of the risks of ART non-adherence, although knowledge about those risks varied and the risks themselves were attended by different levels of affect. It is noteworthy that the only risk that *all* participants mentioned--the desire to not transmit HIV to others--focused on protecting others rather than on personal health. In keeping with their concern, participants

overestimated the probability of transmitting HIV (per single exposure). However, and strikingly, they did not perceive a strong difference in transmission probability between suppressed and unsuppressed conditions. This knowledge inaccuracy is especially problematic, since daily ART dosing prevents transmission and could be understood as a major benefit of adherence. Fears about the risk of developing AIDS were also prominent, often informed by personal experiences or stories of people who had died due to AIDS. The least mentioned and least worried about fear was that of developing resistance to ART.

### ***Perceived Costs***

Beginning at the top center of **figure 3.1**, the node “Perceived costs” includes all concerns participants have for the short and long-term effects of medication as well as the economic, social, physical or emotional costs identified as influential in their decision to consistently take their medication. 29% of overall coded mentions during the interviews were related to costs. **Figure 3.2** shows the weighted frequency of mentions of each of the links.

### ***Side Effects***

The most prominently mentioned contributor to “Perceived Costs” was “Side Effects”, with 22% of perceived costs mentions related to this issue. The physical and life discomforts associated with side effects (SEs) are acknowledged in the literature as having a heavy impact the perceived costs of taking medication. In our interviews, experiencing SEs was sometimes referenced as an unmediated link to non-adherence



(completely bypassing any specific cost-benefit analysis in 3% of total mentions), as a link through alienation (where participants realized that the added daily effort and negative affect influenced their adherence) and through HIV/ART mechanism into perceived risk (where participants cited SEs as causing them to think of potential long-term harm to their bodies).

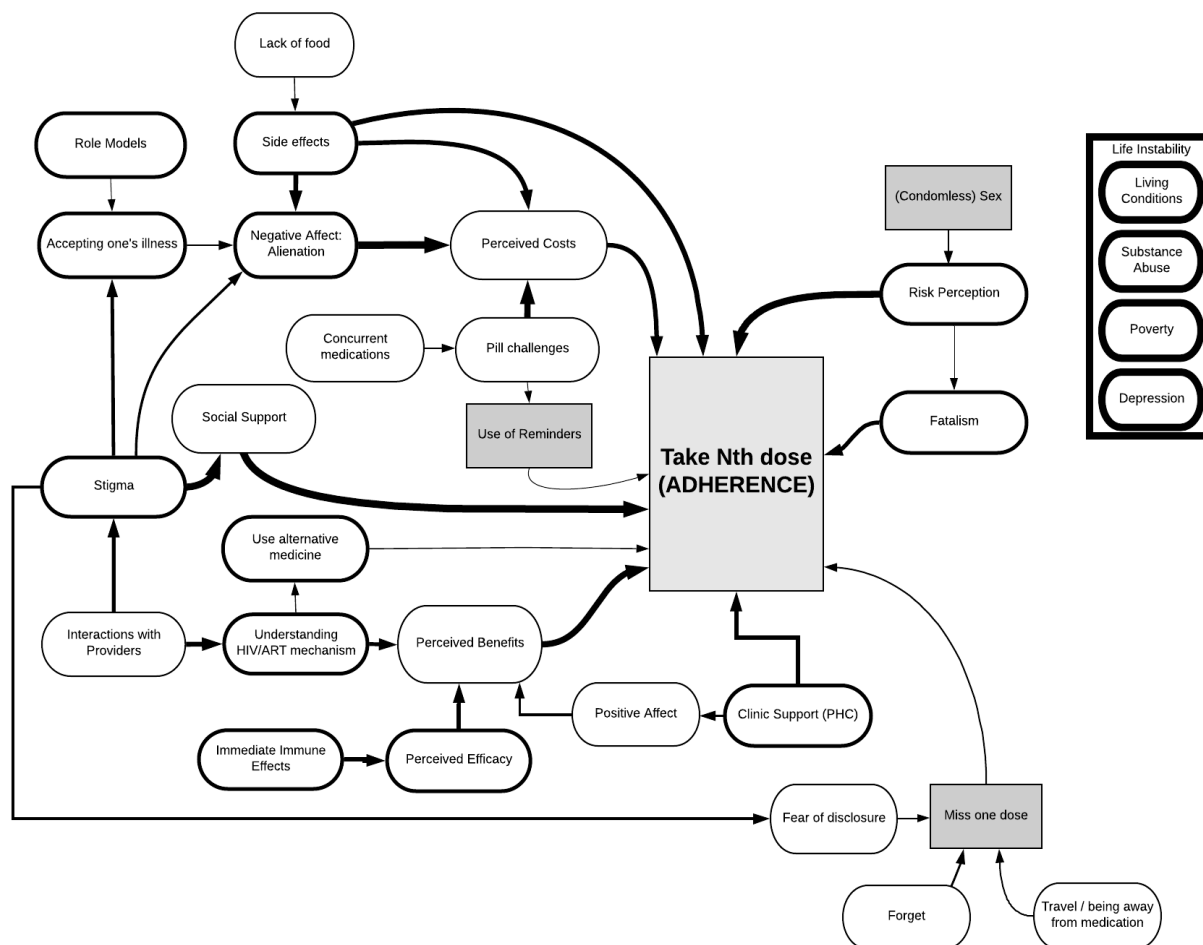
While the experience of short-term SEs was always characterized as unpleasant, participants identified digestive SEs such as diarrhea and nausea to be most debilitating in how they impacted their daily life. Daily dosing left them feeling both vigilant about their need to prepare before going out, and uncertain as to what they would be able to do or accomplish before they felt incapacitated, or before “an accident” occurred. Most importantly, having to deal with these sorts of side effects led some participants to feel they could not lead a normal life. As one recounted:

*S: I might have to turn around and go home because I had an accident or something. I always carry two sets of clothing in my car, so.*

*I: Yeah. [laugh]*

*S: [laugh] That's why when I say normal life...People don't do that. People don't put two sets of clothes in their car, that way if they have an accident they have a set of clothes there. Or, you sit on a plastic bag. (P-9)*

This loss of normal life was often then linked to feeling a specific type of negative affect labeled “Alienation” in our model, where participants themselves felt “not normal” because of HIV, ART’s daily dosing rituals, and its side effects. “Negative Affect/Alienation” will be discussed further below.



**Note:** Boxes represent decision points, and ovals represent variables influencing those decisions. Solid black arrows are weighted according to participants' frequency of mention

**Figure 3.2** Influence Diagram of ARV Adherence

Additionally, participants referenced their perceptions of ART's long-term side effects as a reason for non-adherence to antiretroviral medication. One participant relayed his fear of how long-term toxicity might damage his organs, referencing that the risk was much higher for him because of his race (103, 104):

*[My concern is] long term. [The] effects on your livers and kidneys. This medication is different in African-Americans than it is in others. Our bodies are different, it absorbs differently, [its] different. And that's part of the [barrier to adhering to ARTs]. (P-1)*

Lastly, in two instances short-term SEs were inaccurately interpreted as a symptom of longer-term ART side effects (here, nightmares being seen as a sign of pending cognitive decline). Said one participant, in his own words:

*I: So, you asked your doctor because of the dreams to switch you [to a different medication] ...Does the fact that you have these dreams also affect your medication adherence?  
S: Yes, that's why sometimes I don't want to take it. Because I see people [at the clinic] that take their medication and they're like coco for cocoa puffs. You know what I'm saying? (P-6)*

Noteworthy here is how the patient concluded a connection between ART and cognitive decline—even asking his doctor to change his medication—without also asking his doctor to confirm the conclusion. This ability to be influenced by other patients rather than doctors, often in ways that confused the HIV/ART mechanism, showed up frequently in the interviews.

### *Alienation and Negative Affect*

One of the most important findings from the interviews was captured in what we are calling “Negative Affect/Alienation,” which was coded into the appropriate link when

emotions such as alienation, sadness or fear were mentioned. “Negative affect/Alienation” comprised 39 per cent of the “Perceived Costs” mentions (and 15 per cent of the total model) and was referenced by five out of nine participants. In these interviews, negative affect/alienation presented as a generalized feeling of being “not normal” and “less than,” as in the words of participant 5 when asked “What first comes to your mind when I say ‘HIV’?”:

*I don't know. What comes to mind? Different. You being different. Everything turns around. You feel less than the next. You feel like can't do as much as everybody because you have [HIV]. Dying. Living. Being sick. (P-5)*

Alienation is a type of negative affect, defined as “the state or experience of being isolated from a group or an activity to which one should belong, or in which one should be involved.” (105) It can be related to feelings of discrimination, isolation and loneliness, and, potentially, a feeling that one has lost significance (106). One much-reviewed factor linking to “Negative affect / Alienation” was a participant’s sense of “Stigma,” with 16% of the mentions of how stigma impacts their life being related to this construct; another, also identified in the existing literature, was whether they had been able to “Accept one’s illness.” However, of note is how three participants attributed their feeling of alienation to the daily act of taking their medication. As explained by this participant:

*S: Normal people don't take medicine.*

*I: Mmm.*

*S: Umm normal people don't have to deal with a disease every day.*

*I: Okay.*

*S: So, to say— to, like— when the doctor says you can live a normal life with HIV, they're lying to you. Flat out lie because a normal life means that you're not taking all that medicine that you've been taking. (P-9)*

Participant 2 explained how she almost forgets about her diagnosis and the negative feelings associated with it, but then the act of taking her medication reminds her:

*Yeah, because I got [sic] to take it every day and I'll have something to remind myself. [I'll think] I'm taking some medication for something, but I won't know what for... I say [to myself], 'I got diabetes and something else.' And I feel bad. But I don't know why. Then I have to remind myself, 'Oh, I have the [HIV] virus.'*

Seeing role models who could successfully cope with HIV and treat it like a chronic disease appeared to help participants, who reported that it had a positive effect on their ability to accept their illness and made them feel less alienation and negative affect.

### ***Poverty and Life Instability - A Common Thread***

Participants described life circumstances tantamount to constant and sometimes wild fluctuations in living conditions. We have labeled this node “life instability,” intending for it to capture an environmental influence on participants’ ability to adhere to medication. We note that poverty, housing, stress, substance abuse and mental illness have previously been cited as barriers to adherence in the literature (64, 72, 107, 108), as variables with discrete influence on access or cognition. For conceptual purposes in this qualitative research, we grouped them under one category capturing a set of conditions that often coexist and interact. Recent work in behavioral economics suggests that scarcity and conditions of resource instability may directly influence the process of cost-benefit calculus within a given domain via deficits of will power, attention and cognitive performance (109). Consider that, for many low-income families and individuals, daily life involves agonizing tradeoffs (“Should I pay the rent or the heating bill? Should I fill this prescription or buy food?”). The process of making those painful

tradeoffs comes at a significant cognitive cost, equivalent to living each day as if one hadn't slept the night before (110). In effect, scarcity increases *present bias*—when the costs one would pay today are felt more urgently than those in the future (and its corollary, e.g., when the benefits of tomorrow seem to matter less today)—which is a bias we all suffer from (111). In terms of ART adherence, then, scarcity and its effects on attention, will power and cognition, will make it harder for patients to value future ART benefits as much as its daily, current costs. References to “Life Instability” occurred 65 times, comprising 23% of thematic mentions in the overall model.

One way that participants conceived of the impacts of life instability was “stress.” In general, participants reported that dealing with stressful situations resulted in them either neglecting or choosing not to take their antiretroviral medication. As P-1 explained:

*This [episode of non-adherence] has been six months. The stress was very high, very high at [my job at a transition home for drug addicts]. And it started getting to me. I just said, 'I'll take it tomorrow, I'll take it tomorrow.' And then tomorrow never got here until a doctor showed me my numbers and they were very alarming.*

Housing issues were also found in this sample, arising as 3% per cent of mentions in the “Life Stability” node. Two participants had experienced eviction, one had to move out of shared homes, and one was living in temporary housing at the time of the interview. Here, P-4 describes how being evicted resulted in a physical barrier to daily dosing:

*S: My viral [count] was [high] and then [the Doctor] will say, 'Well, why aren't you taking your medicine?' And then I would say, 'Because I've been going through so much.' ...My medicine was locked up in [the apartment from which the patient*

*was evicted] for a month. All my daughter's medications was [sic] locked up. And then I had to file a motion with the judge to open up the door to let me in to get the medicines. It was just horrible.*

Another influence on life stability, often cited in the literature, was substance abuse (112). This comprised 16 per cent of the life instability node. As P-7 commented, taking ART and being under the influence is sometimes simply not compatible:

*I: So, tell me a little bit about your day. ...*

*S: Well, usually I would take my medication...but if I'm in, like, in a bad spot with drugs, or depression, I probably won't take my medication, and that can go on for weeks and weeks and weeks.*

Lastly, and as has previously been mentioned in the literature, PLWH tend to have higher than average incidences of depression (113), which can affect a patient's cognitive ability, energy level and motivation to take medication (114). In this sample, three participants mentioned mental health conditions for which they are currently being medically treated, while others mentioned depression, even if they have not been formally diagnosed. In both cases, participants reported thoughts of giving up on life in general, which would no doubt have bearing for one's cost-benefit analysis in terms of daily dosing.

### ***Perceived Benefits***

Continuing at the center left of **figure 3.1**, "Perceived benefits" of taking ART medication links to the perceived effectiveness of the medication. The interviews attempted to measure each participant's knowledge of the disease and treatment, asking: 1) How does HIV work, or what is HIV doing in the body that can make you sick? 2) What ways do you know of to treat HIV, and for each of them, how do they work? and 3) How can

HIV be prevented? While knowledge is generally acknowledged to influence adherence (115), one critical input into our samples' ability to perceive ART benefits was whether patients were aware of the mechanism through which antiretroviral medication treats HIV ("Understanding HIV/ART mechanism"). Specifically, not understanding viral count numbers and symptoms resulted in participants undervaluing the benefits of continuous medication, such as diminishing their transmission risk, and even preventing the development of AIDS. For example, two participants mentioned that they had stopped taking their medication when they reached an undetectable status. Others who didn't develop any symptoms after long periods of non-adherence relayed a belief that they did not need their medication anymore. Once again, many of the interviewees referenced personal experience or discussions with others PLWH in their network—rather than clinician sources—to explain their beliefs about these issues. Regardless of their source, an (in)accurate understanding of the way viral counts affect the body in the short and long term was an important factor in how ART benefits were assessed by participants.

If insufficient knowledge about HIV and ARV mechanism made it more difficult for participants to interpret their lack of symptomology when they were non-adherent, the lack of a noticeable benefit from taking ART also seemed to lead some participants to question its worth. As one interviewee shared:

*I don't want to take them because I know - I don't know, sometimes I feel like it don't [sic] help me because I'm still the same. Nothing bad happened, nothing worse happened. So, I don't know. It's just probably a mind thing, I'll be just thinking. Because I know I have to take them, but I don't want to take them or I don't feel like it. I don't know, it's just a feeling. (P-5)*



For participants in this sample, then, the perceived benefits of ART were few and scarcely felt. For instance, despite the fact that all participants worried about transmitting HIV to others, none of them seemed to know or believe that suppression precluded that possibility. Further, while non-adherence was believed to lead to the risk of developing AIDS, neither adherence nor non-adherence led them to feel immediate, tangible physical consequences that would activate the risk. Lastly, while several participants worried about developing a resistance to ART, there were no signals to indicate when and how this would happen. Indeed, participants described how both non-adherence and daily dosing with ART resulted in feeling “the same.” Ultimately, participants struggled between what they “know”—the effortful, slow and deliberate thinking of System 2— and what they “felt”—the automatic and implicit processing of System 1 (93). Ironically, without the tangible, physical consequence of (non)adherence, participants were not compelled to understand the mechanism of HIV or ART, and without an understanding of HIV or ART mechanism, participants had no story to explain lack of physical consequence.

We note that “Positive Affect” links into “Perceived Benefits,” but since such references originated entirely from discussions about “Clinic Support” or “Social Support,” we wait to discuss them below.

### ***Clinic-Specific Support & Interventions***

A unique characteristic of this sample’s participants was the amount of support they received from their current health provider. Several participants mentioned how their current treatment program at the clinic helped them adhere to medication when

struggling (“Clinic support”). These programs included: a version of directly observed therapy where patients are watched as they ingest their medication, financial incentives for adherence, and various support groups available at the clinic. Importantly, participants described both the support groups and directly observed therapy as a source of emotional support. As described by P-8:

*They want to see me ... yeah, they wanna (sic) help me take my medicine every day....Because they care about me. And they want to see me here.*

We note that emotional support generated through clinical relationships would constitute an immediate, tangibly felt benefit—the likes of which was clearly lacking in the benefit assessment above. In our model, we have thus linked “Clinic Support” to “Positive Affect,” which then links to “Perceived Benefits.” For the receiver, emotional support manifests as positive affect (through its chemical substrates, such as dopamine and oxytocin, tied to relational and achievement-oriented goal attainment and to affiliative exchanges, respectively). Critically, the positive affect that patients experience through clinical relationships would not be considered an incidental emotion—that is, an emotional response to a random environmental factor that could nonetheless influence one’s motivations. Instead, clinically-sourced positive affect would be tied specifically to ART—a social world filled with social emotions around taking ART, committing to ART, and attaining goals with ART. ART itself could, over time, be branded by these healthy emotions.

This sample emphasized the role of the patient-doctor relationship in serving as a reward as well. Several mentions described how feeling listened to and cared for as a person could have on individual adherence behavior. As participant P-1 relays here:

*S:[...] The good thing about my doctor, I told her. When I was at the other doctor, I cannot take the pill [and they said] 'Oh, you have to take it.' I don't like that...Because if you want me to take it and I tell you that I can't, you got [sic] to listen. You know what I mean? So, [my current doctor] listens to me. I think I'm more involved with my medication now, than before.*

*I: Because, you switched it? Or because, the doctors are really listening to you?*

*S: Doctors are really listening to me.*

In addition to receiving emotional support from their clinics, three participants highlighted how their support groups provided them a much-needed opportunity for them to help others. We included such references in the “clinic support - positive affect” link, given that helping others leads to positive feelings about one’s self as well as an enhanced connection to a value outside of one’s self, e.g., that of being useful or helpful to others.

Of course, if the emotional rewards of feeling heard and supported, or of being a worthy part of a relationship attend the clinician-patient interaction, then they become a tool which can also be taken away—intentionally or inadvertently. One participant pointed out this vulnerability by discussing the consequences of staff overturn at the clinic. In his words:

*It's a lot of turnover [with the social workers] right now, [and for] the last two years. I have an issue, when I give you my personal life and we have this relationship, and then all of a sudden, you're gone and then I have to get a new relationship. That's what I'm in now with [staff member]...She's helped me transition. She's very good. ... but the social workers are leaving. We just need somebody who's going to stick and stay. (P-1)*

Similarly, as part of the patient’s social world, clinic support groups may not always work as intended. At least one participant reported feeling that his clinical support group was a focal point for judgment and negative energy in his life.

### 3.5. Discussion

Adherence to ART medication is a complex challenge that, as many previous studies have argued, involves overcoming cognitive limitations. The current study suggests the need to overcome additional barriers, including information retrieval and affect heuristics, and the implications of a scarcity mindset, which may be amplified for high-risk non-adherents.

#### ***For High-Risk Non-Adherents, Costs May Loom Larger Than Benefits***

We employed a mental models methodology to compare a normative cost-benefit analysis of ART adherence to how individuals' actually experience that cost-benefit analysis. For the individuals in this sample, unfortunately, costs often loomed larger than benefits. They perceived the costs of taking ART as immediate, with physical, logistical, and emotional consequences, experienced through side effects, profound impact on daily life and productivity, and a sense of alienation. Further, these effects were inextricably tied to dosing, meaning they had to proactively choose to subject themselves to suffering in the moment in order to achieve a benefit that felt far away. In sum, for this sample, the primary challenge of ART is an acute *present bias*: The costs of ART—physical, logistical and emotional—are all squarely in the present, while the benefits of ART are in the future. Unfortunately, in this sample, participants were not knowledgeable about all of ART's benefits, and even when they professed to “knowing” ART would prevent them from developing AIDS, the lack of immediate signals—e.g., physical symptoms of non-adherence or physical consequences of adherence— left them struggling between what “felt” real and what they knew they should do.

Below, we explain the knowledge, affect and context gaps behind this cost-heavy equation, then discuss implications for interventions.

### ***Knowledge Gaps***

This study revealed knowledge gaps in two domains. The first dealt with participant's understanding of non-adherence risks and ART benefits. Participants identified three major risks of non-adherence: transmitting HIV to others, developing AIDS, and developing a resistance to ART. Unfortunately, participants vastly overestimated their risk of transmitting HIV to others, providing transmission estimates that were nearly the same when hypothetically suppressed as when unsuppressed. This knowledge gap meant participants did not recognize a major benefit of adherence to ART: the peace of mind that comes with knowing one cannot transmit HIV to others, and that one is not a danger to others. We note that this knowledge gap also has bearing for the ART-related negative affect described in the interviews: if individuals believed themselves to be a significant source of danger to others *even when their viral load was undetectable*, feelings of being not normal, alienated, or "less than" would understandably be amplified.

Additionally, participants exhibiting a lack of understanding of the mechanism of HIV and ART, which often led to more cost-heavy interpretations of side effects (e.g., my nightmares indicate cognitive decline), and left them with no accurate explanation for why they did not feel more immediate symptoms when non-adherent, or benefits when adherent.

Lastly, we note that the availability heuristic seemed to play an immense role in how participants accessed knowledge, and what knowledge they stored. Often, a significant part of their social network included other PLWH, exposure to who led patients to expect short- and long-term side effects and anticipate risks based on their observation of inappropriate or outlier cases, their identification with the case of a close other, or hearsay anecdotes from other patients. We note that correcting such misinformation may be difficult for reasons outside of the availability bias: a growing body of work on the *illusory truth effect* shows that being exposed to mis-information repeatedly leads to acceptance of a belief, and that this effect is not buffered by prior knowledge (116). The source of corrective information may also be a challenge in some cases, since these interviews demonstrated a lack of reliance on, or even suspicion of, clinical sources of information.

### ***Affect Gaps***

This study also identified several ways in which adhering to ARVs induced negative affect, which can have its own influence on a cost-benefit analysis, and in this case an impetus to “withdrawal.” Participants frequently referenced a type of negative affect—alienation—when they described feeling different or “not normal” because of side effects or daily dosing rituals. According to dual processing models of cognition in psychology (117), affect and associations are processed in the brain differently than more rational, effortful, and explicit “cognition.”(93) Studies of affect and decision making have shown how affect has its own power and influence, often fast and implicit, on one’s cost-benefit calculus (118, 119). In fact, when cognitive and emotional reactions to a given behavior

are different, there is some evidence that emotion will be the main driver (120). The node we labeled “Negative Affect/Alienation” comprised alienation, sadness and fear. Importantly, each of these negatively slanted emotions share a similar action tendency—that of withdrawal from a stimulus (rather than an approach, or goal-oriented, action tendency) (121).

### ***Context Gaps, or Scarcity***

Our participants reported being in a constant state of instability and stress, life contexts resembling environments that have recently garnered attention in psychology for their ability to render a “scarcity” mindset. That research has demonstrated that people undergoing high stress and low autonomy, or instability, have a finite amount of mental bandwidth or will power (109, 110). For most in this sample, the physical, logistical and emotional costs of daily ART dosing were competing against urgent needs such as housing or lack of money, amidst an environment of constantly changing financial and relational stressors.

### ***Implications for Interventions and Practice***

Though preliminary, this research suggests potentially important implications for clinical practice and behavioral interventions. First, to the extent that the knowledge gaps identified in this research exist more generally in high-risk non-adherents, we would recommend an information campaign dedicated to bridging these gaps, including:

*Building awareness that HIV cannot be transmitted to others when one is adherent to ART or suppressed. By connecting adherence to the reality that one*

can no longer be a danger to others, clinicians can illuminate a major benefit of ART therapy for patients, and potentially also minimize feelings of alienation.

*Relaying the mechanism by which HIV and ART work.* Such an explanation should be simple and yet detailed (and race-sensitive) enough that patients can draw on it to: explain short- and long-term side effects; to counter community memes of why juicing and eating organic can defeat HIV; illustrate why one would not experience symptoms immediately following non-adherence.

However, since participants in this sample often relied on friends and support groups as sources of information about ART and HIV (rather than clinicians), feeding both an *availability heuristic* and/or an *illusory truth effect*, we would suggest that any such information campaign be enacted through social channels in addition to regular clinician talking points. That is, these facts can be discussed or relayed via illustrative videos in support groups, where they are monitored for accuracy and followed by a group discussion which can provide a social, affective and possibly norm-based element to the memory. Support groups could even pledge a commitment to foster an environment of correct information, similar to the type of “fake news” pledges happening on social media today (e.g. <https://www.protruthpledge.org>) which have demonstrated their effectiveness at getting people to be more skeptical of sources, the validity of information, and their own role in spreading mis-information (122).

To address present bias, or the imbalance of immediate, felt costs compared to benefits, we note that many clinical support programs are based on the idea of immediately felt benefits—emotional, social, or financial. Clinics can develop



programming — whether it be clinician or patient-led — with an eye towards creating positive affect (e.g., laughter, bonds, trust, respect, personal growth) that is tied to treatment. The goal would be to add more immediate, positive emotional impact to the “benefits” in the ART cost-benefit equation. Another intervention that might be explored, previously used in non-health domains to counter-act present bias, would be a “future self” exercise that enables patients to connect and identify with their future self in order to motivate current decisions for future benefit (123, 124).

In this same vein, since most programming is created in order to serve patients themselves, we would note the frequency with which our participants talked about wanting to or being grateful for opportunities to help others. Just as self-reported meaning scores (e.g., giving behavior) hold different and important health implications versus self-reported happiness scores (e.g., taking behavior) (125–128), it may be that opportunities to help others, or to matter outside of one’s self, can serve a novel and potentially higher motivational purpose for high-risk non-adherents. The clinical activities chosen to serve this goal could be generated organically, within support communities. Another behavioral intervention to enhance meaning, or values larger than one’s self, and to do so at low-cost, would be written value-affirmation exercises (129–131). These have been shown to increase academic performances amongst minority populations, and to increase interest in and uptake of social services in a homeless population (132, 133). Lastly, given that clinics and the PLWH community are primary supports for high-risk non-adherents, clinics might reevaluate the costs of staff turnover and organizational change in terms of impacts on their patients.

As its last gap analysis, this research emphasized the potential role that life context—in this case, scarcity—may play in hindering high-risk non-adherents' attention, cognition and affect regulation abilities. The growing literature on scarcity offers a simple suggestion for helping individuals in such contexts overcome barriers to performance: Make it easier. Embed services in places that high-risk non-adherents will already be in, or tangibly find a way to bring them to the clinic or its supports.

### **3.6. Limitations & Future Research**

Due to the small sample size, this research was probably not able to identify rare belief systems. Moreover, the influence diagram represents frequency of mention within our specific sample, but this cannot be extrapolated for high-risk non-adherents generally. Also, we note that the clinic we collaborated with offers unique services that are not often a part of the standard of care for PLWH—which might mean that this sample's adherence barriers were less extreme than other at-risk non-adherents, or that their coping resources were higher. Lastly, most of our participants identified as African American, which might limit generalizability to a larger at-risk non-adherent population. We do not see these limitations as reason to question any of our findings, but rather a limitation to their prevalence and generalizability.

Future survey research drawing on these findings could explore the prevalence of these factors as barriers for the larger population, and potentially tie them to demographic and other risk factors. Laboratory or survey experiments would be able to better test the mechanisms at work in affective heuristics or the role of knowledge about HIV and ART mechanisms on adherence decisions or behavior.

### **3.7. Conclusions**

Using a mental model's approach, we were able to validate factors related to ART non-adherence already found in the literature as well as reveal several previously unidentified psychosocial and affective barriers that may be amplified for the high-risk nonadherent population, including: the potential for a scarcity mindset and its consequence or present bias; affective biases attending felt side effects and the ritual of daily dosing; and, information retrieval heuristics with bearing on how one views their own likelihood of non-adherence and risk of AIDS, and how they absorb information about HIV and ART. Taken together, these factors appear to lead patients to an ART cost-benefit analysis whereby costs outweigh, and loom larger than, benefits. We suggest that the decision-making process for high-risk non-adherents may belong in its own category of study, and that the biases and heuristics identified here should be further assessed for prevalence and, if born out, addressed in future interventions. Those future interventions would focus on: providing accurate knowledge about HIV and ART to patients in ways that incorporate their PLWH communities; finding ways to balance the negative affect that accompanies daily dosing with positive affect due to clinical or social interventions, potentially exploring the creation of social endeavors to help others, or future selves exercises and value affirmations; and putting more resources into making ART treatment and support a seamless and easy part of life for patient, e.g., bringing them to services or services to them. Further work will be necessary to determine how prevalent our findings are for the broader high-risk non-adherent population and for PLWH as a whole.

## **4. Health Utility, Discounting and Expectations of the Older Self**

### **4.1. Introduction**

Many leading causes of mortality and morbidity in developed countries stem from individual choices (134). For example, physical inactivity and an unhealthy diet result in a higher risk for chronic diseases such as high blood pressure, diabetes, and heart disease (135). A decision-maker who exercises and eats a healthy diet is willing to endure physical discomfort from exercising and delay the immediate gratification of unhealthy foods in exchange for better health in the future. However, those health benefits are often psychologically distant and uncertain, as it is difficult to quantify how a 30-minute daily exercise routine today will affect health 1, 5, or even 20 years in the future. For this reason, improving decision-makers' understanding of how benefits will accrue to themselves in the future might be the key to improving health outcomes over the lifespan.

A classical solution to this problem is for a decision-maker to step outside of her immediate perspective, examine her entire life, and construct a plan such that decisions at each point in time optimize consequences across the entire lifespan. While such an approach is not impossible in principle, it is clearly impractical, and several studies including hypothetical decision scenarios (136), real choice experiments (137) and neuroimaging studies (138), suggest that decision-makers do not view themselves across the lifespan as the same person, instead seeing their future self as a stranger or an "other." Without a strong connection to one's self across time, a decision-maker is likely to care about the needs of this future self as much (or as little) as she would care

about the needs of a random stranger (139). This connection is conceptualized as different levels of *overlap* or *continuity* with the current self (140, 141).

Previous work on the continuity of the self has found that higher levels of overlap between the current and future self are associated with a greater concern for the future (142, 143). Moreover, theoretical and experimental work suggests that a higher degree of connection results in future oriented behavior (144). These findings have led to the development of interventions that aim to enhance a decision-maker's connection to the future self in order to foster this type of behaviors (145–147). Future self interventions (FSI) use letter writing exercises and visual representations of the aged decision-maker to increase the vividness and salience of the future self (139). The argument is that in order to connect with a future version of the self, it is necessary to mentally create a representation of the future through one's imagination and, with a greater distance into the future, this representation is less detailed and more abstract (148, 149). Visual and written depictions of the future self aim to overcome these failures of imagination by aiding in the construction of vivid mental images of the aged decision-maker (150).

There is some evidence that this effect may be pertinent to health behavior, with recent work showing that a greater connection prompted through a written FSI was associated with an increased likelihood of exercise (151). Nevertheless, for some decision-makers, connecting to a future self might not be a positive event due to negative perceptions of aging (152). Research on aging and attitudes show that there are pervasive negative attitudes toward aging linked to existing stereotypes about growing old (153, 154). While positive views of old age are related to the enjoyment of

freedom and personal growth, more negative perceptions relate mostly to the view of declining health or illness during this period (154, 155). The physical signs of aging have been shown to produce strong negative sentiment and there is some evidence that contact with elderly people or knowledge about aging might increase anxiety about growing older (156–158). When considering health outcomes, affective and impulse-driven influences such as disgust and fear, have been linked to different health choices than those expected by an emotion-less utility model (159, 160).

FSI place the decision-maker in direct contact with an aged version of the self, which might activate aging stereotypes that can produce anxiety and influence expectations of aging. Facial cues and word exercises that associate older adults to specific stereotypical behaviors have been found to activate these stereotypes and produce negative affect (156, 161). College students exposed to an age progressed self-image reported greater aging anxiety when compared to those exposed to an aged image of a stranger, and found the image to be less believable (152). This suggests that FSI that are efficient in creating a closer connection to the future self might inadvertently activate a decision-maker's stereotypes about their own health during old age.

When stereotypes become increasingly self-relevant they shape perceptions of self-aging and the view of the physical state of the older self (161–165). Although there is a natural decline of health that results from aging, subjects are likely to underestimate their future quality of life (166). Hence, expectations of self-aging influenced by negative stereotypes may lead to a reduced valuation of future health. Additionally, negative

views of aging are correlated with a lower desire of additional years of life, suggesting a low valuation for longevity (167). Thus, if the decision-maker visualizes “full health” in old age as inherently worse than “full health” when younger, the value for a unit of time of full health will also be lower. This valuation may also influence the weight assigned to a health outcome in the future, which is often measured through a health discount rate (168).

Temporal discounting or time preference is a term used in economic and psychological literature to describe the way that people usually care less about future outcomes (159, 169). A discount of future outcomes is measured in different domains by determining the tradeoff point between present and future wins or losses (168). Previous work on future self connection has found that a greater connection is correlated to lower monetary discount rates (139, 142, 143, 170). However, less research has been done on the relationship between this construct and the health discount rate (HDR). Due to an increase in care for the future self, we might expect a similar negative correlation between future self connection and the HDR, however, there is no evidence that this is the case. Furthermore, domain dependence for the discount rate has been found across several items and it has been postulated that some of these differences are related to affective issues (171). In the case of the aforementioned aging anxiety, affective factors related to the anticipation of poor future health might have specific effects on how health is discounted in the long term.

Within the existing context described above, there is an indication that factors related to perceptions of aging and their influence on anticipated future health need to

be explored further. Moreover, these factors might influence the intended effect of FSI and how health utility is assigned throughout a decision-maker's lifetime. While FSI may increase the concern for the future self, they may also aid in the visualization of the aged self and generate anxiety about growing older. Additionally, existing expectations about aging could become more relevant to the decision-makers own aging process and their anticipated utility of health. Finally, this valuation could impact tradeoffs between future and present health.

#### **4.2. The Present Study**

While FSI are promising tools that could potentially be used to promote future oriented health behaviors, it is necessary to understand how these types of interventions might influence a decision-maker's expectation of future health as well as affective responses to aging. The main goals of this study are to a) examine the relationships between future self connection, aging anxiety and expectations about aging for younger adults when participating in FSI, and, how these constructs may influence the valuation of future health and b) investigate if this anticipated valuation of future health, along with anxiety about aging and future self connection, impact the health discount rate.

FSI increase vividness of a specific version of the future self. We expect that, similar to what other studies that use FSI have found, the increased vividness of the future self generated by FSI will result in an increase in future self connection. An increase in connection is associated with concern and positive feelings about the future self (172). However, the vividness generated through an FSI may additionally highlight the negative aspects of aging, an effect that will be stronger when the intervention



requires a visualization of the elderly self. This newly highlighted view of aging could have effects on aging anxiety and how the decision-maker uses existing expectations of aging to conceptualize the anticipated utility of health.

Hence, we hypothesize that the increase in future self connection will have an overall positive effect on the anticipated utility of health. However, different types of interventions will have different effects. While a greater connection generated by an intervention might in fact emphasize the positive aspects of growing older, such as personal growth, the vividness of the negative physical aspects generated by an intervention to an elderly version of the self will affect how this connection influences anticipated health utility.

H1a: A higher connection to the future self will increase the anticipated utility of future health. However, the magnitude of this effect will be different depending on the intervention used. The effect will be higher for those participating in the 20-year future writing exercise compared to those participating in the 68-year-old writing exercise (**Equation 4.1**).

Additionally, the vividness of the future self might cause expectations about aging to be more relevant to the decision-maker's own aging process, particularly when that vividness is related to the aged version of the self in the 68-year-old writing exercise. We anticipate that both the decision-maker's existing beliefs about aging and the type of intervention used will influence the valuation of future health (**Figure 4.1**):

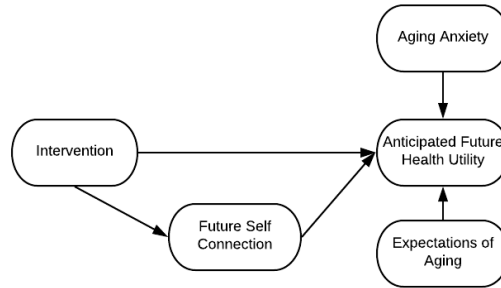
H1b: Higher expectations regarding aging will increase the anticipated utility of future health. However, the magnitude of this effect will be different depending on the intervention used. The effect will be of a higher magnitude for those participating in the 68-year-old writing exercise compared to those participating in the 20-year future writing exercise (**Equation 4.1**).

We also presume that aging anxiety, which might be activated and increased by the intervention, will have an influence on anticipated health beliefs and negatively affect how the decision-maker values future health. This value will depend on the connection with the future self, as we expect that aging anxiety will have a lower effect on the anticipated quality of life for the elderly self as future self connection increases.

H1c: Participating on an intervention will increase aging anxiety. This increase will be higher for those participating in the 68-year-old writing exercise.

H1d: Higher magnitudes of aging anxiety will decrease the anticipated utility of future health. The magnitude of this effect will be moderated by connection with the future self, where a higher connection will increase the magnitude of the negative effect of aging anxiety (**Equation 4.1**).

**Figure 4.1** Predicted causal relationships between future self connection, expectations regarding aging and anticipated future health utility



$$AHU = \beta_0 + \beta_1 * Int + \beta_2 * FSC + \beta_3 * EA + \beta_4 * ANX + \beta_5 * Int * FSC + \beta_6 * Int * ERA + \beta_7 * FSC * ANX + \varepsilon$$

**Equation 4.1**

For our next hypothesis, we use the construct of temporal discounting for health and the health discount rate. We propose that the magnitude of anticipated future utility contributes to the time preference for health. This premise suggests that when a decision-maker anticipates that health will be more valuable in the future, she is likely to assign a higher weight to future health outcomes. The health discount rate will capture this lower valuation of future health along with the inclination of a decision-maker to prefer present rewards or, in the case of ill health, to avoid present losses.

H2a: Anticipated future health utility will be negatively associated to the health discount rate (**Equation 4.2**).

Furthermore, although affective factors are recognized as an influence on health discounting, no existing studies have tried to directly understand how aging anxiety impacts the weight the decision-maker is likely to assign to future health. Due to the

relationship between health discounting and affective responses, we anticipate that aging anxiety will have a negative effect on how much health utility a decision-maker is willing to assign to the future self. This effect is expected to be stronger for those who are primed to the elderly self condition as the negative affect relates directly to the visualization of poor future health during the elderly years (**Figure 4.2**).

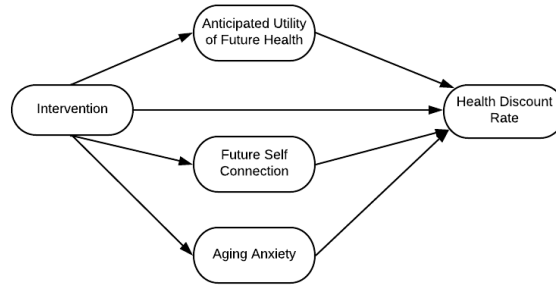
H2b: Higher levels of aging anxiety will increase the health discount rate.

This effect will be moderated by the type of intervention used. For those participating in the 68-year-old writing exercise, the effect of aging anxiety will be higher in magnitude, followed by the 20-year future writing exercise and finally the control group.

Finally, we also expect that future self connection will increase concern for the future self and, similar to the effect found in the domain of monetary discounting, reduce the health discount rate. Nevertheless, aging anxiety will act as a moderator to the effect of future self connection on the health discount rate. Previous research has shown that the effect of vividness on the continuity of the self may be mediated or moderated by affect (147). Similarly, we could suggest that aging anxiety, as an affective response, might mediate the relationship between connection and how health is visualized and discounted.

H2c: Higher levels of future self connection will decrease the health discount rate. This effect will be moderated by aging anxiety, where a higher level of aging anxiety will decrease the magnitude of the negative relationship.

**Figure 4.2** Predicted causal relationship of variables and the health discount rate



$$HD = \beta_0 + \beta_1 * Int + \beta_2 * Anx + \beta_3 * FSC + \beta_4 * AHU + \beta_5 * Anx * FSC + \beta_6 * Anx * Int + \varepsilon$$

**Equation 4.2**

## 4.3. Method

### 4.3.1. Participants and Procedure

Participants between the ages of 18 and 45 were recruited via Amazon's Mechanical Turk and compensated \$5.00 for their participation in the completion of a 25-minute survey and intervention. A sample size of 180 was chosen to yield a power of 0.90 and detect the medium effect of size 0.6 found in previous studies (139). For our final sample we eliminated 11 observations from participants who failed 3 or more of 6 dominant questions and that of one participant who did not complete the survey. Our final sample consisted of 168 participants (45% female,  $M_{age}=30.8$ , Median=31).

After reading a brief introduction to the study, participants were randomly assigned to one of three conditions, each initially with an equal number of participants. All groups were tasked with a writing exercise that served as the manipulations and

control. Based on FSI used for previous research (124, 151) participants were asked to write a letter to themselves in the future with the following instructions: *“Take a moment to form an image of yourself (3 months/20 years/at age 68). In the box below, please start off by thinking about yourself (3 months/20 years/at age 68) and write about the person you will be, which topics are important and dear to you, and how you see your life.”*. Those participating in the first group were required to write the letter about their 68-year-old self, the second group was asked to write a letter about themselves 20 years in the future and the final group wrote about themselves 3 months in the future. The latter condition, which used the near-self, acts as a control in order to avoid the confounding possibility that the effect of the intervention might be due to future oriented thinking regardless of temporal distance.

It is important to point out that previously used written FSI have only tasked subjects in the intervention condition to write a letter to themselves 20 years in the future. In this study we chose to include a new condition that asks participants to write a letter to an older version of themselves. While we expect the original 20-year condition to affect aging anxiety due to lifetime expectations of decline, we presume that this relationship will be moderated by the participants age. We add this new condition in order to determine how a connection with an elderly version of the self will influence all subjects regardless of current age. Additionally, visual representations used in FSI often use aged depictions of the subjects that present facial cues that are associated with elderly adults. Our intent is to offer some insight into the use of these types of FSI as well.

#### 4.3.2. Measures

*Baseline Health Utility (BHU) and Anticipated Health Utility (AHU):* For this item we used the PROPr tool in order to have a quantifiable and comparable measure of present and anticipated health utility. PROPr is a preference-based scoring system which can be used to estimate health-related quality of life valuation (173). We started by assessing quality of life measurements in seven PROMIS® (Patient-Reported Outcomes Measurement Information System®) domains: cognitive function, emotional distress, fatigue, pain interference, physical function, ability to participate in social roles and activities, and sleep disturbances. The domains, sourced from the PROMIS-29 questionnaire and the PROMIS Cognition 4-item short form, were selected as part of the PROMIS-Preference (PROPr) scoring project. Participants were asked to answer these questionnaires for their current health status, which was used for their BHU, and answer the same questionnaire with the anticipated characteristics of their health status at the age of 68 for their AHU. The final utility scores were calculated using the PROPr multi-attribute valuation process (174).

*Health discounting (HD):* Health discounting was measured using delayed choices of a generic health state. We used a similar state as the one described in Van der Pol and Cairns (175) which reads as follows: “You have some problems with performing your usual activities (e.g. work, study, housework, family or leisure activities) and you have moderate pain or discomfort. You have no problems in walking about, nor with washing or dressing yourself and you are not anxious or depressed.” Participants were first asked to choose between a number of ill years one month from now and a larger

number of years of ill health after a delay. Through an iterative process, we add years of future ill health if the delayed amount is chosen or reduce the number of years if the original number of years of ill health in the near future is chosen. This process is repeated six times until the approximate indifference point is found.

*Monetary discounting (MD):* To measure discounting we use the Kirby Monetary Choice Questionnaire which consists of 27 choice trials of a smaller immediate reward paired with a larger delayed reward (176). Values for the rewards range from \$11 to \$85 with delays between 7 and 186 days. We will add three choice trials of a smaller and bigger present reward as an attention check.

*Connection to the Future Self (FSC):* Connection will be assessed using the Index of Future Self-Continuity (136, 142) in which participants will be presented with three images of interlinked circles (no overlap, some overlap and complete overlap) that describe how similar and connected the subject feels to their future self at different points in time. We use a line that allows the participant to choose a level of connectedness, using the circles as a reference. Additionally, using a 7-point Likert scale, they will rate how much they care and like their future self (136). For our measure of FSC, we use a composite measure of these four constructs (connection, similarity, like and care).

*Expectations of Aging (ERA):* For this construct we will use the 12-item Expectations Regarding Aging Survey (ERA-12) which measures beliefs about aging in 4 domains (177). Participants will be asked to rate, in a 4 item Likert scale (from definitely true to definitely false), 12 statements that measure expectations regarding physical and



mental health as well as cognitive function when people get older. Initially created as a measurement to determine near future expectations for older adults, this measurement has been used reliably for younger populations (178, 179). Both a global and an independent physical health, mental health and cognitive function scores can be calculated.

*Aging Anxiety (ANX):* For this measurement we used the Anxiety about Aging Scale (180), with 20 items that measure four dimensions of aging anxiety. In this study we use the subscales for psychological and physical concerns related to aging. Participants indicated their agreement to each item using a five-point Likert scale. This scale has been validated as a construct to measure aging anxiety across different age groups and genders (181).

*Control Variables:* Additional measures were included in the questionnaire which are used as control variables in our model. Participants indicated their age, gender and other demographic variables. They also answered questionnaires regarding their health locus of control beliefs and subjective health. Finally, participants were asked to self-report how frequently they practiced eight preventive health behaviors in the last 6 years. These behaviors were then aggregated as a single preventive health index (182).

#### **4.4. Results**

The final sample of 168 participants was distributed in the three conditions as follows: 53 in the control group ( $M_{age} = 31.4$ , 40% female), 54 in the 20-year intervention ( $M_{age} =$

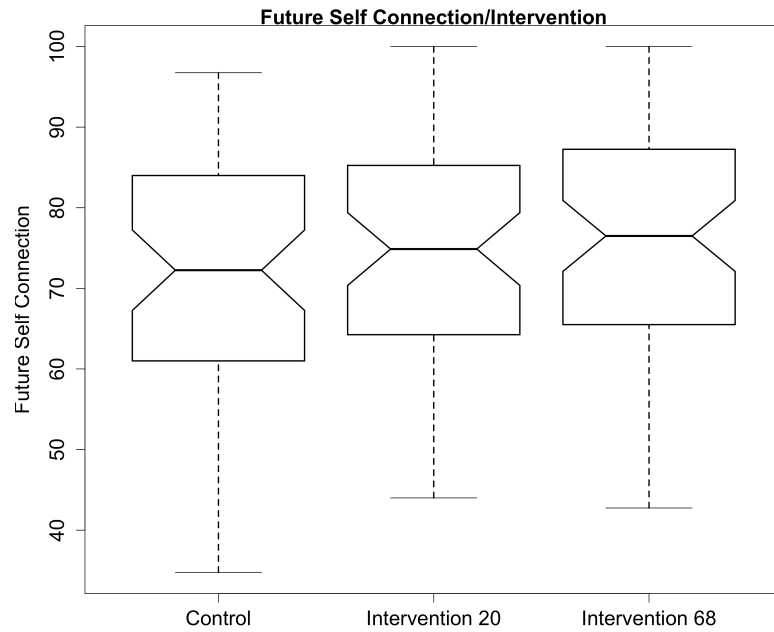
30.6, 48% female) and 61 in the 68-year-old intervention ( $M_{\text{age}} = 30.5$ , 48% female).

General demographic information for these samples is found on Appendix 3.

On **figure 4.3** we find the effect of the manipulation on our variables of interest. Contrary to previous work, which has found an increase on the measure of future self connection when participants are exposed to FSI, we find a small non-significant increase on connection for our intervention groups (**Figure 4.3(a)**). We also find that the manipulation does not have a direct effect on our first independent variable, anticipated health utility (**Figure 4.3(b)**).

#### Anticipated Health Utility

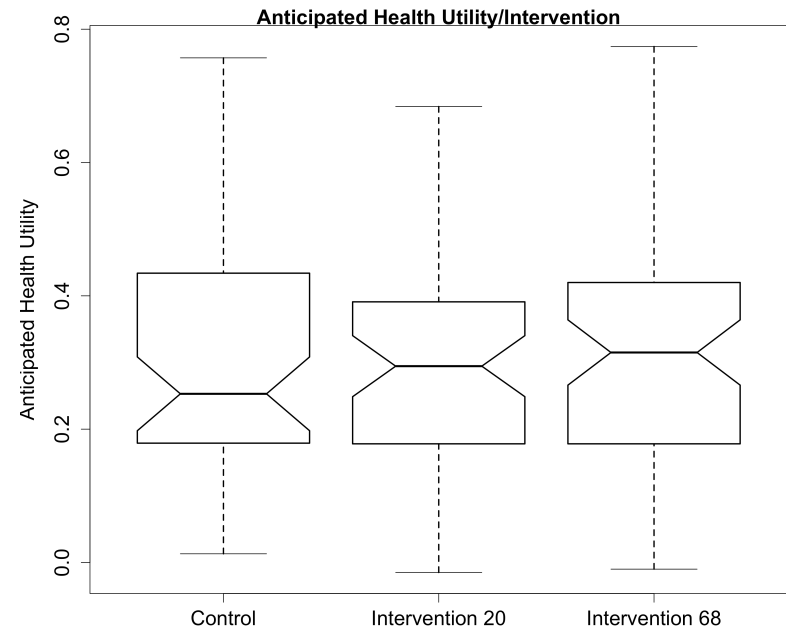
For our first hypothesis we expected a relationship between our measure of anticipated future health utility, future self-connection, aging anxiety and expectations regarding aging. Intercorrelations, means and standard deviations for these variables and other suggested control variables are found on Appendix 4. The directional relationships of our variables of interest and our independent variable Anticipated Health Utility (AHU) are summarized in **Figure 4.4**, with a detailed table of the model results in Appendix 5. Results for the multivariable linear regression to test hypothesis 1a to 1d (**Equation 4.1**) are found in this figure.



(a) FSC Cohen's d

$d_{C-20} = 0.15$

$d_{C-68} = 0.27$

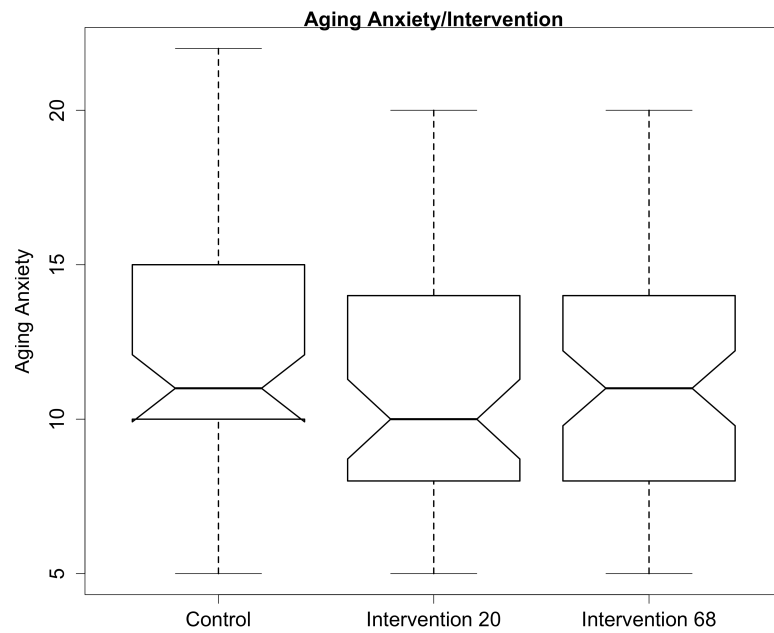


(b) AHU Cohen's d

$d_{C-20} = 0.00$

$d_{C-68} = 0.04$

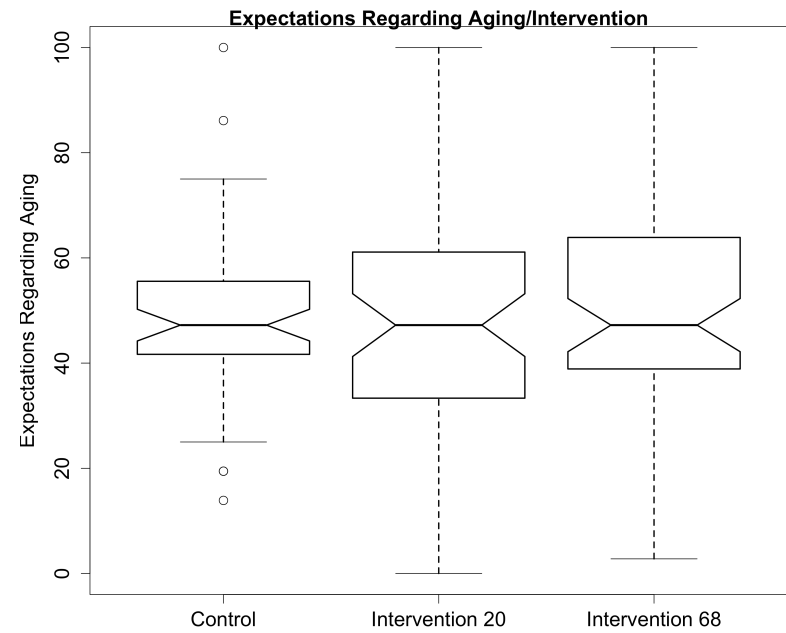
**Figure 4.3** Effect of Manipulation on Variables of Interest  
Future Self Connection (left) and Anticipated Health Utility



(c) ANX Cohen's d

$d_{C-20} = 0.15$

$d_{C-68} = 0.11$

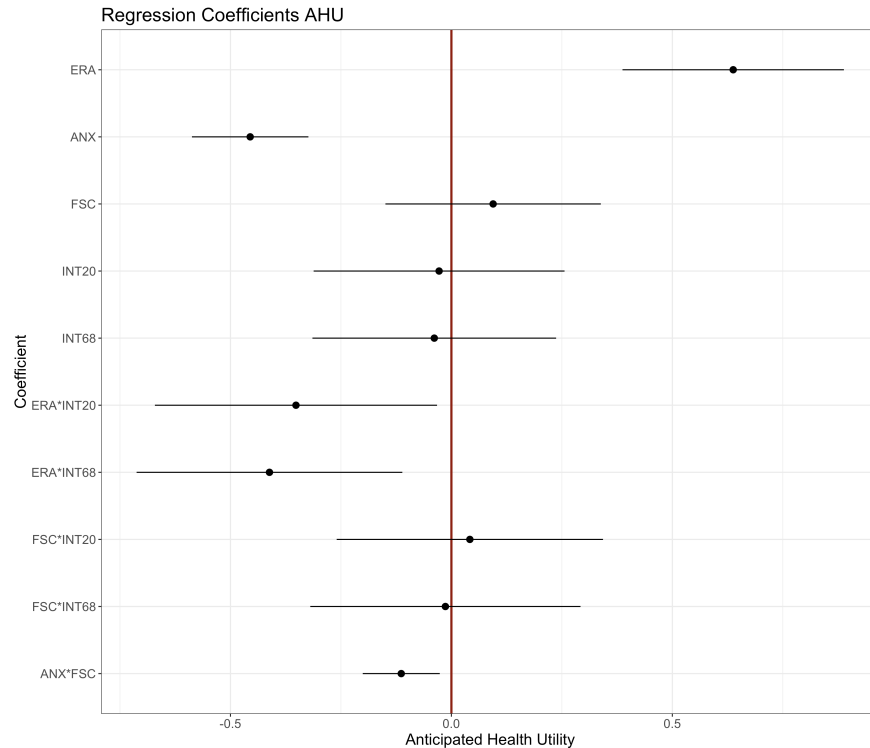


(d) ERA Cohen's d

$d_{C-20} = 0.19$

$d_{C-68} = 0.01$

**Figure 4.3** Effect of Manipulation on Variables of Interest (Cont.)  
Aging Anxiety (left) and Expectations Regarding Aging (right)



**Figure 4.4** Coefficients Linear Regression Anticipated Health Utility

### ***Future Self Connection***

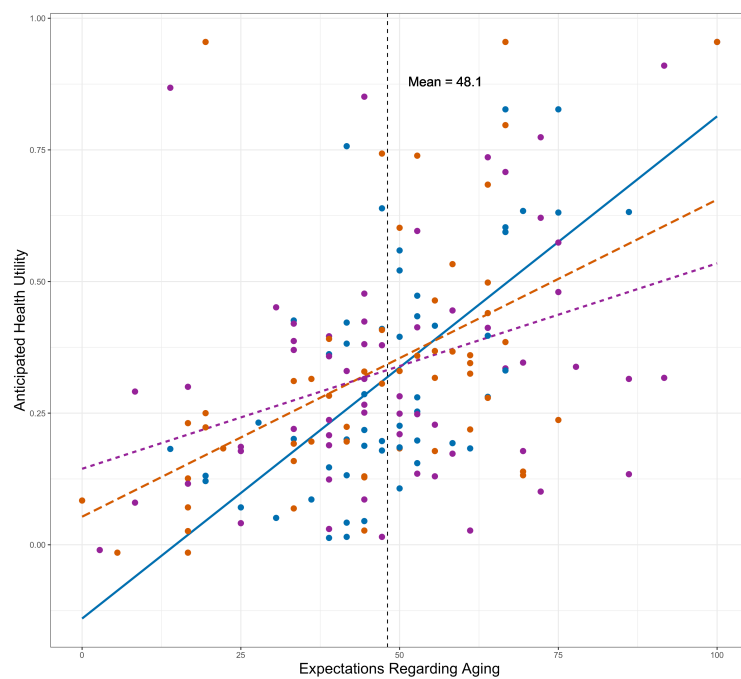
We expected that closeness to a future version of the self, often related to positive feelings and expectations for the future, would result in more positive anticipated values of health utility at old age. As suggested by hypothesis 1a, future self connection had a positive effect on anticipated health utility overall, however, the value for this coefficient was not significant. Similarly, we suggested that the connection generated by a vivid image of the elderly self for those in the 68-year-old letter writing condition would accentuate negative physical stereotypes that may directly affect health valuation.

While the coefficient for this interaction is in fact negative, it is very close to zero and not significant.

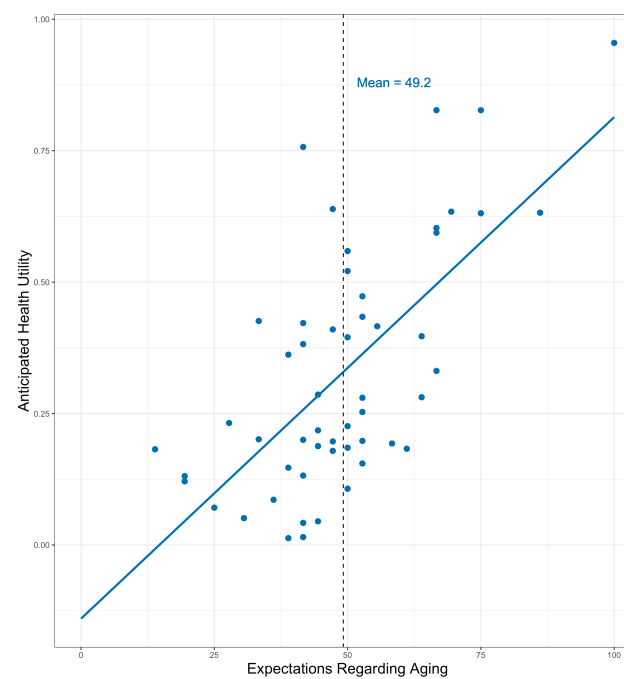
### ***Aging: Expectations and Anxiety***

Our two constructs of aging beliefs, used to measure expectations and affect, had a significant relationship with the way that anticipated health is evaluated. A more positive expectation of aging is correlated to a higher valuation of anticipated future health utility, with a standardized coefficient  $b = 0.32$ ,  $SE = 0.06$ ,  $t(5) = 5.05$ . Similarly consistent, greater aging anxiety (ANX) has a negative effect on the measure of anticipated health utility ( $b = -0.45$ ,  $SE = 0.07$ ,  $t(5) = -6.55$ ).

The relationship between AHU and expectations (ERA) remains positive when we add the hypothesized interactions, suggesting that general expectations of aging, whether negative or positive, influence how a decision-maker views her own future health. However, unlike what we predicted (H1b), when mediated by the intervention the effect of expectations regarding aging on anticipated health utility does not increase in magnitude. **Figure 4.5** represents the simple slope of the relationship between ERA and AHU for the participants in each of the three groups (a). The effect of this interaction on the coefficient of ERA is of a negative magnitude for both interventions, reducing the slope of the linear relationship. While the control group (b) has a highly positive relationship, with increases in ERA correlated to large increases in AHU, this effect is less pronounced for the intervention groups (c and d). Hence, the valuation of future health is less influenced by expectations of aging for those participants in the intervention group, with a less steep slope for those in the 68-year-old intervention.



(a)

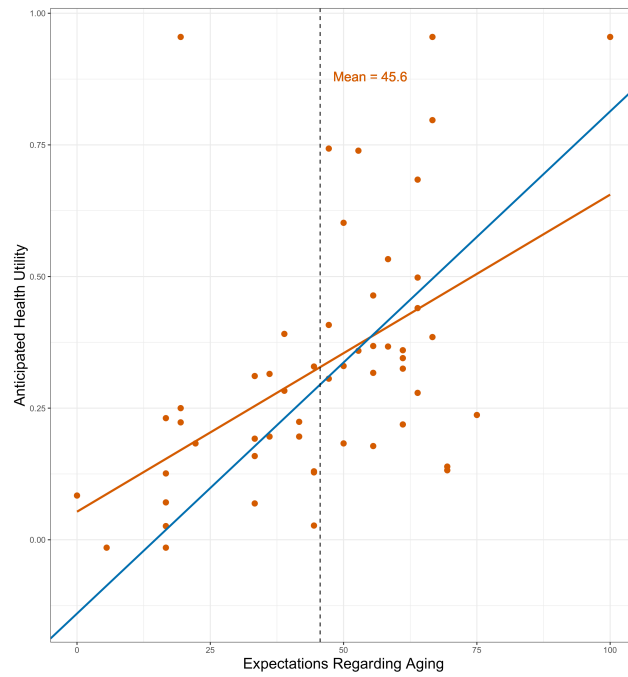


(b)

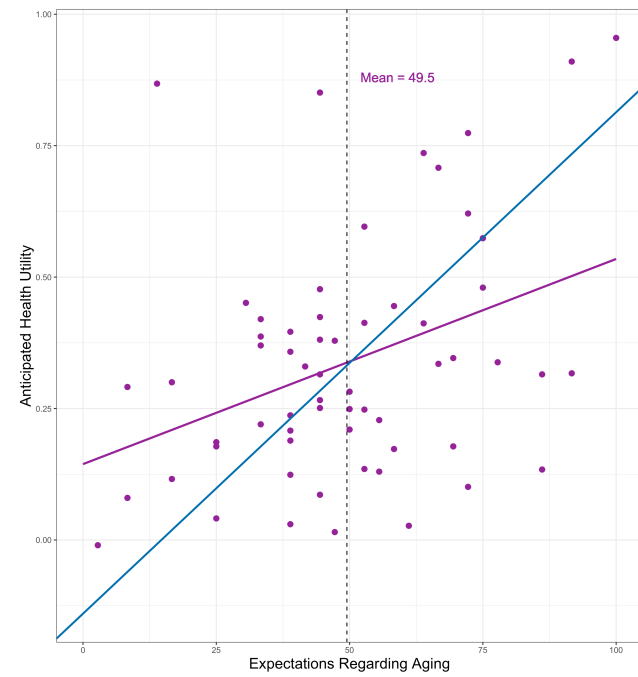
**Intervention Type**

- CONTROL
- INTERVENTION 20
- INTERVENTION 68

**Figure 4.5** Relationship between ERA and AHU



(c)



(d)

**Intervention Type**

- CONTROL
- INTERVENTION 20
- INTERVENTION 68

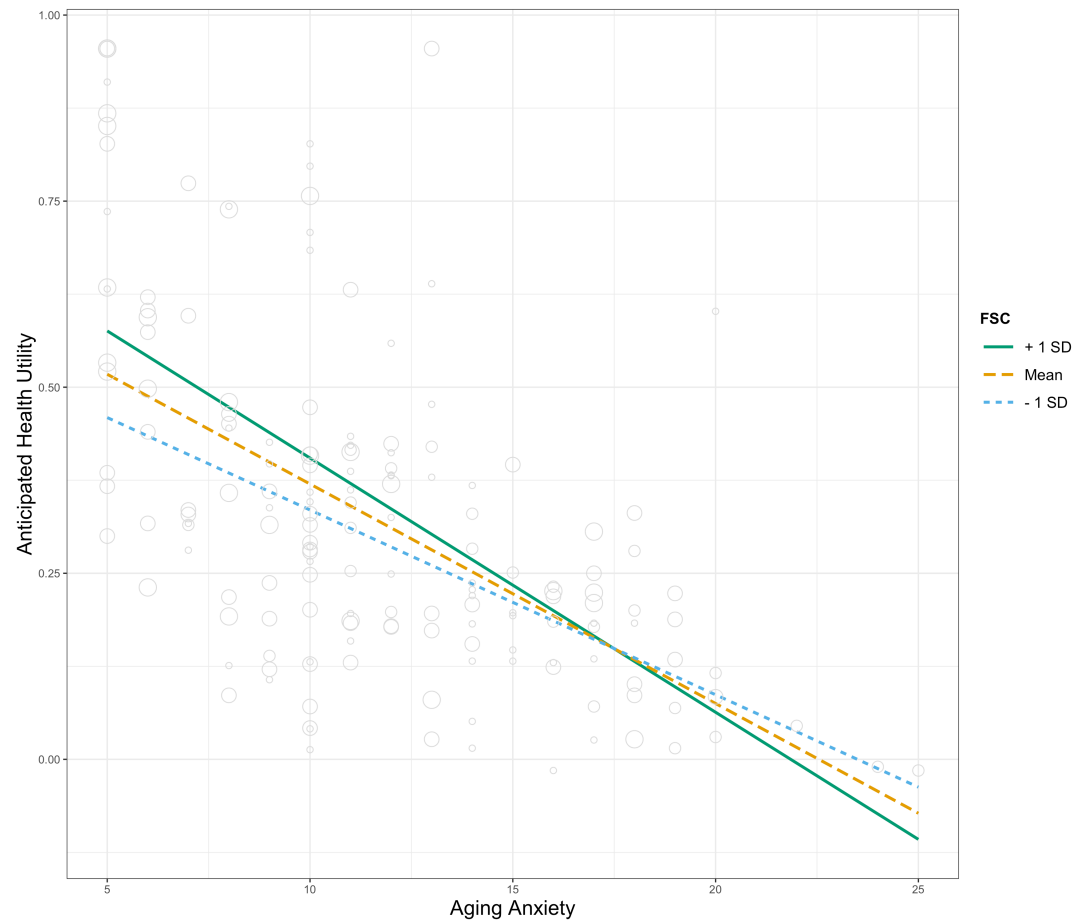
**Figure 4.5** Relationship between ERA and AHU (Cont.)



We had also hypothesized that, as the decision maker is faced with a version of its elderly self, the interventions may have had a direct effect on aging anxiety (H1c). However, we find a very small effect of either of the interventions on our measure of aging anxiety, described by a Cohen's  $d_{C-20} = 0.15$  and  $d_{C-68} = 0.11$  for the 20 year and 68-year-old intervention respectively (**Figure 4.3** (c)).

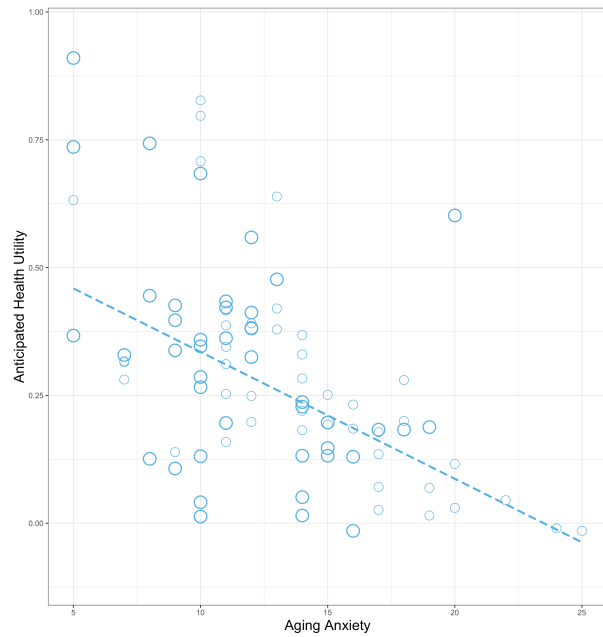
As proposed by hypothesis H1d, we find that the effect of aging anxiety on AHU is negative. We also hypothesized an interaction between ANX and the level of overlap with the future self, with higher values of FSC increasing the negative effect of aging anxiety on AHU. The simple slope relationship in **Figure 4.6** (a) shows the different slopes that result from different levels of future self connection.

In **figure 4.6** (b) we show the relationship between Aging Anxiety and AHU when FSC is set at its mean minus 1 standard deviation. The plotted data represent subjects whose FSC measure is under the population mean ( $M_{FSC}=73.7$ ). We can compare this value with **figure 4.6** (c), which shows the relationship between ANX and AHU when FSC is set at +1 standard deviation of its mean value and plots subjects with an FSC value above the mean. The steeper negative slope of the later represents how higher values of FSC increase the magnitude of the negative relationship between Aging Anxiety and AHU.

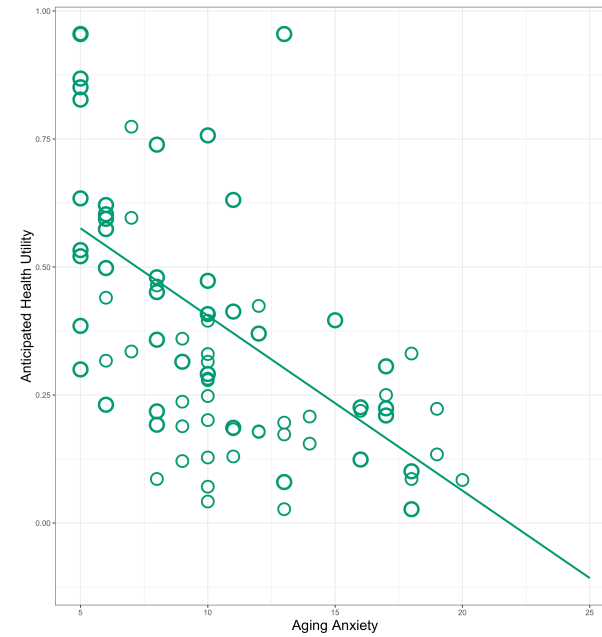


(a)

**Figure 4.6** Relationship between Aging Anxiety and AHU at different levels of FSC



(b)



(c)

**Figure 4.6** Relationship between Aging Anxiety and AHU (Cont.)  
Future Self Connection set at mean -1SD (left) and Future Self Connection set at mean +1SD (right)

## Health Discount Rate

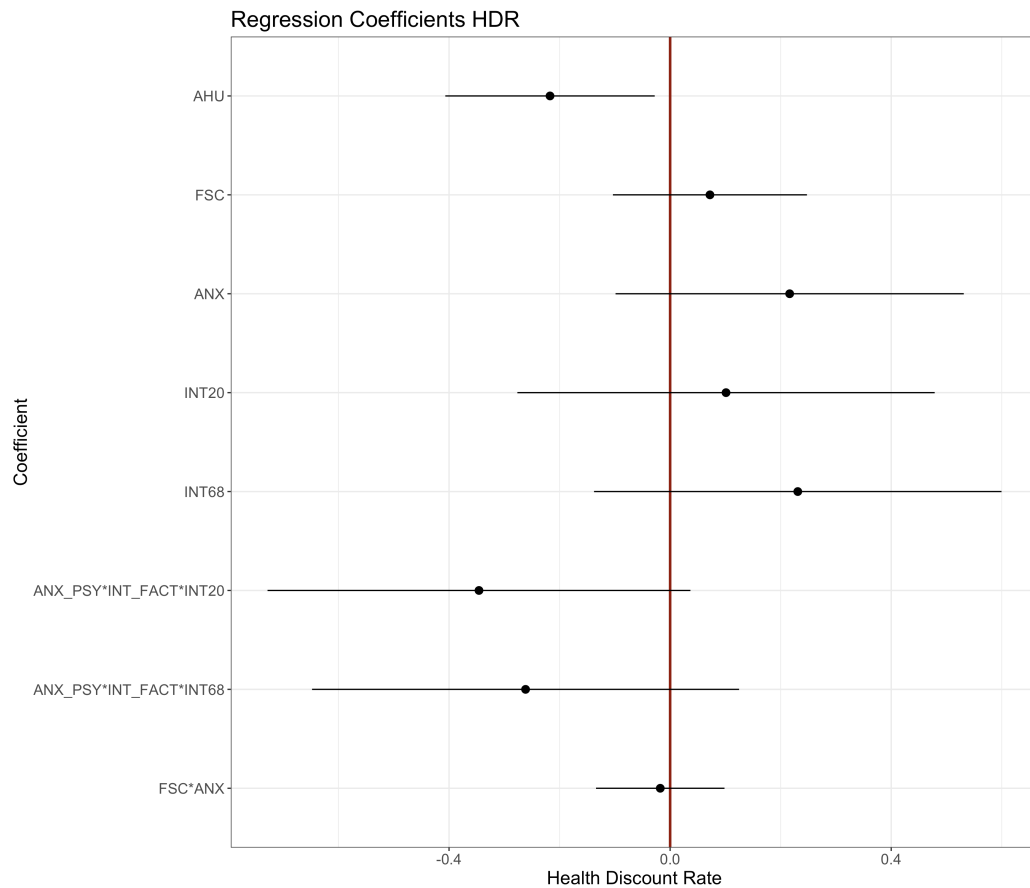
For hypothesis 2a, 2b and 2c we wanted to test the effect of different constructs on the health discount rate. Results of this regression are found on Appendix 6.

### ***Future Self Connection***

Unlike previous work that suggest that a higher future self connection will reduce discounting for future monetary outcomes, we find that this relationship does not exist in the case of the Health Discount Rate. It is important to note that our measure of connection is in fact positively correlated to the health discount rate, however, this coefficient is not significant which limits our interpretation (**Figure 4.7**).

### ***Anticipated Health Utility and Discounting***

As predicted in H2a, we find that a greater value of anticipated health utility reduces the health discount rate. This effect is consistent as we add other predictors and it is the only coefficient significant at the  $p=0.05$  level in our predicted model (**Equation 4.2**), with a standardized coefficient of  $b= -0.22$  and a  $SE= 0.09$ .



**Figure 4.7** Coefficients Linear Regression Health Discount Rate

## 4.5. Discussion

The goal of the current study was to determine how aging anxiety and expectations influence the way that future health utility is valued and discounted. Furthermore, we wanted to inform how FSI, used as tools to influence health behavioral change, may have unintentional outcomes specific to health valuation. Our results suggest that expectations of the aging process and anxiety about aging do in fact influence how a decision-maker assesses her anticipated future quality of life and its utility value. Furthermore, we also find evidence that the different interactions resulting from FSI may

have significant effects on how these constructs relate to anticipated health utility. Finally, we also find evidence that health discounting decreases as the assessed anticipated health valuation increases.

Through our results we confirm our hypothesis that both lower aging anxiety and higher expectations regarding aging are significantly correlated to a higher valuation of the anticipated utility of health. For the former, we find that aging anxiety interacts with future self connection to decrease anticipated health utility. Hence, existing anxiety related to aging and an enhanced identification with the future self result in a greater negative valuation of the quality of life that is expected during old age. However, our results may also be interpreted as aging anxiety having a moderating effect on future self connection. Although causality cannot be determined from the data collected for this study, we could hypothesize that aging anxiety might influence how much of the positive versus negative stereotypes of aging are relevant to the visualization of the future self. This is supported by the fact that greater aging anxiety has been shown to be correlated with increases in negative aging stereotypes (158). Furthermore, aging anxiety might allow for different levels of connection as a coping mechanism (183), where the decision-maker is connected to the wiser older version of the future self but disconnected from its perceived physically frail body.

Previous studies have found that FSI increase group identification with the elderly and positively impact views toward older adults, changing existing perceptions (184). Our results give some insight into how the decision-maker might conceptualize its own future health after participating in FSI. We find a decrease in the magnitude of the

influence of expectations regarding aging in the valuation of anticipated health utility for those participating in the interventions. This departure from our predicted result suggest that the vividness of the self, enhanced by the intervention, may actually replace expectations of aging with more personal representations of the aged self, diminishing the effect of these preexisting beliefs in how future quality of life is valued.

Previous work suggests that once a connection to a version of the future self is enhanced, future oriented thinking may establish a relevance between different temporal selves and highlight a positive outlook of the future, including the future of the 68-year-old self for whom anticipated quality of life is measured in this study (150). Nevertheless, we hypothesized, when this connection is directly to the elderly self, physical and negative health aspects of the aged future self might be emphasized. However, we find a non-significant effect of a closer connection on anticipated health utility. A preliminary review of the written letters suggests that most participants in the intervention groups highlighted positive non-health related future outcomes when visualizing the future self. A different result might be expected for visual FSI which emphasize the physical aspects of connection through visual/facial cues.

Another important finding relates to the effect of anticipated utility of health on health discounting. While we were unable to find significant relationships between aging anxiety and the health discount rate, we found support for our hypothesis that a greater anticipated utility of health is correlated with a reduction in the health discount rate. This confirms our idea that if a decision-maker anticipates poor health in the future, she is less likely to highly weight future outcomes. However, it is important to state that our

measure of health discount rate measures health losses. The effect might be different if we were to measure health gains.

Further research must be conducted to determine how this utility valuation affects behavior. There is consistent evidence that positive perceptions of aging are correlated with more future oriented health behaviors. A longitudinal study found that a measure of self-perceptions of aging is positively correlated to an increase in preventive health behavior, with positive perceptions linked to the practice of more preventive health tasks over a period of 20 years (182). While most studies that have found a relationship between preventive health and aging have focused on older adults (185), more recent work has found that positive self-perceptions of aging are predictive of healthy eating in different age groups (186). We found that FSI affect the self-perception of anticipated health states for younger populations. Additional research is necessary to determine if the mechanisms that change future health valuation might have an impact on the likelihood of engaging in preventive health behaviors as well.

Future research directions include testing how facial renderings used in FSI impact both of our dependent variables. Our initial results suggest that contact with what could be considered an elderly version of the self, in our case through a written exercise to a 68-year-old self, has an effect on how much aging anxiety and expectations of aging become self-relevant. However, we didn't find significant evidence that the use of a written FSI increased aging anxiety or future self connection. Facial renderings will often use facial cues that activate aging stereotypes that have been shown to increase aging anxiety (152) and may further affect self-perceptions of aging. While we are not



suggesting that FSI, both written and visual, are not effective in enhancing future-oriented health behaviors for older or younger adults, more research is necessary to determine if there are potential tradeoffs that result from using a connection to stereotypical aged versions of the future self.

Finally, a few of the measurement tools used in this study require that participants in both the intervention groups and the control condition think about aging beyond the initial intervention. There is the possibility that by asking participants to evaluate their expectations of aging and to think about their quality of life at a future age, we are in fact activating existing aging stereotypes for all conditions. We attempt to minimize this possible confound by randomizing the order in which the questions are presented. However, we recognize that this might limit our interpretation of the results.

#### **4.6. Conclusion**

The use of FSI to promote future oriented health behavior involve placing the decision-maker in contact with its aged self. Due to persistent negative beliefs of aging, including preexisting expectations and anxiety about the aging process, this type of interventions may have unintended consequences on how the decision-maker values future health. We find evidence that aging anxiety and expectations of aging affect how anticipated future health is valued. Furthermore, the use of an intervention also has specific effects on this valuation. Due to the fact that anticipated health utility influences how much weight a decision-maker is willing to assign to future health outcomes, it is important to evaluate how the use of FSI might motivate negative views of the physical aged self. For this reason, further research that involves the use of FSI in the field of health

behavior must consider existing negative expectations of aging, as well as the possible consequences of using virtual representations with facial cues that might diminish the effect of connection on health behavior.

## **6. Conclusions**

The three papers in this dissertation address different issues in the implementation of technologies and interventions that aim to improve health outcomes. While the topics in each chapter differ, they are linked together in their effort to inform where implementation barriers may be found and how they can be addressed. Furthermore, they offer insight into how different areas of research, such as network analysis and decision sciences, may be used to tackle these issues.

Our second chapter focuses on the hospital level information exchange through the use of Electronic Health Records (EHR). Identifying the barriers for information exchange is a necessary step to achieve the goals of the implementation of EHRs, which include creating a more efficient and effective healthcare system. Policy incentives implemented through Meaningful Use have left gaps which allow EHR vendors to implement information exchange capabilities in different ways. Our research suggests that this permits for the creation of proprietary exchange networks that foreclose some hospitals. In our analysis at the state level we find no significant relationship between the percentage of hospitals that participate in health information exchange and the policies implemented through the State Health Information Exchange Cooperative Agreement Program. We suggest that future state level policies should consider the different market conditions of EHR vendors in order to accommodate hospitals that may be left out of large proprietary networks.

In our third chapter, we aimed to identify barriers for high risk non-adherent people living with HIV (PLWH) that hindered the effectiveness of clinical interventions

used to incentivize their ART medication adherence. Identifying the decision-making processes of such “high risk” PLWH, people who repeatedly struggle with adherence yet continually fall between the cracks of current interventions, is an important step toward creating more inclusive treatment options. Through a mental model’s approach, we were able to validate some of the factors and links related to ART medication non-adherence found in the literature. More importantly, we were also able to identify several psychosocial and affective barriers that had not yet appeared in previous research of ART adherence including: present bias and the effects of scarcity, affective biases, and information retrieval heuristics. Further work is necessary to determine how prevalent our findings are for this specific population as well as for PLWH as a whole. However, even this preliminary research on the context and barriers facing ART patients points to important implications for clinical practice.

The fourth chapter addresses potential barriers in the use of Future Self Interventions (FSI) to incentivize future oriented health behavior. FSI have been shown to be effective in promoting future oriented behavior in other areas. However, the use of these interventions involves placing the decision maker in contact with its aged self. Due to persistent negative beliefs of aging, including preexisting expectations and anxiety about the aging process, these interventions have specific effects on how future health is valued. We find that greater aging anxiety and lower expectations of aging decrease the value of anticipated future health. Furthermore, anticipated health utility influences how much weight a decision maker is willing to assign to future health outcomes. Our results suggest that in the context of health decision making, it is important to evaluate how the use of FSI might motivate negative views of the physical

aged self. For this reason, FSI that use virtual representations with facial cues need to evaluate how activating aging stereotypes may diminish the effects of future self connection.

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## Appendices

### Appendix 1: Additional Descriptive Statistics Chapter 2

**Table A**

Characteristics of Sample Hospitals for Logistic Regression Model

		<i>Sample Hospitals</i>	<i>Percentage (N=1871)</i>
Hospital Size	Small (<100 beds)	870	47%
	Medium (100-399 beds)	754	40%
	Large ( $\geq$ 400 beds)	247	13%
Ownership	Non-Profit	1321	71%
	For-Profit	155	8%
	Public	395	21%
Affiliated to an IDS	Yes	1135	60%
	No	672	36%
	No Information	64	3%
Capable of Using CCR, CDA or CCD	Yes	1486	79%
	No	183	10%
	Do Not Know	202	11%

**Table B**

Percent of Hospitals that Share Clinical Care Summaries with Other Hospitals Outside their Health System

(Null hypothesis is that the difference in percent share is zero)

<b>State</b>	<b>% Share Clinical Care Summary</b>	<b>n(N)</b>	<b>Reject Null Hypothesis p value*</b>
Alaska	33%	2(6)	
Alabama	48%	15(31)	
Arkansas	26%	9(35)	
Arizona	33%	11(33)	
California	32%	47(148)	
Colorado	57%	24(42)	p<0.05
Connecticut	31%	4(13)	
District Of Columbia	0%	0(4)	
Delaware	67%	2(3)	
Florida	23%	19(82)	p<0.05
Georgia	40%	17(43)	
Hawaii	55%	6(11)	
Iowa	29%	20(70)	
Idaho	47%	9(19)	
Illinois	19%	22(118)	p<0.05
Indiana	46%	24(52)	
Kansas	38%	30(78)	
Kentucky	31%	18(59)	
Louisiana	29%	11(38)	
Massachusetts	24%	8(33)	
Maryland	36%	10(28)	
Maine	37%	7(19)	
Michigan	31%	20(65)	
Minnesota	56%	57(102)	p<0.05
Missouri	21%	24(112)	p<0.05
Mississippi	22%	6(27)	
Montana	23%	5(22)	
North Carolina	56%	27(48)	p<0.05
North Dakota	54%	7(13)	
Nebraska	43%	13(30)	
New Hampshire	55%	6(11)	
New Jersey	64%	27(42)	p<0.05
New Mexico	14%	3(21)	p<0.05
Nevada	18%	2(11)	
New York	40%	36(89)	
Ohio	63%	55(87)	p<0.05

<b>Oklahoma</b>	19%	9(48)	p<0.05
<b>Oregon</b>	71%	15(21)	p<0.05
<b>Pennsylvania</b>	34%	35(103)	
<b>Rhode Island</b>	0%	0(7)	p<0.05
<b>South Carolina</b>	38%	6(16)	
<b>South Dakota</b>	52%	12(23)	
<b>Tennessee</b>	23%	10(43)	p<0.1
<b>Texas</b>	27%	53(199)	p<0.05
<b>Utah</b>	29%	6(21)	
<b>Virginia</b>	64%	25(39)	p<0.05
<b>Vermont</b>	50%	3(6)	
<b>Washington</b>	65%	22(34)	p<0.05
<b>Wisconsin</b>	50%	47(94)	p<0.05
<b>West Virginia</b>	20%	5(25)	p<0.1
<b>Wyoming</b>	31%	4(13)	

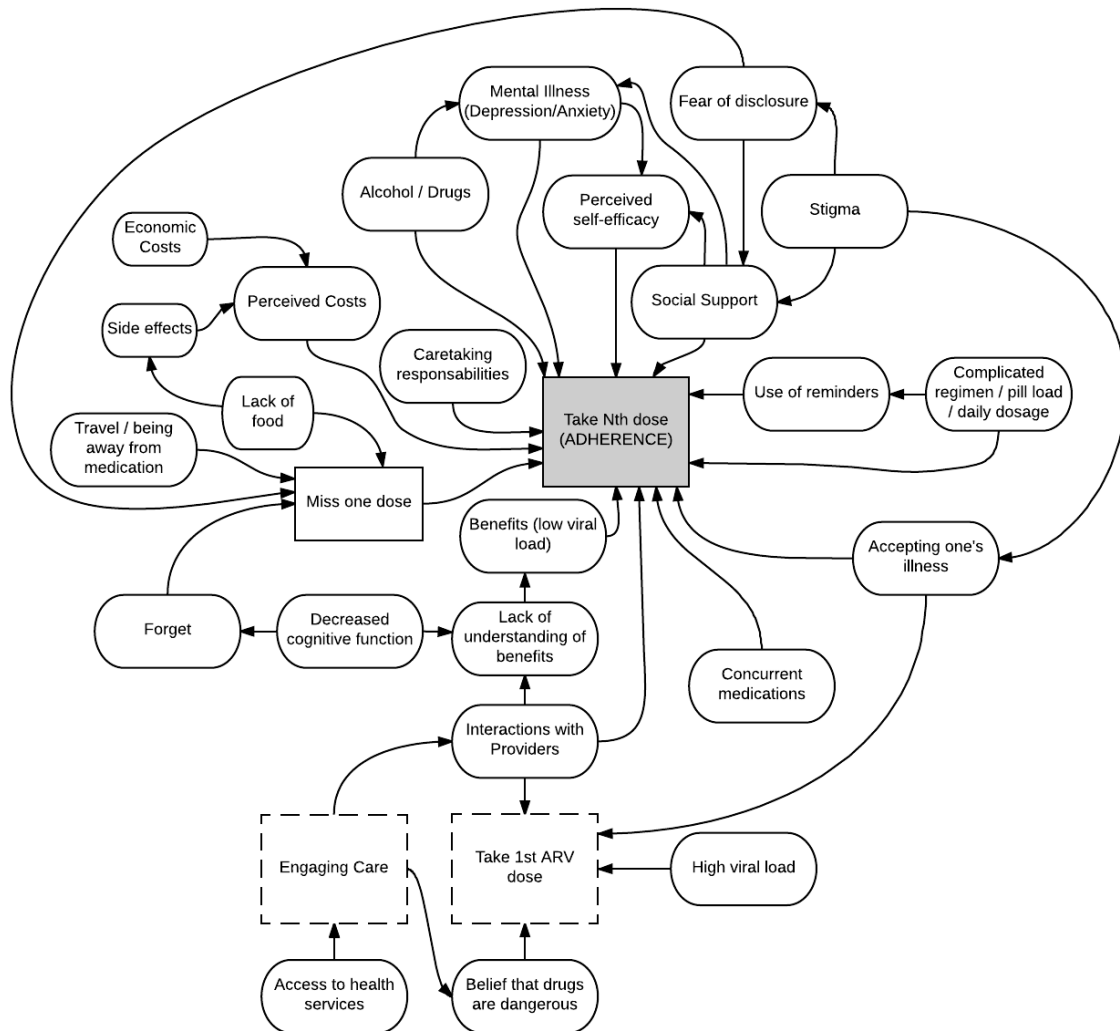
*Note:*

n = Number of hospitals that share clinical care summaries with hospitals outside their health system

N = Total number of hospitals per state in the database that responded to the variable of analysis

\*Percentage share of other states is not significantly different than the total mean

## Appendix 2: Expert Model Chapter 3





### Appendix 3: Sample Demographic Chapter 4

	Total (N=168)	Control Group (N=53)	Intervention 20 years (N=54)	Intervention 68-year-old (N=61)
<b>Gender</b>				
Female	45%	40%	48%	48%
Male	55%	60%	52%	52%
<b>Education</b>				
Less than high school	1%	0%	0%	2%
High school graduate	14%	13%	19%	10%
Some college, no degree	23%	26%	20%	23%
Bachelor's/Associate's degree	52%	53%	50%	54%
Graduate degree	10%	8%	11%	11%
<b>Employment Status</b>				
Employed	89%	91%	89%	87%
Unemployed	8%	6%	9%	8%
Student	3%	4%	2%	3%
Disabled	1%	0%	0%	2%
<b>Income</b>				
Less than \$25,000	17%	21%	20%	11%
\$25,000 to \$34,999	20%	21%	9%	30%
\$35,000 to \$49,999	20%	15%	33%	13%
\$50,000 to \$74,999	21%	21%	22%	21%
\$75,000 or more	21%	23%	15%	25%
<b>Race</b>				
African American	7%	6%	6%	10%
Asian	10%	2%	15%	11%
American Indian or Alaska Native	3%	4%	2%	3%
White	78%	89%	74%	72%
Other	2%	0%	4%	3%
<b>Health Status</b>				
Excellent	20%	17%	19%	25%
Good	59%	57%	67%	54%
Fair	18%	23%	11%	20%
Not so good	3%	4%	4%	2%

#### Appendix 4: Table of Intercorrelations Equation 4.1

	<i>Intercorrelations</i>							
	1	2	3	4	5	6	7	8
1. FSC								
2. ERA	0.17*							
3. BHU	0.31***	0.25***						
4. ANX	-0.43***	-0.34***	-0.47***					
5. LOC	0.22**	0.18*	0.27***	-0.41***				
6. AGE	0.16*	-0.1	0.20**	-0.23**	0.01			
7. PREV	0.29***	0.06	0.31***	-0.25***	0.17*	0.06		
8. AHU	0.32***	0.48***	0.66***	-0.59***	0.33***	0.13	0.27***	
Mean	73.7	48.1	0.52	11.6	26.4	30.8	29.8	0.33
Standard deviation	16.1	19.4	0.28	4.4	4.8	5.5	4.7	0.23
<i>Note:</i>						*p<0.05; **p<0.01; ***p<0.001		

## Appendix 5: Linear regression Anticipated Health Utility Equation 4.1

	<i>Dependent variable:</i>		
	Anticipated Health Utility		
	(1)	(2)	(3)
ERA	0.318*** (0.063)	0.638*** (0.128)	0.489*** (0.111)
ANX	-0.448*** (0.068)	-0.455*** (0.067)	-0.256*** (0.064)
FSC	0.075 (0.065)	0.094 (0.124)	-0.100 (0.109)
INTERVENTION20	-0.025 (0.148)	-0.028 (0.145)	0.106 (0.128)
INTERVENTION68	-0.036 (0.143)	-0.039 (0.141)	0.080 (0.122)
BHU			0.445*** (0.060)
LOC			0.069 (0.056)
ERA*INTERVENTION20		-0.352** (0.163)	-0.201 (0.141)
ERA*INTERVENTION68		-0.412*** (0.153)	-0.295** (0.133)
FSC*INTERVENTION20		0.042 (0.154)	0.243* (0.134)
FSC*INTERVENTION68		-0.014 (0.156)	0.105 (0.134)
ANX*FSC		-0.113** (0.044)	-0.092** (0.038)
Constant	0.021 (0.105)	-0.030 (0.104)	-0.109 (0.090)
Observations	168	168	168
R <sup>2</sup>	0.44	0.49	0.63
Adjusted R <sup>2</sup>	0.42	0.46	0.61
Residual Std. Error	0.76 (df = 162)	0.74 (df = 157)	0.63 (df = 155)
F Statistic	25.6*** (df = 5; 162)	15.1*** (df = 10; 157)	22.3*** (df = 12; 155)

*Note:*

\*p<0.1; \*\*p<0.05; \*\*\*p<0.01

## Appendix 6: Linear Regression Health Discount Rate Equation 4.2

	<i>Dependent variable:</i>		
	Health Discount Rate		
	(1)	(2)	(3)
AHU	-0.213** (0.095)	-0.217** (0.097)	-0.229** (0.113)
FSC	0.066 (0.086)	0.072 (0.090)	0.095 (0.091)
ANX	-0.003 (0.100)	0.216 (0.161)	0.227 (0.161)
INTERVENTION20	0.093 (0.192)	0.101 (0.193)	0.160 (0.197)
INTERVENTION68	0.217 (0.187)	0.231 (0.188)	0.267 (0.190)
PREV			-0.142* (0.084)
BHU			0.058 (0.107)
ANX* INTERVENTION20		-0.346* (0.195)	-0.361* (0.196)
ANX* INTERVENTION68		-0.262 (0.197)	-0.288 (0.197)
FSC*ANX		-0.018 (0.059)	-0.020 (0.059)
Constant	-0.109 (0.137)	-0.133 (0.138)	-0.166 (0.140)
Observations	168	168	168
R <sup>2</sup>	0.05	0.07	0.09
Adjusted R <sup>2</sup>	0.02	0.027	0.03
Residual Std. Error	0.99 (df = 162)	0.99 (df = 159)	0.99 (df = 157)
F Statistic	1.66 (df = 5; 162)	1.45 (df = 8; 159)	1.46 (df = 10; 157)
<i>Note:</i>			*p<0.1; **p<0.05, ***p<0.01