



# Quality of Life, Health-Related Stigma, and the Social Context: Longitudinal Analyses of PLWHA in Uganda and a Literature Review

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**Quality of life, health-related stigma, and the social context: longitudinal analyses of PLWHA in Uganda and a literature review**

The dissertation examines the experience of living with stigmatized health conditions in the social context.

The first paper examines the dynamic, bi-directional relationship between social support and HIV-related stigma. I use data from a prospective cohort of people living with HIV/AIDS (PLWHA) initiating antiretroviral therapy in rural Uganda. I use multilevel regression to model the contemporaneous and time-lagged relationships between two dimensions of stigma and social support. The results suggest that the two dimensions of stigma may compromise the ability to maintain and access social support. I also found that social support may be protective against future experiences of discrimination.

The second paper examines the trajectory and determinants of health-related quality of life (HRQOL) of PLWHA initiating antiretroviral therapy. Using the same data set as paper one, I compared two types of multilevel models for change in which HRQOL is specified as linear and quadratic functions of time. Analyses indicated that HRQOL follows a quadratic trajectory that is concave to the time axis. Self-reported symptoms, food insecurity, and HIV-related stigma are negatively correlated with HRQOL, suggesting the importance of addressing social and economic situations of PLWHA in addition to clinical symptoms.

The third paper is an interdisciplinary review of health-related stigma. The social psychology literature describes stigma as a product of individual traits and personalities that has roots in the biological instinct to avoid poor partners of social exchange. In contrast, the

historical, anthropological, and autobiographical literatures highlight the role of social forces outside of the individual in the production of stigma. I argue that health-related stigma is based on the ever-changing understandings about disease causality that reflects contemporary ideas about morality. Further, stigmatization is contingent on a social structure in which differential access to social, economic and political power determines who is stigmatized. Finally, stigmatization dehumanizes individuals who are already vulnerable, and erects barriers to health and social resources to further exacerbate social inequalities. Therefore, health-related stigma should not be used as a tool to promote public health, and societal efforts should focus on eliminating health-related stigma.

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## **CHAPTER 1**

**Health-related quality of life among people living with HIV/AIDS initiating antiretroviral therapy in rural Uganda**

## INTRODUCTION

The health-related quality of life (HRQOL) has become a priority in the care of people living with HIV/AIDS (PLWHA), especially as access to Highly Active Antiretroviral Therapy (HAART) expands across the globe, making HIV/AIDS a long-term chronic, rather than an acute, condition. Measure of HRQOL captures not only the subject's appraisal of health status but also its impact on functional status such as the ability to perform self-care and daily activities, decreased pain and discomfort, improved strength and appetite, and improved mental functioning.<sup>1-3</sup> Such self-reported HRQOL is valuable because it can allow the assessment of the experience of illness that cannot be evaluated by medical experts,<sup>4</sup> and has been correlated with other measures of overall wellbeing such as happiness.<sup>5</sup>

Many studies of PLWHA report improvement in the HRQOL after being treated with HAART, either compared to pre-treatment baseline or compared to their untreated counterparts.<sup>6-</sup><sup>8</sup> These improvements have in part been attributed to improvements in immunologic outcomes from HAART. PLWHA on HAART have reported increases in CD4 count and reduction in detectable viral load,<sup>9</sup> and these clinical indicators have been consistently associated with improvements in reports of both physical and mental aspects of HRQOL.<sup>1,6,9,10</sup>

Non-health circumstances such as access to basic economic and social resources are believed to have a significant impact on HRQOL, particularly in resource-poor settings and vulnerable populations.<sup>11</sup> While there is an emerging interest in examining the correlates of HRQOL among PLWHA that are outside the domain of clinical indicators, there is limited systematic exploration of the relationship between social and economic factors and HRQOL of PLWHA.



Various indicators of poor economic situation have been consistently negatively correlated with HRQOL. In sub-Saharan Africa, PLWHA who owned fewer household goods and depended on others for their main source of income reported lower both physical and mental components of health-related quality of health.<sup>1,6,12</sup> Among the homeless in the US, those who reported unmet subsistence needs reported lower physical HRQOL.<sup>13</sup> Even among populations who are not considered particularly vulnerable in the United States and Europe, lower education, poorer housing, lower income and unemployment predicted lower HRQOL.<sup>8,10,14,15</sup> Evidence suggests that the positive association between economic wellbeing and HRQOL could be because patients placed on HAART partially regain their ability to work,<sup>3,16,17</sup> and consequently have access better nutrition.<sup>2</sup> Recently, Weiser and colleagues have indeed found that food security and quality of life were inversely correlated across time after initiation of HAART.<sup>18</sup>

Social factors have been strongly associated with measures of health-related quality of life among PLWHA as well.<sup>10,19,20</sup> Studies on the effect of social support on PLWHA have shown that social support has positive effects on PLWHA including less depression, improved coping with their disease, positive health behaviors, and slower progression of disease.<sup>21-24</sup> Social support may contribute to the HRQOL of PLWHA by enabling them to take part in the life of the community, as well as to access more tangible resources through friends and family. (Sen, Social Exclusion) Further, a handful of studies have examined the relationship between HIV-related stigma and HRQOL among PLWHA. Three cross-sectional studies found that high reports of HIV-stigma correlated with low measures of HRQOL, and one longitudinal study found that stigma was correlated with lower initial status of QOL.<sup>25</sup> An extensive literature exists outside of the HRQOL literature on how stigma negatively impacts the psychosocial wellbeing

of PLWHA, including stress, fear, anxiety, and depression<sup>26-29</sup> as well as poor engagement with care.<sup>30,31</sup>

Another aspect of debate is the trajectory of HRQOL once a PLWHA is placed on HAART. Some studies have shown steady improvement that was sustained for the duration of the study, which ranged from one<sup>1,25</sup> to three years,<sup>16</sup> accompanied by an increase in labor force participation.<sup>32</sup> Some studies have found an initial upward trajectory of quality of health, followed by a plateau. The duration of the increase in quality of health varied by study, ranging from one month,<sup>32</sup> three months,<sup>2</sup> six to nine months,<sup>33</sup> and one year<sup>15</sup> after initiation of HAART. Finally, some studies found no change,<sup>9</sup> or a deterioration in the quality of health.<sup>8,34</sup> Understanding the trajectory of HRQOL is important, because it would allow clinicians and public health programs to be vigilant for declines in HRQOL at critical times and to time the delivery medical or social services to modify the trajectory at critical times.

The discrepancies of these studies may reflect some of the methodological limitations of these studies. First, the duration of these studies are as short as one year,<sup>1,8,12</sup> which limits the ability to detect the longer-term trajectory. Second, is the limited number of time points at which data is collected, which limits the analytic methods as discussed below. Third, the sample size of many of these studies is limited.<sup>9</sup> Fourth, many of the studies rely on inadequate analytic models to detect change in HRQOL. One such method is statistical comparison of group means between baseline and an end-point.<sup>8</sup> Two waves of longitudinal data represent an extremely limited design for investigating change because the amount of change between the first and second occasions of measurement cannot tell us anything about the shape of each person's individual growth trajectory between those times, and estimates of true change are difficult to obtain from the observed two-wave data.<sup>35</sup> Another method is regression models with duration of treatment

as dummy variables to analyze the effect of time on treatment on HRQOL,<sup>1,16</sup> which also cannot tell us the shape of the trajectory. Finally, the studies are limited in the social and economic variables that are examined as controls and covariates. These problems limit the ability to detect the true trajectory and determinants of the HRQOL of PLWHA on HAART.

The goal of this study is to contribute to the literature on the determinants and the trajectory of physical and mental quality of health among PLWHA on HAART in a resource poor setting.

## **METHODS**

We used data from an ongoing, prospective cohort of PLWHA taking antiretroviral therapy (ART) in rural Uganda. Eligibility criteria included having no prior history of treatment with HIV ART, being over 18 years of age, and living within 20 km of the Immune Suppression Syndrome (ISS) Clinic at the Mbarara Regional Referral Hospital. The ISS Clinic is located in Mbarara District, 275 km southwest of Kampala, and provides free ART for people living with HIV/AIDS in southwestern Uganda, Rwanda and the Democratic Republic of Congo.<sup>36</sup> The majority of the population in Mbarara district is ethnically Ankole, and the local language is Runyankole. The local economy is largely based on subsistence agriculture.

Our analyses are based on data from participants who were enrolled into the cohort from 2007 through 2010. Survey questions were translated into Runyankole, back-translated into English, further modified through focus groups with key informants, and pilot-tested to ensure clarity and relevance. Trained research assistants who spoke Runyankole interviewed participants every three months in a private room at the site research office near the ISS Clinic. Each survey took approximately one hour to complete.

Informed consent was obtained from all study participants. Ethical approval for all study procedures was obtained by the Committee on Human Research, University of California at San Francisco; the Partners Human Research Committee at Massachusetts General Hospital; and the Institutional Ethical Review Committee, Mbarara University of Science and Technology.

Study variables were assessed at baseline and at each quarterly follow-up interview using the scales described below.

### **Health-related quality of life**

The primary outcomes are the physical health summary (PHS) and mental health summary (MHS) scores of the Medical Outcome Study-HIV (MOS-HIV).<sup>37,38</sup> MOS-HIV is 35-item questionnaire used widely in research and clinical trials of treatments with HIV-infection, and has shown very good internal consistency, construct validity, test-retest reliability, have good discriminant validity and clinical responsiveness in a variety of settings<sup>39,40</sup> including rural Uganda.<sup>12</sup> MOS-HIV assesses multiple dimensions of HRQOL, including perceived ability to work and perform daily role, perceived health functioning, perceived vitality, memory and reasoning, affect, and a self-rating of perceived general health. Factor analyses have consistently identified physical health (PHS) and mental health factors (MHS) that are used as summary indicators.<sup>40</sup> A higher score reflects a better health-related quality of life.

### **Clinical Indicators**

In our regression models, we adjusted for self-reported symptoms, depression, and CD4+ T-lymphocyte cell count. I measured 32 symptoms, such as headache, pain, and fatigue, and created a summary index composed of equally weighted average of z-scores of its components as described by Kling and colleagues, with higher scores indicating a greater symptoms burden.<sup>41</sup>

Because prior studies have shown that depression is associated with HRQOL,<sup>20,34</sup> I also adjusted for depression symptom severity. We measured depression using a version of the 15-item Hopkins Symptom Checklist for Depression<sup>42</sup> that was adapted to the local context with the addition of a 16th item, “feeling like I don’t care about my health.”<sup>27,43</sup> I restricted the calculation of the score to the 12 affective items in light of prior research suggesting that the somatic items overlap with symptoms of HIV infection and may inflate the prevalence of depression among PLWHA.<sup>44,45</sup> Participants were classified as having probable depression based on the conventional threshold score of 1.75.<sup>46</sup>

### **Economic Indicators**

I examined the following economic indicators: asset ownership, unemployment, and food insecurity. I measured baseline asset ownership using a household asset index,<sup>47</sup> which was entered into the models as a continuous variable, with higher values of the asset index indicating greater household wealth relative to other households in the sample. I used the Household food insecurity access scale (HFIAS) to measure food insecurity. This nine-item scale asks about uncertainty or anxiety over food, perceptions about quantity, quality, reduction of food intake, consequences of reduced food intake, shame. These questions attempt to capture the household’s perception of changes to the quality of their diet regardless of the diet’s objective nutritional composition. Participants were identified as being food secure, or mildly, moderately, and severely food insecure.

### **Social Indicators**

I examined social support, internalized stigma, and enacted stigma for our social indicators. I measured social support using the Social Support Scale,<sup>48</sup> which contains 10 items

about instrumental and emotional social support. High scores reflect higher levels of social support. This scale is adapted from the Duke-University of North Carolina Functional Social Support Questionnaire, which was designed to measure multiple dimensions of social support among patients in a primary care setting.<sup>49</sup> Internalized HIV stigma was measured using the Internalized AIDS-Related Stigma Scale, which contains six items corresponding to the guilt, shame, and worthlessness in Goffman's conceptualization of stigma.<sup>50-52</sup> To measure enacted stigma, we asked participants about whether they had experienced 14 discriminatory events in the past three months as a result of their HIV status, such as abandonment, housing, or property loss, or physical violence.<sup>53</sup> The enacted stigma scale was calculated as the sum of the 14 items, with higher scores indicating greater intensity of enacted stigma experienced.

Finally, I adjusted for a range of other baseline (time-invariant) demographic covariates with potential for influencing HRQOL. We adjusted for baseline age, sex, educational attainment and marital status. Time was measured in years since starting HAART.

### **Data analysis**

I used multilevel model for change to investigate the change in HRQOL over time. The dependent variable used in these analyses was HRQOL as measured in the PHS and MHS components of MOS-HIV. The multilevel model for change simultaneously uses data on all individuals at every time-point to concurrently investigate within- and between-individual change. Further, with the multiwave data, the model permits the flexible specification and rich investigation of nonlinear individual change over time. The multilevel model for change hypothesizes that, for each individual, the continuous outcome variable is a specified function of time plus error.<sup>54</sup> For my level-1 submodel that describes how HRQOL in each individual

changes over time, we specified two types of trajectories. The first model stipulates that HRQOL has a linear relationship with time. The second model stipulated that HRQOL has a curvilinear relationship with time. Based on examination of preliminary empirical growth plots, I decided to use a polynomial growth model containing a quadratic function of time. Once an individual growth trajectory is specified to represent individual change over time, I specified a level-2 submodel that describes how these changes differ across individuals. In my analyses, the hypothesized levels 1 and 2 statistical models were fitted simultaneously to the data using PROC MIXED on SAS statistical software (version 9.2, SAS Institute Inc., Cary, North Carolina).

I conducted the analyses sequentially. I initially conducted a set of unconditional growth analyses in which I posited a linear individual change trajectory at level 1, but did not attempt to predict inter-individual variation in the growth parameters by between-subject factors. Second, I conducted a set of conditional analyses in which I examined systematic inter-individual differences in intercept, slope, and curvature using between-subject predictors: demographics, clinical, economic, and social variables.

## **RESULTS**

The total sample size was 422. Table 1.1 summarizes baseline characteristics of the respondents. Women were slightly overrepresented in the sample (71% women v 29% men). The mean age was 34 years, and participants were followed for a median duration of 2.08 years. Forty-four percent of participants were married, 85% had a primary school education or more. At baseline, sixteen percent of participants were depressed, the median symptom index was 0.066, and the median CD4 cell count was 203 cells/mm<sup>3</sup>. Twenty-nine percent of participants were unemployed, and 39% were severely food insecure. Participants cored a median of 1 point on

the internalized stigma scale, 0 points on the enacted stigma scale, and 3.9 points on the social support scale.

**Table 1.1 Participant Baseline Characteristics (N=422)**

<b>Characteristic</b>		<b>N (%) or median (Q1-Q3)</b>
Gender		
	Female	298 (71%)
	Male	124 (29%)
Age at start of study		34.08 years (29.01-40.00)
Time in study		2.08 years (1.82-2.79)
Marital status		
	Not married	238 (56%)
	Married	184 (44%)
Education		
	None	65 (15%)
	Primary or more	357 (85%)
Depression Symptom Index		0.066 (-0.16 – 0.52)
CD4 count		203 cells/mm <sup>3</sup> (129-294)
Unemployed		124 (29%)
Severely Food Insecure		164 (39%)
Internalized stigma	6-item scale	1 (0-2)
Enacted stigma	14-item scale	0 (0-0)
Social support	4-point scale	3.9 (3.5-4.0)

Table 1.2 shows the taxonomy of multivariate multilevel model for change for the effect of time on PHS. There are eight pairs of linear (level-1 model stipulates that HRQOL has a linear relationship with TIME) and quadratic models (level-1 model stipulates a quadratic growth model of HRQOL containing TIME and TIME<sup>2</sup>) that adjust for level-2 predictors to explain any between-individual differences in HRQOL initial state and trajectory. Using the unconditional analyses I computed the intraclass correlation of PHS, which compares the relative magnitude of the variance components by estimating the proportion of total variation in PHS that is between individuals. The intraclass correlation for PHS was 0.42, signifying that over 50% of the total



variation in both quality of life indicators is attributable to differences within individuals over time.

For all pairs of quadratic and linear models fitted for PHS, intermodal comparisons of goodness-of-fit statistics showed that the quadratic models better describe the relationship between HRQOL and TIME, and that the inclusion of demographic, social, and economic predictors significantly improved the fit. For example, comparing the fully-adjusted quadratic model with the fully-adjusted linear model, the deviance statistic declines by 44.2. This exceeds the 0.01 critical value of a chi-square distribution on four degrees of freedom ( $TIME^2$  and the variance and covariance parameters), so we reject the null hypothesis that the four additional parameters are simultaneously zero, and conclude that the quadratic growth model better describes the relationship between HRQOL and TIME.

The trajectory of PHS with time described by the fully-adjusted quadratic model gives the instantaneous rate of change of PHS at  $TIME=0$  as 1.80 (95% CI 0.72, 2.89,  $p=0.0012$ ), and the curvature parameter associated with  $TIME^2$  that signifies the changing rate of change as -0.54 (95% CI -0.82, -0.25,  $p=0.0003$ ). This means that the trajectory is concave to the time axis, in which PHS initially rises at the start of treatment, peaks at 1.67 years after initiating treatment and declines.

This fully adjusted quadratic model shows that age is negatively correlated with PHS ( $b = -0.071$ , 95% CI -0.14, -0.0043,  $p=0.04$ ). Both self-reported symptoms ( $b = -10.61$ , 95% CI -11.48, -9.74,  $p<0.0001$ ) and depression ( $b = -2.74$ , 95% CI -3.95, -1.53,  $p<0.0001$ ) are negatively correlated with PHS, while CD4 count is not ( $b = 0.11$ , 95% CI -0.085, 0.30,  $p=0.28$ ). Notably, the effect of TIME and  $TIME^2$  on PHS is significantly attenuated with the addition of self-

reported symptoms into the model, although the effects of both still remain statistically significant. Food insecurity has a negative relationship with PHS that remains fairly stable even after adjusting for other factors ( $b = -0.42$ , 95% CI  $-0.67, -0.16$ ,  $p=0.0016$ ). Asset ownership does not show a statistically significant relationship with PHS ( $b= 0.084$ , 95% CI  $-0.30, 0.47$ ,  $p=0.67$ ), and the effect of unemployment is attenuated when food insecurity is added to the model ( $b = -0.071$ , 95% CI  $-0.14, -0.0043$ ,  $p=0.04$ ). Both internalized stigma ( $b = -0.38$ , 95% CI  $-0.59, -0.18$ ,  $p=0.0002$ ) and enacted stigma ( $b = -0.88$ , 95% CI  $-1.30, -0.45$ ,  $p<0.0001$ ) are negatively correlated with PHS, while social support does not have a statistically significant relationship with PHS at the level of  $p<0.05$  ( $b = 0.28$ , 95% CI  $-0.37, 0.94$ ,  $p=0.39$ ).

**Table 1.2 Taxonomy of multilevel models describing the relationship between PHS and time, controlling for demographic, clinical, economic, and social variables**

	Unadjusted model	Unadjusted model, Time <sup>2</sup>	Adjusted for demographics	Adjusted for demographics, Time <sup>2</sup>
	Beta (95% Confidence Interval [CI])	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)
<b>Fixed Effects</b>				
Intercept	47.36*** (46.32, 48.39)	44.79***(43.56, 46.02)	52.85*** (48.92, 56.78)	49.17***(45.23, 53.11)
Time	2.21*** (1.71, 2.71)	7.02*** (5.67, 8.37)	2.24*** (1.74, 2.74)	7.08*** (5.73, 8.43)
Time <sup>2</sup>		-1.66*** (-2.03, -1.27)		-1.67*** (-2.06, -1.28)
Sex (Female)			-1.97** (-3.43, -0.51)	-1.65* (-3.09, -0.22)
Marital Status (Married)			-0.66 (-1.68, 0.36)	-0.56 (-1.55, 0.42)
Education (Primary school and above)			1.43 (-0.30, 3.17)	1.91* (0.19, 3.62)
Age			-0.14*** (-0.22, -0.07)	-0.13*** (-0.21, -0.05)
Symptom Index Depression				
CD4 T cell count *100				
Asset Ownership				
Unemployed				
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	44.42***	41.14***	44.42***	41.09***
L2: btwn person variance in intercept	72.47***	84.49***	70.84***	83.81***
L2: btwn person variance in rate of change	11.69***	79.21***	11.67***	80.12***
L2: btwn person variance in curvature		14.14***		5.80***
<b>Goodness-of-fit</b>				
-2LL	19172.0	19033.8	19151.3	19013.3

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.2 Continued**

	<b>Adjusted for demographics and symptoms</b>	<b>Demographics, symptoms, Time<sup>2</sup></b>	<b>Demographics, symptoms, depression</b>	<b>Demographics, symptoms, depression, with Time<sup>2</sup></b>
	<b>Beta (95% CI)</b>	<b>Beta (95% CI)</b>	<b>Beta (95% CI)</b>	<b>Beta (95% CI)</b>
<b>Fixed Effects</b>				
Intercept	51.93***(48.52, 55.34)	50.16*** (46.71, 53.60)	52.21*** (48.81, 55.61)	50.48*** (47.05, 53.91)
Time	0.20 (-0.21, 0.61)	2.17*** (1.06, 3.27)	0.17 (-0.24, 0.58)	2.06*** (0.96, 3.16)
Time <sup>2</sup>		-0.61*** (-0.91, -0.32)		-0.59*** (-0.89, -0.30)
Sex (Female)	-0.015 (-1.30, 1.27)	0.18 (-1.09, 1.45)	0.018 (-1.26, 1.29)	0.23 (-1.04, 1.49)
Marital Status (Married)	-0.28 (-1.16, 0.61)	-0.18 (-1.05, 0.69)	-0.25 (-1.13, 0.63)	-0.15 (-1.02, 0.71)
Education (Primary school and above)	0.99 (-0.53, 2.50)	1.09 (-0.42, 2.60)	1.01 (-0.50, 2.52)	1.11 (-0.39, 2.61)
Age	-0.076*(-0.14, -0.0077)	-0.066 (-0.13, 0.0022)	-0.079* (-0.15, -0.011)	-0.069* (-0.14, -0.00092)
Symptom Index Depression	-12.18*** (-12.97, -11.39)	-11.78*** (-12.60, -10.97)	-11.45*** (-12.29, -10.61)	-11.06*** (-11.92, -10.19)
CD4 cell count *100			-2.94*** (-4.15, -1.72)	-2.94*** (-4.16, -1.73)
Asset Ownership				
Unemployed				
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	31.59***	31.59***	32.80***	31.37***
L2: btwn person variance in intercept	50.83***	50.83***	43.24***	50.48***
L2: btwn person variance in rate of change	36.99***	36.99***	5.12***	37.34***
L2: btwn person variance in curvature	2.10**	2.10**		2.15**
<b>Goodness-of-fit</b>				
-2LL	18046.2	18046.2	18070.9	18023.8

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.2 Continued**

	Demographics, symptoms, depression, CD4	Demographics, symptoms, depression, CD4 with Time <sup>2</sup>	Demographics, symptoms, depression, CD4, wealth and unemployment	Demographics, symptoms, depression, CD4, wealth and unemployment with Time <sup>2</sup>
	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)
<b>Fixed Effects</b>				
Intercept	52.01*** (48.59, 55.43)	50.27*** (46.82, 53.73)	51.96*** (48.48, 55.44)	50.11*** (46.61, 53.62)
Time	0.11 (-0.33, 0.54)	2.00*** (0.89, 3.11)	0.098 (-0.33, 0.53)	2.00*** (0.89, 3.10)
Time <sup>2</sup>		-0.59*** (-0.89, -0.30)		-0.59*** (-0.89, -0.30)
Sex (Female)	-0.023 (-1.30, 1.26)	0.18 (-1.02, 1.45)	0.15 (-1.14, 1.43)	0.39 (-0.89, 1.66)
Marital Status (Married)	-0.25 (-1.13, 0.63)	-0.15 (-1.02, 0.71)	-0.26 (-1.15, 0.62)	-0.18 (-1.05, 0.69)
Education (Primary school and above)	1.01 (-0.50, 2.52)	1.12 (-0.39, 2.62)	0.90 (-0.62, 2.41)	0.96 (-0.54, 2.47)
Age	-0.078* (-0.15, -0.0097)	-0.068 (-0.14, 0.00)	-0.082* (-0.15, -0.014)	-0.073* (-0.14, -0.0047)
Symptom Index	-11.43*** (-12.27, -10.59)	-11.04*** (-11.90, -10.17)	-11.42*** (-12.27, -10.58)	-11.02*** (-11.88, -10.15)
Depression	-2.92*** (-4.14, -1.70)	-2.92*** (-4.14, -1.71)	-2.95*** (-4.17, -1.73)	-2.96*** (-4.18, -1.75)
CD4 cell count *100	0.092 (-0.10, 0.29)	0.095 (-0.099, 0.29)	0.09214 (-0.10, 0.29)	0.096 (-0.097, 0.29)
Asset Ownership			0.14 (-0.26, 0.53)	0.19 (-0.20, 0.58)
Unemployed			-0.70 (-1.46, 0.064)	-0.77* (-1.54, -0.012)
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	32.81***	31.37***	32.85***	31.40***
L2: btwn person variance in intercept	43.07***	50.71***	42.45***	49.56***
L2: btwn person variance in rate of change	5.07***	37.44***	4.90***	36.82***
L2: btwn person variance in curvature		2.17**		2.08**
<b>Goodness-of-fit</b>				
-2LL	18070.1	18022.9	18066.2	18017.9

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.2 Continued**

	Demographics, symptoms, depression, CD4, wealth, unemployment, and FI	Demographics, symptoms, depression, CD4, wealth, unemployment, and FI with Time <sup>2</sup>	Demographics, symptoms, depression, CD4, wealth, unemployment, FI, stigma, and social support	Demographics, symptoms, depression, CD4, wealth, unemployment, FI, stigma, and social support with Time <sup>2</sup>
	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)	Beta (95% CI)
<b>Fixed Effects</b>				
Intercept	53.25*** (49.73, 56.77)	51.36*** (47.80, 54.92)	52.78*** (48.51, 57.04)	50.98*** (46.71, 55.25)
Time	0.081 (-0.34, 0.51)	1.87*** (0.78, 2.97)	0.091 (-0.33, 0.51)	1.80** (0.72, 2.89)
Time <sup>2</sup>		-0.56*** (-0.85, -0.27)		-0.54*** (-0.82, -0.25)
Sex (Female)	0.23 (-1.05, 1.50)	0.45 (-0.81, 1.72)	0.34 (-0.92, 1.60)	0.54 (-0.70, 1.79)
Marital Status (Married)	-0.29 (-1.18, 0.59)	-0.21 (-1.08, 0.66)	-0.33 (-1.21, 0.54)	-0.25 (-1.11, 0.61)
Education (Primary school and above)	0.92 (-0.58, 2.43)	0.98 (-0.52, 2.48)	0.86 (-0.62, 2.35)	0.93 (-0.55, 2.40)
Age	-0.072* (-0.14, -0.0041)	-0.065 (-0.13, 0.0031)	-0.078* (-0.14, -0.010)	-0.071* (-0.14, -0.0043)
Symptom Index	-11.25*** (-12.09, -10.40)	-10.87*** (-11.74, -10.00)	-10.96*** (-11.81, -10.12)	-10.61*** (-11.48, -9.74)
Depression	-2.92*** (-4.13, -1.70)	-2.93*** (-4.15, -1.72)	-2.72*** (-3.93, -1.51)	-2.74*** (-3.95, -1.53)
CD4 cell count *100	0.091 (-0.10, 0.28)	0.093 (-0.10, 0.29)	0.11 (-0.087, 0.30)	0.11 (-0.085, 0.30)
Asset Ownership	0.03 (-0.36, 0.43)	0.096 (-0.30, 0.49)	0.035 (-0.35, 0.43)	0.084 (-0.30, 0.47)
Unemployed	-0.57 (-1.33, 0.19)	-0.66 (-1.42, 0.11)	-0.53 (-1.28, 0.22)	-0.61 (-1.36, 0.15)
Food Insecurity	-0.52*** (-0.78, -0.27)	-0.46*** (-0.72, -0.20)	-0.47*** (-0.73, -0.21)	-0.42** (-0.67, -0.16)
Internalized Stigma			-0.40*** (-0.60, -0.19)	-0.38*** (-0.59, -0.18)
Enacted Stigma			-0.87*** (-1.29, -0.44)	-0.88*** (-1.30, -0.45)
Social Support			0.26*** (-0.40, 0.92)	0.28 (-0.37, 0.94)
<b>Variance Components</b>				
L1: within person	32.84***	31.40***	32.64***	31.27***
L2: btwn person variance in intercept	42.71***	49.89***	40.70***	48.85***
L2: btwn person variance in rate of change	4.51***	35.46***	4.26***	35.15***
L2: btwn person variance in curvature		2.02**		2.01**
<b>Goodness-of-fit</b>				
-2LL	18050.7	18005.8	18018.2	17974.0

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

Table 1.3 shows the taxonomy of multivariate multilevel model for change for the effect of time on PHS. There are eight pairs of linear (level-1 model stipulates that HRQOL has a linear relationship with TIME) and quadratic models (level-1 model stipulates a quadratic growth model of HRQOL containing TIME and TIME<sup>2</sup>) that adjust for level-2 predictors to explain any between-individual differences in HRQOL initial state and trajectory. The intraclass correlation for MHS was 0.48, signifying that over 50% of the total variation in both quality of life indicators is attributable to differences within individuals over time. Similarly to models for PHS, intermodal comparisons of goodness-of-fit statistics showed that the quadratic models better describe the relationship between HRQOL and TIME, and that the inclusion of demographic, social, and economic predictors significantly improved the fit.

The trajectory of MHS with time described by the fully-adjusted quadratic model gives an instantaneous rate of change of MHS at TIME=0 as 1.35 (95% CI 0.38, 2.32, p=0.0064), and the curvature parameter associated with TIME<sup>2</sup> that signifies the changing rate of change as -0.31 (95% CI -0.55, -0.076, p=0.0097). This means that the trajectory is concave to the time axis, in which MHS initially rises at the start of treatment, peaks at 2.18 years after initiating treatment and declines.

This fully adjusted quadratic model shows both self-reported symptoms (b= -10.30, 95% CI -11.10, -9.50, p<0.0001) and depression (b = -6.69, 95% CI -7.81, -5.58, p<0.0001) are negatively correlated with MHS, while CD4 count is not (b = 0.14, 95% CI -0.036, 0.32, p=0.12). Similarly to the PHS models, the effect of TIME and TIME<sup>2</sup> on MHS is significantly attenuated with the addition of self-reported symptoms into the model, although the effects of both still remain statistically significant. Both food insecurity (b = -1.11, 95% CI -1.35, -0.87, p=0.0001) and unemployment (b = -0.86, 95% CI -1.56, -0.16, p=0.016) have a negative

relationship with MHS. Asset ownership does not show a statistically significant relationship with MHS ( $b = 0.13$ , 95% CI  $-0.22, 0.48$ ,  $p = 0.46$ ). Both internalized stigma ( $b = -0.44$ , 95% CI  $-0.62, -0.25$ ,  $p < 0.0001$ ) and enacted stigma ( $b = -0.54$ , 95% CI  $-0.93, -0.14$ ,  $p < 0.0075$ ) are positively correlated with MHS, while social support does not have a statistically significant relationship with MHS at the level of  $p < 0.05$  ( $b = 0.18$ , 95% CI  $-0.42, 0.79$ ,  $p = 0.55$ ).



**Table 1.3 Taxonomy of multilevel models describing the relationship between MHS and time, controlling for demographic, clinical, economic, and social variables**

	Unadjusted model	Unadjusted model, Time <sup>2</sup>	Adjusted for demographics	Adjusted for demographics, Time <sup>2</sup>
	b (95% CI)	b (95% CI)	b (95% CI)	b (95% CI)
<b>Fixed Effects</b>				
Intercept	46.23*** (45.14, 47.31)	43.87*** (42.58, 45.16)	50.22*** (46.08, 54.37)	47.05*** (42.95, 51.14)
Time	2.79*** (2.25, 3.33)	6.91*** (5.61, 8.22)	2.82*** (2.28, 3.36)	6.96*** (5.65, 8.27)
Time <sup>2</sup>		-1.43*** (-1.78, -1.07)		-1.43*** (-1.79, -1.08)
Sex (Female)			-2.67*** (-4.21, -1.12)	-2.46** (-3.96, -0.97)
Marital Status (Married)			-0.67 (-1.68, 0.35)	-0.59 (-1.58, 0.39)
Education (Primary school and above)			0.72 (-1.12, 2.55)	1.12 (-0.67, 2.92)
Age			-0.070 (-0.15, 0.013)	-0.062 (-0.14, 0.019)
Symptom Index				
Depression				
CD4 cell count *100				
Asset Ownership				
Unemployed				
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	38.78***	36.98***	38.84***	36.96***
L2: btwn person variance in intercept	89.46***	95.02***	85.68***	90.47***
L2: btwn person variance in rate of change	17.36***	65.29***	17.22***	65.57***
L2: btwn person variance in curvature		3.43*		3.54*
<b>Goodness-of-fit</b>				
-2LL	18993.7	18881.5	18980.2	18868.1

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.3 Continued**

	<b>Adjusted for demographics and symptoms</b>	<b>Demographics, symptoms, Time<sup>2</sup></b>	<b>Demographics, symptoms, depression</b>	<b>Demographics, symptoms, depression, with Time<sup>2</sup></b>
	<b>b (95% CI)</b>	<b>b (95% CI)</b>	<b>b (95% CI)</b>	<b>b (95% CI)</b>
<b>Fixed Effects</b>				
Intercept	49.68*** (46.33, 53.01)	48.84*** (45.47, 52.21)	50.32*** (47.11, 53.54)	49.53*** (46.29, 52.77)
Time	0.65** (0.21, 1.10)	1.91*** (0.86, 2.96)	0.58** (0.17, 1.00)	1.73*** (0.73, 2.74)
Time <sup>2</sup>		-0.41** (-0.67, -0.15)		-0.38** (-0.63, -0.13)
Sex (Female)	-0.75 (-2.01, 0.50)	-0.70 (-1.94, 0.55)	-0.66 (-1.87, 0.56)	-0.59 (-1.79, 0.61)
Marital Status (Married)	-0.38 (-1.22, 0.47)	-0.31 (-1.14, 0.53)	-0.32 (-1.15, 0.50)	-0.25 (-1.06, 0.56)
Education (Primary school and above)	0.19 (-1.30, 1.66)	0.15 (-1.32, 1.62)	0.19 (-1.24, 1.61)	0.15 (-1.27, 1.57)
Age	-0.0074 (-0.074, 0.060)	-0.0052 (-0.072, 0.061)	-0.013 (-0.078, 0.052)	-0.010 (-0.074, 0.054)
Symptom Index Depression	-12.79*** (-13.55, -12.03)	-12.61*** (-13.39, -11.84)	-11.11*** (-11.89, -10.32)	-10.95*** (-11.76, -10.14)
CD4 cell count *100			-6.92*** (-8.06, -5.79)	-6.85*** (-7.98, -5.72)
Asset Ownership				
Unemployed				
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	28.57***	27.85***	27.61***	26.90***
L2: btwn person variance in intercept	46.48***	56.70***	38.66***	46.73***
L2: btwn person variance in rate of change	8.87***	33.33***	7.14***	28.59***
L2: btwn person variance in curvature		0.98*		0.89*
<b>Goodness-of-fit</b>				
-2LL	17836.6	17794.8	17697.6	17659.1

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.3 Continued**

	<b>Demographics, symptoms, depression, CD4</b>	<b>Demographics, symptoms, depression, CD4 with Time<sup>2</sup></b>	<b>Demographics, symptoms, depression, CD4, wealth and unemployment</b>	<b>Demographics, symptoms, depression, CD4, wealth, unemployment, Time<sup>2</sup></b>
	<b>B (95% CI)</b>	<b>B (95% CI)</b>	<b>B (95% CI)</b>	<b>B (95% CI)</b>
<b>Fixed Effects</b>				
Intercept	49.98*** (46.73, 53.23)	49.20*** (45.92, 52.47)	49.69*** (46.41, 52.97)	48.92*** (45.62, 52.22)
Time	0.47* (0.031, 0.91)	1.63** (0.61, 2.64)	0.46* (0.024, 0.89)	1.65** (0.65, 2.66)
Time <sup>2</sup>		-0.38** (-0.63, -0.13)		-0.39** (-0.64, -0.14)
Sex (Female)	-0.72 (-1.94, 0.50)	-0.65 (-1.86, 0.55)	-0.46 (-1.68, 0.75)	-0.36 (-1.56, 0.84)
Marital Status (Married)	-0.32 (-1.14, 0.50)	-0.24 (-1.06, 0.57)	-0.39 (-1.22, 0.43)	-0.31 (-1.13, 0.50)
Education (Primary school and above)	0.19 (-1.24, 1.62)	0.16 (-1.27, 1.58)	-0.053 (-1.48, 1.37)	-0.11 (-1.53, 1.31)
Age	-0.011 (-0.076, 0.053)	-0.0087 (-0.073, 0.056)	-0.021 (0.086, 0.043)	-0.019 (-0.084, 0.045)
Symptom Index	-11.07*** (-11.86, -10.28)	-10.92*** (-11.73, -10.11)	-11.04*** (-11.83, -10.26)	-10.88*** (-11.68, -10.07)
Depression	-6.90*** (-8.03, -5.77)	-6.82*** (-7.96, -5.69)	-6.98*** (-8.11, -5.85)	-6.91*** (-8.05, -5.78)
CD4 cell count *100	0.15 (-0.030, 0.34)	0.15 (-0.033, 0.33)	0.15 (-0.030, 0.34)	0.15, (-0.033, 0.33)
Asset Ownership			0.34 (-0.029, 0.72)	0.35 (-0.015, 0.72)
Unemployed			-1.00** (-1.72, -0.29)	-1.15** (-1.87, -0.43)
Food Insecurity				
Internalized Stigma				
Enacted Stigma				
Social Support				
<b>Variance Components</b>				
L1: within person	27.58***	26.87***	27.67***	26.94***
L2: btwn person variance in intercept	38.68***	46.67***	36.84***	44.41***
L2: btwn person variance in rate of change	1.28***	28.67***	6.63***	28.21***
L2: btwn person variance in curvature		0.93*		0.92*
<b>Goodness-of-fit</b>				
-2LL	17695.0	17656.5	17683.7	17642.6

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

**Table 1.3 continued**

	Demographics, symptoms, depression, CD4, wealth, unemployment, and FI	Demographics, symptoms, depression, CD4, wealth, unemployment, and FI with Time <sup>2</sup>	Demographics, symptoms, depression, CD4, wealth, unemployment, FI, stigma, and social support	Demographics, symptoms, depression, CD4, wealth, unemployment, FI, stigma, and social support with Time <sup>2</sup>
	b (95% CI)	b (95% CI)	b (95% CI)	b (95% CI)
<b>Fixed Effects</b>				
Intercept	52.65*** (49.44, 55.85)	51.95*** (48.71, 55.20)	52.36*** (48.49, 56.24)	51.92*** (48.04, 55.81)
Time	0.42* (0.0016, 0.84)	1.43** (0.45, 2.41)	0.42* (0.0060, 0.83)	1.35** (0.38, 2.32)
Time <sup>2</sup>		-0.33** (-0.57, -0.090)		-0.31* (-0.55, -0.073)
Sex (Female)	-0.23 (-1.39, 0.93)	-0.12 (-1.28, 1.03)	-0.16 (-1.29, 0.98)	-0.045 (-1.17, 1.08)
Marital Status (Married)	-0.45 (-1.25, 0.36)	-0.34 (-1.14, 0.45)	-0.48 (-1.27, 0.31)	-0.38 (-1.16, 0.41)
Education (Primary school and above)	-0.044 (-1.41, 1.32)	-0.13 (-1.50, 1.23)	-0.095 (-1.43, 1.24)	-0.19 (-1.51, 1.14)
Age	-0.0010 (-0.063, 0.061)	0.0014 (-0.060, 0.063)	-0.0074 (-0.068, 0.053)	-0.0051 (-0.065, 0.055)
Symptom Index	-10.67*** (-8.02, -5.78)	-10.53*** (-11.33, -9.73)	-10.42*** (-11.20, -9.64)	-10.29*** (-11.09, -9.49)
Depression	-6.90*** (-8.02, -5.78)	-6.85*** (-7.97, -5.73)	-6.75*** (-7.86, -5.63)	-6.70*** (-7.82, -5.58)
CD4 cell count *100	0.14 (-0.035, 0.32)	0.14 (-0.040, 0.32)	0.15 (-0.027, 0.33)	0.14 (-0.033, 0.32)
Asset Ownership	0.103 (-0.26, 0.46)	0.12 (-0.24, 0.47)	0.13 (-0.22, 0.48)	0.13 (-0.22, 0.48)
Unemployed	-0.74* (-1.44, -0.035)	-0.88* (-1.59, -0.18)	-0.71* (-1.41, -0.014)	-0.86* (-1.55, -0.16)
Food Insecurity	-1.16*** (-1.40, -0.92)	-1.15*** (-1.39, -0.91)	-1.11*** (-1.35, -0.88)	-1.11*** (-1.35, -0.87)
Internalized Stigma			-0.44*** (-0.63, -0.25)	-0.44*** (-0.62, -0.25)
Enacted Stigma			-0.48* (-0.88, -0.088)	-0.54** (-0.93, -0.14)
Social Support			0.22 (-0.39, 0.82)	0.18 (-0.42, 0.79)
<b>Variance Components</b>				
L1: within person	27.25***	26.55***	27.30***	26.61***
L2: btwn person variance in intercept	36.05***	45.36***	32.90***	42.47***
L2: btwn person variance in rate of change	5.85***	27.11***	5.46***	26.88***
L2: btwn person variance in curvature		0.90*		0.91*
<b>Goodness-of-fit</b>				
-2LL	17596.1	17557.0	17568.2	17528.5

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

## DISCUSSION

In our study of 421 PLWHA initiating HAART in rural Uganda, we found that the trajectories of the PHS and MHS components of HRQOL to be curvilinear and identified clinical, economic, and social predictors of HRQOL. Our fully-adjusted quadratic growth models showed that both PHS and MHS gradually increased after initiating HAART, peaked at 1.67 years and 2.18 years after initiation, respectively, and gradually declined. Given that we measured HRQOL more frequently (quarterly) and for a longer duration (mean duration of 2.28 years per patient) than previous studies, this result may explain the inconsistencies among the previous studies that showed improvement<sup>1,16,25</sup> increase followed by a plateau,<sup>2,15,32,33</sup> no change,<sup>9</sup> or a deterioration in the HRQOL<sup>8,34</sup> using less frequent data collection or shorter study duration.

What accounts for the curvilinear relationship between HRQOL and time? There still remains a sizable fraction of the variance component within individuals that has not been taken into account with the predictors in our model. Adaptation level theory suggests that people's judgments of wellbeing is subject to the effects of contrast – positive experiences result in an upward shift in adaptation level, that experiences thereafter seem less positive – and habituation – the effect of positive experiences eventually wear off.<sup>55</sup> It is possible that the initial gains in HRQOL experienced at the initiation of HAART increase PLWHA's expectations of subjective wellbeing, and that the impact of initial gains wear off in time, resulting in an initial increase, followed by a plateau and decrease in HRQOL.

Taking into account that the median survival without HAART once AIDS has developed has been reported to be 9.2 months in rural Uganda,<sup>56</sup> HAART offers a significant benefit in

terms of both survival and HRQOL. Still, we also found clinical, economic, social factors that may be targets of interventions to further improve HRQOL.

We found that self-reported symptoms were a significant predictor of HRQOL, and when added to the model, significantly decreased the magnitude of the relationship between HRQOL and TIME and TIME<sup>2</sup>. Previous studies have found that PLWHA report onset of symptoms that are likely adverse effects of HAART, such as diarrhea, nausea, abdominal pain and headache,<sup>8,57</sup> and these treatment toxicities have been found to be associated with deterioration of health-related quality of life.<sup>15,58</sup> In our study, CD4 count was not a strong predictor of HRQOL, a finding that was also reported by Andrinopoulos and colleagues among young women in the US.<sup>20</sup> This may be because studies that found significant relationship between CD4 cell count and HRQOL used very low cutoffs for CD4 T cell count of 50 to 200 cells per mm.<sup>312,15</sup>

Another factor affecting HRQOL is the persistence of economic and social problems for PLWHA in rural Uganda. It is possible that, once PLWHA begin treatment and the survival becomes a less immediate concern, the social and economic factors such as obtaining food and gaining employment become more salient.<sup>59</sup> Food insecurity was negatively associated with both PHS and MHS, while unemployment was only associated with MHS, and asset ownership was not associated with either HRQOL scores. Food insecurity may be a more sensitive indicator of economic wellbeing in resource-poor settings than employment or asset ownership, where many people engage in informal economic activities. A qualitative study in Uganda found that after being on HAART for six months, PLWHA's capacity to engage in work-related activities increased substantially, but participants who were salaried employees in the formal labor market were unable to resume their former employment after being infected with HIV.<sup>3</sup> In our study,

such a person may consider him or herself unemployed, but may still contribute to measurably to household food intake through informal activities such as tending to their gardens.

Both enacted stigma and internalized stigma were negatively correlated with PHS and MHS scores. This is consistent with previous literature that describes impact of stigma on the psychosocial wellbeing of PLWHA, including stress, fear, anxiety, depression, and strained relationships with loved ones.<sup>26-29</sup> These results show the importance of intervening on the economic and social situations of PLWHA in addition to managing their clinical condition.

We acknowledge several limitations of this study. First, our measures are self-reported and therefore suffer challenges generic to all analyses based on self-reported data. Second, it is difficult to disentangle the extent to which the estimated associations may simply reflect an unmeasured common factor. Our analyses address this issue by using multilevel models that nest interviews within individuals. Finally, an individual's assessment of HRQOL may not be reliable, especially among disadvantaged socioeconomic groups. The unequal reliability could be because people in less advantaged settings have limited access to education and health facilities to accurately perceive their state of health.<sup>4</sup>

## **CHAPTER 2**

### **The dynamic relationship between social support and HIV stigma among people living with HIV/AIDS in rural Uganda**



## **INTRODUCTION**

HIV stigma is a well-documented barrier to the health and well-being of people living with HIV/AIDS (PLWHA). As described by Goffman, stigma is a discrediting attribute that reduces a person from a whole person to a tainted or discounted person<sup>60</sup> and has been associated with delaying or avoidance of HIV testing,<sup>61,62</sup> poor adherence to HIV antiretroviral treatment,<sup>30</sup> and poor engagement with care.<sup>31</sup> In addition, PLWHA experience numerous mental and psychological sequelae of stigma, including stress, fear, anxiety, and depression.<sup>26-29</sup>

Recent studies have shown that PLWHA who report experiences of stigma also report lower levels of perceived social support.<sup>29,63-65</sup> That HIV-related stigma adversely affects the social experience of PLWHA has critical public health implications because social support has powerful health benefits for PLWHA, including less depression, improved coping with their disease, positive health behaviors, and slower progression of disease.<sup>21-24</sup> Social support has been found to be beneficial for a wide range of health outcomes, and its health benefits have been attributed to its various functional aspects, including emotional, instrumental, and/or appraisal support.<sup>66-68</sup> Through these mechanisms, social support is thought to influence cognitive and emotional states, such as self-esteem and self-efficacy, and promote functional and adaptive coping with stressors. These psychosocial and behavioral benefits translate to health benefits through decreased physiological stress responses, adoption of health-promoting behaviors, and avoidance of health-damaging behaviors.

### **Conceptual model**

Based on evidence that stigma is a multi-dimensional construct, researchers in clinical epidemiology have developed and utilized a conceptual model that separates the experience of HIV stigma into interpersonal and intrapersonal experiences. The interpersonal experience of stigma is called enacted stigma and is defined as discriminatory behaviors directed towards people with the stigmatized condition.<sup>26</sup> The intrapersonal experience of stigma is called internalized stigma and is defined as the guilt, shame, and self-blame that result when people with the stigmatized condition internalize the beliefs imposed by the majority group.<sup>28</sup>

Historically, models of stigma have predominantly focused on the characteristics of individuals - the stigmatized person and the stigmatizing person – and their cognitive, affective and behavioral processes, but recent sociological and anthropological models of stigma have proposed to embed stigma in the social space.<sup>69</sup> Of particular importance is how the effects of stigma extend to the affected individual's close social ties, and how social ties in turn shape their experience of stigma. Qualitative studies have shown stigmatization of family and close friends of PLWHA, termed courtesy stigma, creating a strain in the relationships. Family members of PLWHA fear discrimination and loss of social standing in the community,<sup>70</sup> such that they reluctant to disclose the serostatus of the affected family member to others.<sup>26</sup> In addition, close social ties can often be the sources of stigmatizing attitudes and actions. Family and friends become perpetrators of stigma in response to the devalued status they acquire through their association with the stigmatized person,<sup>70</sup> and PLWHA experience avoidance, ostracism, and verbal insults from their relatives.<sup>26</sup> Furthermore, HIV-related stigma can profoundly limit the ability of PLWHA to seek and maintain supportive relationships. Disclosure is essential for people to receive social support;

yet, fear of discrimination prevents PLWHA from disclosing their status,<sup>71,72</sup> and the higher their shame and guilt, the more likely they are to avoid disclosure and interactions with others.<sup>28</sup> Finally, HIV stigma has been correlated with depression,<sup>29</sup> which may also limit PLWHA's capacity for forming and maintaining social relationships.

The recent findings linking social support and HIV stigma, though suggestive, were based on cross-sectional data<sup>29,63,64</sup> or data from two time points,<sup>65</sup> limiting our ability to illuminate the dynamic relationship between social support and HIV-related stigma. Further, these studies have not examined how the interpersonal and intrapersonal dimensions of HIV stigma could differentially affect the social experience of PLWHA. To address these gaps in current understanding of HIV-related stigma and social support, we examined the dynamic relationship between social support and two dimensions of HIV stigma using longitudinal data collected from PLWHA receiving antiretroviral therapy, collected over three years at a public hospital in rural Southwest Uganda. The primary aim was to use time-lagged models to understand how the interpersonal and intrapersonal experiences of HIV stigma shape the social support networks of PLWHA, and how these relationships in turn shape the experience of HIV stigma.

## **METHODS**

We used data from an ongoing, prospective cohort of PLWHA taking antiretroviral therapy (ART) in rural Uganda. Eligibility criteria included having no prior history of treatment with HIV ART, being over 18 years of age, and living within 20 km of the Immune Suppression Syndrome (ISS) Clinic at the Mbarara Regional Referral Hospital. The ISS Clinic is located in Mbarara District, 275 km southwest of Kampala, and provides free ART for people living with

HIV/AIDS in southwestern Uganda, Rwanda and the Democratic Republic of Congo.<sup>36</sup> The majority of the population in Mbarara district is ethnically Ankole, and the local language is Runyankole. The local economy is largely based on subsistence agriculture.

Our analyses are based on data from participants who were enrolled into the cohort from 2007 through 2010. Survey questions were translated into Runyankole, back-translated into English, further modified through focus groups with key informants, and pilot-tested to ensure clarity and relevance. Trained research assistants who spoke Runyankole interviewed participants every three months in a private room at the site research office near the ISS Clinic. Each survey took approximately one hour to complete.

Informed consent was obtained from all study participants. Ethical approval for all study procedures was obtained by the Committee on Human Research, University of California at San Francisco; the Partners Human Research Committee at Massachusetts General Hospital; and the Institutional Ethical Review Committee, Mbarara University of Science and Technology.

The three variables of interest were social support, internalized stigma, and enacted stigma. These variables were assessed at baseline and at each quarterly follow-up interview using the scales described below. We measured social support using the Social Support Scale,<sup>48</sup> which contains 10 items about instrumental and emotional social support. High scores reflect higher levels of social support. This scale is adapted from the Duke-University of North Carolina Functional Social Support Questionnaire, which was designed to measure multiple dimensions of social support among patients in a primary care setting.<sup>49</sup>

We measured internalized HIV stigma using the Internalized AIDS-Related Stigma Scale, which contains six items corresponding to the guilt, shame, and worthlessness in Goffman's conceptualization of stigma.<sup>50,51</sup> To measure enacted stigma, we asked participants about whether they had experienced 10 discriminatory events in the past three months as a result of their HIV status, such as abandonment, housing, or property loss, or physical violence.<sup>53</sup> The enacted stigma scale was calculated as the sum of the 10 items, with higher scores indicating greater intensity of enacted stigma experienced.

In our regression models, we adjusted for baseline and quarterly health status using CD4+ T-lymphocyte cell count and physical health-related quality of life, which we measured with the Medical Outcome Study-HIV (MOS-HIV) Physical Health Summary (PHS).<sup>37,38</sup> A higher score reflects a better health-related quality of life. Because prior studies have shown that both HIV stigma and low social support are associated with depression,<sup>27,29</sup> we also adjusted for depression symptom severity. We measured depression using a version of the 15-item Hopkins Symptom Checklist for Depression<sup>42</sup> that was adapted to the local context with the addition of a 16<sup>th</sup> item, "feeling like I don't care about my health."<sup>27,43</sup> We restricted our calculation of the score to the 12 affective items in light of prior research suggesting that the somatic items overlap with symptoms of HIV infection and may inflate the prevalence of depression among PLWHA.<sup>44,45</sup> Participants were classified as having probable depression based on the conventional threshold score of 1.75.<sup>46</sup>

We adjusted for a range of other baseline (time-invariant) demographic and socioeconomic covariates with potential for influencing the relationships among stigma,

social support, and health. We measured household wealth using a household asset index,<sup>47</sup> which was entered into the models as a continuous variable, with higher values of the asset index indicating greater household wealth relative to other households in the sample. We also adjusted for baseline age, sex, educational attainment and marital status. Time was measured in years since starting ART.

Data analysis was conducted using SAS statistical software (version 9.2, SAS Institute Inc., Cary, North Carolina). We employed multilevel modeling to address the lack of independence among residuals in hierarchically structured data. Since our data consisted of measures that are nested within individuals, measures from the same individual may share common, unobserved characteristics that may affect the outcomes of interest. Our modeling technique allowed us to separate the composite residual into two parts: a measure-level residual unique to the particular time at which the survey was conducted, and an individual-level residual unique to a particular individual (but not to a particular time). We used multilevel models for change, in which the models are specified by simultaneously postulating a pair of subsidiary models: a level-1 submodel that describes how each individual changes over time, and a level-2 submodel that describes how these changes differ across individuals.<sup>54</sup> Our level-1 submodel stipulated that the trajectories of stigma and social support are linear with time.

To investigate the dynamic relationships between social support and HIV-related stigma, we estimated both contemporaneous and lagged-covariate multilevel models for change. The first contemporaneous model specified internalized stigma as the outcome and the second specified enacted stigma as the outcome. Both included social support

measured at the same time as the main predictor. We decided that contemporaneous models for social support would be redundant to our analysis because they would show similar relationships between social support and stigma.

In lagged-covariate models, the predictor of interest was lagged by three months. The first model specified internalized stigma as the outcome and lagged social support as the main predictor, while also adjusting for lagged internalized stigma in addition to the other covariates as described above. The second model specified enacted stigma as the outcome and lagged social support as the main predictor, while also adjusting for lagged enacted stigma and the other covariates. In the next set of models, lagged internalized (or enacted) stigma was the main predictor, social support was the outcome, and we also adjusted for lagged social support and the other covariates. In sum, we fit six multilevel regression models for change.

Preliminary analyses supported the use of multilevel models for change and lagged models. Briefly, empirical growth plots showed substantive changes within individuals over time in enacted stigma, internalized stigma, and social support. Further, intraclass correlation indicated large variability within individuals over time. Intraclass correlation for social support was 0.30, indicating that an estimated 30% of the total variation in social support is attributable to differences between individuals while 70% is attributable to variability within individuals. Likewise, the intraclass correlations for internalized stigma and enacted stigma were 0.46 and 0.27, respectively.

## **RESULTS**

Table 1 presents the baseline demographic characteristics of the 413 participants. The average age at baseline was 35 years, and they were enrolled in the study for a median of 2.09 years. The majority of participants (324 [71%]) were female. Approximately half were married and half were widowed or divorced. The majority (246 [60%]) had completed primary school, and 97 (23%) completed secondary school or more. The median internalized stigma score was 0 points (Q<sub>1</sub>– Q<sub>3</sub> = 0 – 2.00, mean=1.05), the median enacted stigma score was 0 points (IQR=1.00, mean=0.38), and the median social support score was 4.00 points (IQR=0.40, mean=3.74) points at baseline. The median CD4 count at baseline was 263 cells/mL (IQR = 176). Approximately 7% of participants were depressed at baseline.

**Table 2.1 Participant Baseline Characteristics (N=413)**

<b>Characteristic</b>		<b>N (%), median (Q<sub>1</sub>-Q<sub>3</sub>)</b>
Gender	Female	293 (71%)
	Male	120 (29%)
Age at start of study		35.00 years (30.00-40.09)
Time in study		2.09 years (1.72-2.78)
Marital status	Not married	30 (7%)
	Married	187 (45%)
	Separated/widowed/divorced	196 (47%)
Education	None	70 (17%)
	Primary	246 (60%)
	Secondary and more	97 (23%)
Internalized stigma	6-item scale	0 (0-2)
Enacted stigma	10-item scale	0 (0-1)
Social support	4-point scale	4.0 (3.6-4.0)
CD4 count		263 cells/mL (176-352)
Physical health	MOS-HIV	52.25 (44.83-57.26)
Depression		30 (7%)



## **Internalized stigma**

We found that social support and internalized stigma measured at the same time-point were negatively correlated (Table 2). On average, individuals who reported higher levels of perceived social support reported lower levels of internalized stigma. Each one-point increase in the social support scale was associated with a 0.28-point decrease in the internalized stigma scale (95% CI, -0.51 to -0.041). Other factors associated with internalized stigma include self-reported physical health, depression, and educational attainment. In the lagged-covariate model, social support was not associated with subsequent internalized stigma ( $b = -0.012$ ; 95% CI, -0.14 to 0.11).

**Table 2.2 The Effect of Contemporaneous Social Support and Lagged Social Support on Internalized Stigma**

		Contemporaneous	Lagged
Fixed effects		b (95% confidence interval [CI])	b (95% CI)
Intercept		1.62 (0.66, 2.58)*	0.57 (-0.038, 1.18)
Social support		-0.28 (-0.51, -0.041)*	-----
Lagged social support		----	-0.012 (-0.14, 0.11)
Lagged internalized stigma		----	0.12 (0.086, 0.16)***
Time	Years	-0.39 (-0.85, 0.066)	-0.0071 (-0.081, 0.067)
Time*social support		0.10 (-0.023, 0.22)	-----
Gender	Male		
	Female	0.15 (-0.12, 0.42)	0.13 (-0.11, 0.38)
Age	Centered	-0.0073 (-0.022, 0.0076)	-0.0062 (-0.019, 0.0071)
Marital status	Married		
	Separated	-0.049 (-0.24, 0.15)	-0.044 (-0.23, 0.14)
	Single	0.17 (-0.12, 0.51)	0.14 (-0.25, 0.53)
Education	No school		
	Primary school	0.19 (-0.12, 0.51)	0.20 (-0.078, 0.47)
	Secondary school	0.42 (0.045, 0.80)*	0.40 (0.066, 0.73)*
Wealth	Asset index quintile	0.026 (-0.84, 0.89)	0.0084 (-0.069, 0.085)
Physical health	MOS-HIV, centered	-0.015 (-0.022, -0.0079)***	-0.015 (-0.022, -0.0079)***
CD4	x 100 cells /mL	0.0044 (-0.032, 0.041)	0.0019 (-0.034, 0.038)
Depression		0.37 (0.13, 0.61)**	0.43 (0.18, 0.67)***
<b>Variance components</b>			
Level-1: within person		0.97 (0.31, 1.63)***	1.03 (0.96, 1.10)***
Level-2: in intercept		1.00 (-0.95, 2.96)***	0.81 (0.63, 0.99)***
Level-2: rate of change		0.041 (-0.0061, 0.89)*	0
<b>Goodness-of-fit</b>			
-2LL		7288.3	7271.5

\*\*\*P < 0.001, \*\*P<0.01, \*P<0.05

### Enacted stigma

We found that social support and enacted stigma measured at the same time-point were negatively correlated (Table 3). On average, individuals who reported higher levels of perceived social support reported lower levels of enacted stigma. Adjusting for sociodemographic and health characteristics, a one-point increase in the social support

scale was associated with a 0.18-point decrease in the enacted stigma scale (95% CI, -0.31 to -0.046). Self-reported physical health, wealth, marital separation, and educational attainment were also associated with enacted stigma. In the lagged covariate models, we found that enacted stigma was negatively correlated with lagged social support (Table 3). A one-point increase in the lagged social support score was associated with 0.16-point decrease in enacted stigma score, controlling for lagged social support and sociodemographic and health characteristics (95% CI, -0.24 to -0.090).

**Table 2.3 The Effect of Contemporaneous Social Support and Lagged Social Support on Enacted Stigma.**

		<b>Contemporaneous</b>	<b>Lagged</b>
<b>Fixed effects</b>		<b>b (95% CI)</b>	<b>b (95% CI)</b>
Intercept		1.21 (0.69, 1.72)***	1.08 (0.77, 1.39)***
Social support		-0.18 (-0.31, -0.046)**	-----
Lagged social support		-----	-0.16 (-0.24, -0.090)***
Lagged enacted stigma		-----	0.075 (0.035, 0.12)***
Time	years	0.24 (-0.020, 0.50)	0.0058 (-0.033, 0.045)
Time*soc support		-0.070 (-0.14, 0.00081)	-----
Gender	Male		
	Female	0.077 (-0.022, 0.17)	0.085 (-0.0033, 0.0070)
Age	Centered	0.0014 (-0.004, 0.0069)	0.0018 (-0.0033, 0.0070)
Marital status	Married		
	Separated	0.090 (0.0062, 0.17)*	0.085 (0.0040, 0.17)*
	Single	-0.074 (-0.24, 0.090)	-0.074 (-0.23, 0.081)
Education	No school		
	Primary school	-0.14 (-0.25, -0.024)*	-0.13 (-0.23, -0.022)*
	Secondary school	-0.099 (-0.24, 0.037)	-0.099 (-1.39, 1.19)
Wealth	Asset index quintile	-0.039 (-0.071, -0.0075)*	-0.044 (-0.074, -0.014)**
Physical health	MOS-HIV, centered	-0.0090 (-0.013, -0.0051)***	-0.0090 (-0.013, -0.0052)***
CD4	x 100 cells /mL	0.0012 (-0.018, 0.020)	0.0041 (-0.014, 0.023)
Depression		0.14 (0.033, 0.24)	0.14 (-0.0013, 0.27)
<b>Variance components</b>			
Level-1: within person		0.37 (0.35, 0.40)***	0.39 (0.36, 0.42)***
Level-2: in intercept		0.084 (0.054, 0.11)***	0.067 (0.038, 0.096)***
Level-2: rate of change		0.0045 (-0.0037, 0.013)	0.0041 (-0.0034, 0.012)
<b>Goodness-of-fit</b>			
-2LL		4626.8	4754.9

\*\*\*P < 0.001, \*\*P<0.01, \*P<0.05

## Social Support

We employed lagged multilevel models for change to examine determinants of social support. Social support was associated with both lagged internalized stigma as well as enacted stigma (Table 4). A one-point increase in lagged internalized stigma was associated with a 0.015-point decrease in social support (95% CI, -0.027 to -0.0028).

Similarly, a one-point increase in lagged enacted stigma was associated with a 0.035-point decrease in social support (95% CI, -0.058 to -0.013).

**Table 2.4 The Effect of Lagged Internalized Stigma and Lagged Enacted Stigma on Social Support.**

		<b>Lagged int stigma model</b>	<b>Lagged enacted stigma model</b>
		<b>b (95% CI)</b>	<b>b (95% CI)</b>
<b>Fixed effects</b>			
Intercept		3.10 (2.93, 3.28)***	3.1261 (2.95, 3.30)***
Lagged internalized stigma		-0.015 (-0.027, -0.0028)*	-----
Lagged enacted stigma		-----	-0.035 (-0.058, -0.013)**
Lagged social support		0.16 (0.12, 0.20)***	0.15 (0.11, 0.19)***
Time	Years	-0.054 (-0.076, -0.031)***	-0.049 (-0.071, -0.027)***
Gender	Male		
	Female	-0.087 (-0.14, -0.032)**	-0.085 (-0.14, -0.032)**
Age-35	Centered	-0.00048 (-0.0035, 0.0026)	-0.00024 (-0.0032, 0.0027)
Marital Status	Married		
	Separated	0.021 (-0.026, 0.068)	0.020 (-0.036)
	Single	0.062 (-0.029, 0.15)	0.059 (0.15)
Education	No school		
	Primary school	0.035 (-0.027, 0.097)	0.032 (-0.029, 0.0927)
	Secondary school	0.064 (-0.012, 0.14)	0.060 (-0.014, 0.13)
Wealth	Asset index quintile	0.051 (0.034, 0.069)***	0.048 (0.031, 0.066)***
Phs-50	HIV-MOS, centered	0.0039 (0.0017, 0.0061)***	0.0037 (0.0016, 0.0058)***
CD4	x 100 cells /mL	-0.022 (-0.033, -0.011)***	-0.021 (-0.031, -0.011)***
Depression		-0.081 (-0.16, -0.0023)*	-0.063 (-0.14, 0.014)
<b>Variance components</b>			
Level-1: within person		0.12 (0.11, 0.13)***	0.12 (0.11, 0.13)***
Level-2: in intercept		0.025 (0.014, 0.035)***	0.024 (0.014, 0.035)***
Level-2: rate of change		0.0014 (-0.00091, 0.0037)	0.00095 (-0.0011, 0.0030)
<b>Goodness-of-fit</b>			
-2LL		2030.4	2055.3

\*\*\*P < 0.001, \*\*P<0.01, \*P<0.05

## DISCUSSION

In this longitudinal analysis of data from PLWHA initiating ART in rural Uganda, we found evidence that both internalized and enacted stigma may compromise the ability to maintain and access support from friends and family. At the same time, we found that social support was protective against future experiences of enacted stigma but not against internalized stigma. The estimated associations were strong, large in magnitude, and robust to lagged specifications.

In this study, we found a dynamic relationship between enacted stigma and social support. When social support was lagged by one quarter, it had a statistically significant, and inverse association with enacted stigma. Similarly, when enacted stigma was lagged by one quarter, it retained a statistically significant association with subsequent social support. Our findings suggest that PLWHA who report experiences of discrimination are more likely to lose their social support, consistent with the idea that friends and family members, who provide the bulk of social support, are also the sources of discrimination, prejudice, avoidance and abandonment. These findings also suggest that discrimination towards PLWHA negatively affects their friends and family by association. Goffman described the process of “courtesy stigma,” in which people who are “related through the social structure to a stigmatized individual...are all obliged to share some of the discredit of the stigmatized person.”<sup>60</sup> Goffman further states that courtesy stigma “provides a reason why such relations tend either to be avoided or to be terminated.”<sup>60</sup> More recently, Yang and colleagues proposed that stigma threatens interpersonal relationships of affected individuals by threatening the moral standing of their family and other members of their social network,

and this leads them to discriminate against the stigmatized person.<sup>70</sup> As an example, they present a study of mental illness in Hong Kong that found that family members' fear of social contamination and loss of face motivated them to discriminate against and abandon their ill family member.

We found that internalized stigma and social support were negatively correlated with one another, consistent with previous research.<sup>29,63,65</sup> When internalized stigma was lagged by one quarter, it had a statistically significant, and inverse association with social support. This result suggests that PLWHA who experience more shame and guilt about HIV are less able to have supportive relationships with friends and family. This may be because people who report high levels of internalized stigma are less likely to disclose their HIV status to their friends and family or to solicit support from them.<sup>29</sup> Internalized stigma has also been found to correlate with depression,<sup>27,29</sup> which could also compromise affected persons' ability to seek and maintain supportive relationships. Further, caring for PLWHA exerts substantive physical and psychological burdens on caregivers, especially in the setting of depression.<sup>73</sup> This could result in a negative "feedback loop" of social support,<sup>74</sup> in which the strain of supporting a person with a serious illness results in network members withdrawing and severing the relationship in order to cope with the strain.

How can we understand why people living with HIV who report high levels of perceived social support subsequently report low levels of enacted stigma, but not internalized stigma? Having the support of friends and family can protect the person from becoming targets of external, visible acts of discrimination and insults. However, such supportive relationships may not be as instrumental in protecting the individual from their

own beliefs of guilt, immorality, and dirtiness for being infected with HIV. We hypothesize that internalized stigma is determined by a complex set of individual factors such as perception of the legitimacy of stigma and personal identification with the larger group of individuals with the same condition.<sup>75,76</sup>

Our findings suggest that people living with HIV/AIDS who are most affected by HIV stigma may suffer the additional burden of losing social support. The emotional, material, and appraisal resources provided by social support are critical for people living with HIV in resource-poor settings like Uganda, who must address day-to-day economic challenges while adhering to ART, maintaining positive health behaviors, and coping with the burden of illness and stigma. In one qualitative study of 252 PLWHA in three sub-Saharan African settings, social relationships were found to maintain ART adherence not only by providing of money for transport to clinic, encouragement, and regular reminders, but also by presenting a social expectation of adherence that created obligations on the part of the patients to adhere.<sup>77</sup>

We acknowledge several limitations of this study. First, our measures are self-reported and therefore suffer challenges generic to all analyses based on self-reported data. Second, it is difficult to disentangle the extent to which the estimated associations may simply reflect an unmeasured common factor. Our analyses address this issue by using multilevel models that nest interviews within individuals. Furthermore, the lagged models examine determinants of stigma or social support after adjusting for lagged values of the variables. Related to this limitation, the perception of social support may not correlate perfectly with the actual degree of social support received. However, prior studies have



demonstrated that perceived social support is more predictive of health outcomes than actual social support for people living with HIV/AIDS.<sup>22</sup> Second, our study sample consisted of people living with HIV/AIDS who were initiating ART. As stigma is a significant barrier for patients to access and adhere to treatment,<sup>78-81</sup> and access to treatment has been shown to lower stigma,<sup>82,83</sup> it is likely that overall levels of internalized stigma were lower in our sample compared to untreated PLWHA. Because social support is also known to be positively associated with treatment access,<sup>77</sup> this could have biased our estimates away from the null.

In summary, we found that both internalized and enacted stigma may compromise the ability of PLWHA to maintain and access support from close social ties and that social support may be protective against future experiences of discrimination. While many strategies for stigma reduction have been proposed,<sup>75</sup> research that rigorously evaluates interventions on HIV stigma is limited,<sup>84</sup> and those that do often fail to demonstrate enduring effects on stigma.<sup>85</sup> Taken together, our findings about the bidirectional relationships between stigma and social support further emphasize the importance of research on interventions that address HIV stigma, which will not only decrease the burden of stigma but also strengthen social support that is an invaluable resource for people living with HIV/AIDS.

## **CHAPTER 3**

### **Interdisciplinary review of health-related stigma**

## INTRODUCTION

Across time periods and cultures, people have held negative attitudes towards certain health conditions, discriminating against individuals with conditions such as obesity, smoking, mental illness, HIV/AIDS, and cancer. Sociologist Goffman described this negative and discriminatory attitude as stigma - the devaluation of an individual based on some characteristic they possess, such that the person is believed to be not quite human.<sup>60</sup> Since Goffman's benchmark social theory of stigma, social scientists have offered theories regarding the causes, processes, and outcomes of health-related stigma through a variety of disciplinary methods and theoretical frameworks, situating stigma in individual, interpersonal, social, and political spaces.

Health and social policies have used health-related stigma, implicitly or explicitly to discourage from engaging in unhealthy behaviors for the goal of improving the health of the population. One salient instance is the British public health minister's recommendation that health professionals use the term "fat" instead of "obese" to encourage "personal responsibility" on the part of obese people, which received criticism by health experts that such a recommendation could stigmatize those who are overweight.<sup>86,87</sup> However, stigma has been associated with various negative clinical outcomes, including poor adherence to treatment,<sup>30</sup> poor engagement with care,<sup>31</sup> and delayed care-seeking.<sup>61</sup> Furthermore, targets of stigmatization have reported numerous mental and psychosocial sequelae of stigma, including fear, isolation, anxiety, depression, and poor psychological functioning. Should stigma be utilized as a tool to promote public health, or should societal efforts focus on eliminating health-related stigma? In order to address this question, I examine the underlying tension in the stigma literature regarding the origin of stigma. Scholars predominantly in social and evolutionary psychology conceptualize stigma as a product of individual cognitive patterns that evolved as a basic need

for survival, while those in sociology, history, and anthropology conceptualize stigma as a product of social forces rooted in economic and political power differentials that serve to perpetuate and legitimize those injustices. Also central to this discussion – whether stigma can and should be used to promote health – is how the changing notions of who (or what) is responsible for making an individual sick has contributed to the stigmatization of certain health conditions.

The goal of this paper is to explore the scholarly theories on health-related stigma, analyze their contributions to the debate on the causes of health-related stigma. While theories within a discipline offer often-debated explanations of the same reality, theories from different disciplines diverge more widely because of their focus on distinct aspects of the shared referent reality.<sup>88</sup> The individual and interpersonal theories of stigma suggest that stigma is based in the realm of private encounters between two people who possess certain physical and personality traits. In contrast, the conceptualizations of health-related stigma in history, anthropology, and autobiography incorporate the social forces outside of the individual as playing a central role in the production of stigma. I show that policies that stigmatize health behaviors and health conditions have not been shown to be effective in promoting health, especially among those who are the targets of stigma. Moreover, these health policies harm the stigmatized individuals through humiliation and shame and by limiting their access to health and societal resources. I argue that policies that promote or condone the use of health-related stigma ultimately exacerbate the social and economic disparities that underlie stigmatization, which further leads to stigmatized health behaviors and outcomes.

## **INDIVIDUAL AND INTERPERSONAL THEORIES**

### **Social psychology of stigma**

Traditionally, social psychologists have examined the cognitive, affective, and behavioral reactions of persons who interact with stigmatized individuals to understand the individual and interpersonal production of stigma. I focus here on the literature on characteristics of the stigmatized trait and the stigmatizer that determine the nature and extent of the stigma.

Social psychologists have identified a set of core psychological interpersonal responses to deviance across a variety of individual and group stigmas. First, a trait that sets a person apart from others is identified. Second, once a person is labeled as deviant, this person is linked to undesirable characteristics based on dominant cultural beliefs.<sup>89</sup> These perceptions then induce others to systematically alter their expectations and responses when they interact with the labeled person. Labeling theory further asserts that the labeled person incorporates others' expectations into his or her own self-concept, thereby taking on a role identity consistent with the label.<sup>90,91</sup>

Only certain types of traits are likely to be viewed as relevant and consequential to stigmatized conditions, thereby becoming the source of the stigmatizing label. Goffman initially described three groups of characteristics that are likely to receive stigmatization: physical deformities, blemishes of character, and "tribal" characteristics of race, nationality, and religion.<sup>60</sup> Although Goffman's formulation is not specific to health-related stigma, these categories can be readily applied to health conditions. For example, obese individuals may be perceived as possessing a physical deformity and/or manifesting a blemish of character (e.g., lack of motivation).<sup>91</sup> Jones and colleagues add granularity to these stigmatizing characteristics by proposing further dimensions to consider: the concealability of the trait, the course of the trait over time, the disruptiveness of the trait during social interactions, the aesthetic quality of the trait, the origin of the trait, and the danger posed by interacting with a person who possesses the trait.<sup>89</sup> For example, individuals in many societies believe that people with mental illnesses are

chronically affected, demonstrate non-normative behavior that it is disruptive to social encounters, have an unaesthetic, disheveled appearance, and have a tendency towards violent behavior. These beliefs contribute to the stigmatization of mental illness.<sup>91</sup> However, a disease does not necessarily need to fulfill many of these characteristics to be stigmatized: the sheer fear propagated by the media that Severe Acute Respiratory Syndrome (SARS) would propagate uncontrollably, overwhelm public health resources, create global economic disasters, and kill millions of people lead to the stigmatization of people infected with SARS.<sup>92</sup>

While the aforementioned traits and characteristics may identify individuals as deviant, a core factor that translates this identification into stigmatization is attribution, or the notion that an individual is responsible for his or her health condition. Hinshaw suggests that mental illness is often viewed as the product of weak will or other controllable causes.<sup>91</sup> HIV/AIDS is often associated with marginalized behaviors such as sex work, drug use, and homosexual practices.<sup>84</sup> Through social psychology experiments that manipulate the perceiver's understanding of attribution, researchers have found evidence largely supporting this relationship between attribution and stigma. Several interventions that highlight external, uncontrollable causes of obesity improved attitudes towards obese individuals, while others were less conclusive.<sup>93</sup> As I will discuss later, these assumptions about the causes of health conditions is based on a reductionist understanding of personal agency and health.

Social psychologists have also explored the motivation of the stigmatizer to stigmatize. Crandall and Cohen compiled a cluster of personality traits that commonly manifest in people who are more likely to reject a range of stigmatized groups, such as people who are obese, people with schizophrenia, and people with HIV/AIDS. People who stigmatized were found to have the following personality traits in common: included loneliness, alienation, having little

faith in people, submission to traditional authority, and a belief that people get what they earned in life.<sup>94,95</sup> Others have proposed that the act of stigmatizing has functional value for the stigmatizer, given the ubiquitous presence of stigma in a variety of social contexts.<sup>91,96</sup> Specifically, the stigmatization of an out-group helps delineate the distinction between self and others, promoting social identity. Stigmatization of others may also enhance one's own self-esteem by justifying a social structure in which the stigmatizer has privilege over the stigmatized. Furthermore, by rejecting those who deviate from social norms, stigmatization may allow the stigmatizer to validate his or her values and behaviors, and avoid the anxiety of having those values challenged.<sup>96</sup> Finally, fostering a sense of empathy towards the stigmatized individual may lead the stigmatizer to adopt the perspective of the individual, value his or her wellbeing, and soften the feelings of stigma. By experimentally manipulating the participant's empathy towards stigmatized populations, Batson and colleagues found that they could induce enduring positive attitudes towards people with HIV, homeless persons, and convicted murderers.<sup>97</sup>

### **Evolutionary theories of stigma**

Evolutionary theories of stigma offer a different perspective on stigmatized traits and the motivations behind stigmatization by arguing that the human disposition to stigmatize is rooted a biological instinct to avoid dangerous infectious pathogens. Disgust, one of the main emotional characteristics associated with stigma, is believed to have evolutionary origins. Disgust is typically experienced as a feeling of revulsion, sometimes accompanied by nausea, along with a strong desire to withdraw from the eliciting stimulus. Rozin and Haidt argue that the emotion of disgust originated as a rejection response designed to avoid ingestion of dangerous foods.<sup>98</sup> Schaller and colleagues argue more broadly that, because signs of disease consistently elicit

disgust, disgust evolved as a response to infectious agents. They call this particular response the “behavioral immune system,” and hypothesize that it operates through the detection of visual morphological abnormalities in others that signal potential disease.<sup>99</sup> A similar set of disease-predictive cues has been shown to elicit disgust across numerous cultures.<sup>100</sup> For example, Curtis and colleagues found that disease-relevant images significantly elicited more responses of disgust than similar images with little or no disease relevance across nine different cultural regions.<sup>101</sup>

As with disgust toward disease, disgust toward moral offenses has been found across cultures, and how disgust has evolved to respond to a wider range of non-infectious offenses is debated. Oaten and colleagues argue that the moral dimension of disgust is elicited towards activities and behaviors that were originally a means of managing disease-related threats.<sup>100</sup> Disease-avoidant psychological responses may be related to avoiding encounters with foreign people; and indeed, Schaller, Murray, and Damian found that people who live in regions of the world with higher prevalence of infectious diseases are less open to new experiences and unrestricted sociosexuality.<sup>102</sup> An alternative hypothesis is that the disgust response has evolved to be oversensitive, and is more likely to reject healthy individuals rather than accept potentially harmful individuals, as this would be more adaptive. Taken together with the belief that the response is activated through automatic, non-cognitive pathways to allow for rapid withdrawal from pathogenic cues,<sup>100</sup> the behavioral immune response responds to seemingly irrational cues that pose little danger, such as obese individuals and people with cancer. Some evidence suggests the continuity between disease-related disgust elicitors and non-infectious cues. For example, fear of infection is activated when people show disgust toward people with non-infectious conditions. Park and colleagues found that negative feelings toward obese people were



associated with fear of infection, as study participants associated obesity with disease-relevant concepts, and participants who felt more vulnerable to disease were more likely to show antipathy toward obese people.<sup>99</sup>

Finally, some proponents of the evolutionary theory argue that the ubiquitous human practice of stigmatizing others is rooted primarily in the biologically based need to live in effective groups.<sup>103</sup> Kurzban and Leary argue that stigma has evolved as a functional adaptation to avoid associating with those who present any form of evolutionary disadvantage.<sup>104</sup> This theory aims to explain the evolutionary basis of stigmatizing people who serve as poor partners of social exchange, such as people who have little to offer in terms of social gain or show unpredictable behaviors.

In summary, the individual and interpersonal theories of stigma do not offer a strong support for society to intervene to alleviate stigmatizing attitudes. The evolutionary theories of stigma suggest that stigmatization may be an automatic response that is ingrained in the human biology. Further, the assertion that stigmatization evolved as a response to avoid people who are infectious or otherwise pose an evolutionary disadvantage implies that stigmatization is (or has been in the past) a beneficial process that serves to maximize fitness. In the following sections, I discuss the conceptualizations of health-related stigma found in history, anthropology, and autobiography, which shed a different light on health-related stigma by pointing to the social forces outside of the individual as playing a central role in the production of stigma. These show that health-related stigma is a dehumanizing process based on socially constructed ideas about disease causality, that has been used to denigrate those who are on the lower rungs on the ladder of society, and that continues to perpetuates these disparities by limiting access to societal resources.

## **SOCIAL THEORIES OF STIGMA**

### **Stigma and the social construction of disease causations**

The literature on the history of medicine illustrates that evolving understandings about how and why people become sick reflected contemporary social values. These understandings of disease causation lead to the creation of meanings associated with these sicknesses. Leprosy and epilepsy were both believed to be the embodiment of immoral forces outside of the domain of health, whether divine retribution for wrongdoings and character flaws, or possession by the demonic forces. These etiologic understandings shaped the societal responses to mental illness and leprosy, both of which were believed to be contagious because moral failings and possession were seen as contagious.

In China, leprosy was among the many serious ailments, particularly those with conspicuous and unappealing external symptoms on the skin, believed to be retributions for unrepented wrongdoings of the victim or of their ancestors.<sup>105</sup> This belief was reflected in the societal response to people with leprosy, who were targets of numerous forms of structural discrimination, condemned and cursed by the law and in various religious traditions across time. People with leprosy in early imperialist China had “unusual legal status.”<sup>105</sup> For example, in the Qin statutes, a patient with leprosy was deprived of the right to marriage. Further, forms of capital punishment for leprosy criminals were imbued with ritual meanings: people with leprosy were drowned in still water or buried alive, which reflected society’s attempts to ward off the supernatural threats that leprosy patients were considered to personify. Even after such extreme legal practices were discontinued, isolation and segregation of leprosy patients continued. At the same time, while the presumed etiology of leprosy invited harsh legal and religious treatment, it

also invited attempts to cure the disease by restoring the morality of the sufferers.<sup>105</sup> Stories in the Buddhist tradition depict miraculous healings of leprosy patients by morally superior men through show of faith, charity, and sacrifice, while the Daoist tradition approached healing leprosy through bodily self-cultivation, moral discipline, and disdain for worldly comfort.

Similarly, the epileptic was believed to signify possession by gods and demons during the ancient times, and people feared that whoever touched the epileptic might become prey to the demon.<sup>106</sup> Because of its physical and psychic symptoms, magical and natural explanations for epilepsy coexisted during the end of the fifteenth century. Some physicians blamed possession, magic, and witchcraft, some subscribed to a purely medical understanding of epilepsy, and others espoused a kind of merger of the two theories: the demonic acts were an external trigger that set the inner, physiological causes in motion.<sup>106</sup>

The interest in personal responsibility for health emerged far before biomedical understandings of disease elucidated the mechanisms through which health behaviors could promote or endanger health. During the Enlightenment, early statistical studies attempting to identify behavioral causes of epilepsy concluded that fearfulness, masturbation, and drunkenness were among the most frequent causes of epilepsy among their patients.<sup>106</sup> Seventeenth- and eighteenth-century guides for health emphasized the need for individuals to control all aspects of life as much as possible: their diet, exercise, sleep, evacuations, and emotion.<sup>107</sup> The predisposition to both acute and chronic diseases was understood as a cumulative effect of constitution, circumstance, and regimen, and the individual was responsible for acquiring the illness in addition to recovering from it.

The introduction of germ theory led to the belief that disease was a result of the chance encounter between the individual and causal agent, and hence placed emphasis on the existence of discrete, external causes.<sup>107</sup> However, as chronic diseases increased in the 20<sup>th</sup> century, emphasis was again placed on the notion of individual choice and individual responsibility. Epidemiologic studies in the first half of the twentieth century identified specific behaviors such as smoking, diet, and exercise, and offered the possibility of control over one's health.<sup>108</sup> This led to the renewed emphasis on individual responsibility for health; as Rosenberg states "chronic illness becomes in this moral sense an aggregate of cigarettes smoked, seatbelts unfastened, glasses filled and emptied, cheeseburgers devoured."<sup>107</sup> During this time, smoking, sexually transmitted diseases, obesity, and cancer acquired stigmatized status because of the notion of personal agency that accompanied them.

More recently, Gilman proposed that obesity simultaneously evokes both the personal responsibility and infectious disease models of disease. He asserts that, rather than the adverse health consequences of excess weight, the belief that excess weight signifies lack of will that has caused a "moral panic."<sup>109</sup> Thus, dieting has become the means of self-liberation by which the individual reasserts control over his or her body. At the same time, obesity is also understood as if it were infectious.<sup>109</sup> He demonstrates this using two illustrations: first, the popularity of the term "obesity epidemic" connotes excess weight as if it were spreading uncontrollably in the community; second, society views excess weight as if it were monocausal, and hence look for a single magic bullet to offer a quick fix to the disease. The blaming of single food items as responsible for obesity (e.g. saturated fats, high fructose corn syrup, and fast food) and the flooding of diet foods onto the market both signify this belief.

Sontag criticizes society's denial of death and belief that medicine should cure all illness for the creation of health-related stigma. She argues that conditions that are not curable attain a special status and are treated with mystery and fear.<sup>110</sup> Further, because death has come to be understood as an "offensively meaningless event," diseases that are equated with death are extremely feared and concealed from loved ones, and at times from the patients themselves in the case of cancer.<sup>110</sup> In addition, the fear of moral contagion makes friends and family shun people with cancer.<sup>110</sup>

These examples resonate with Brandt's assertion that the "perceptions about what causes disease...reflect powerful moral beliefs," and that these beliefs in turn shape the social response to the disease.<sup>108</sup> Supernatural forces, moral and infectious contagion, lack of self-discipline and self-restraint, and death were concerns that loomed large in each of the time periods, and the stigmatization of leprosy, epilepsy, and obesity can be explained by these fears. It is now known that these many chronic and acute health states have complex causal frameworks. While high levels of stigmatizing attitudes are correlated with the belief that smoking is caused by "weak character,"<sup>111</sup> smoking is increasingly understood to be a complex behavior that is shaped by deep social, cultural, and economic forces, as well as the biological process of addiction.<sup>112</sup> Even the tobacco industry has been implicated in engaging in innovative advertising, marketing, and manipulating scientific debates to engineer a culture in which smoking is mainstream and universal.<sup>113</sup> More generally, a strong association between socioeconomic status and health has been consistently shown across health conditions, prompting Link and Phelan to argue that socioeconomic status affects multiple disease outcomes through multiple mechanisms by limiting access to both material and non-material resources.<sup>114</sup> Stigmatization of health conditions, without the proper acknowledgement of the social forces that constrain agency and

contribute to vulnerability to disease, places those who are affected under a double burden of disease and stigmatization.

### **Race, class, and gender**

It is notable that across time, disease, and continent, one can find instances in which stigma associated with health conditions has been used to not only make disparaging characterizations of individuals, but of groups of individuals based on their race, class, and gender. Many of these were actually motivated by negative social attitudes towards race, class, and gender that already existed in the society, and their association with stigmatized conditions was another indirect way to discriminate against minorities.

Racial minorities have been regarded to be more prone to stigmatized health conditions because of a presumed innate or cultural inferiority. The anti-Semitic medical discourse of the late 19<sup>th</sup> century through mid-20<sup>th</sup> century characterized Jewish people as an overweight race.<sup>109</sup> This was associated with underlying assumptions about a behavioral flaw of over-consuming rich foods and alcohol, or a biological flaw of being predisposed to diabetes and excess weight gain. In China, leprosy became an embodiment of cultural backwardness of the south, based on the epidemiological understanding in the 16th-century when leprosy was mostly endemic in the southern, miasmatic region. Leung argues that these beliefs polarized the country, creating a “dividing line between...center and south...the civilized and the savage that continued into the modern period.”<sup>105</sup> Even as recently as the Severe Acute Respiratory Syndrome (SARS) epidemic in 2003, the perceived linkage between SARS and ethnicity led to the irrational avoidance of Asians in many parts of the world.<sup>92</sup>

In addition, women have been believed to suffer from stigmatized diseases because of their comparatively weak composition and spirit. In China, leprosy was also believed to be the disease of morally base women, because it was thought to be transmitted sexually from female sufferers.<sup>105</sup> In the United States, women in popular fiction and cartoons in the 19<sup>th</sup> century were featured as overweight, representing them as sexually loose, primitive and repulsive,<sup>115</sup> and lacking in sufficient rational qualities to control the impulses of corporal desires.<sup>115</sup> Notably, this tactic to mock women was used by women themselves. During the American suffrage movement, suffragist and anti-suffragist women ridiculed the members of the opposing group by exploiting the various unattractive associations of excess weight. In their propaganda posters, anti-suffragists aimed to portray the unflattering lack of femininity of the suffragists by depicting them as overweight. Meanwhile, suffragists used obesity to symbolize the old-fashioned and aging quality of anti-suffragists. In contrast, both parties portrayed themselves as thin, white and attractive.<sup>115</sup>

In terms of social class, scholars have noted that the emergence weight bias coincided with the emergence of a middle class in the 19<sup>th</sup> century.<sup>109</sup> Prior to this time, excess weight was seen as a privilege, a symbol of power and affluence accessible to very few as illustrated in the “fat cat” cartoons of rich, powerful men with a large belly.<sup>115</sup> During the economic and social changes in the late 19<sup>th</sup> century, the American nouveau riche began to enjoy the new economic and social liberties previously reserved for the elite. Excess weight came to be associated with the lack of self-restraint demonstrated by the middle class: the cartoons mocked overweight middle-class people who can no longer fit in their suits or their swimming pools.<sup>115</sup>

Some have implicated that health care providers have taken advantage of the stigmatized status of health conditions to assert their greater social status over patients. Gilman argues that

lay health practitioners and health and nutrition vendors have capitalized on the stigma of obesity to encourage dieting and attract overweight people as their clients <sup>109</sup>. Luker, in her historical account of abortion in the United States, illustrates how anti-abortion physicians sought to frame the abortion debate by asserting that they had claim to superior scientific knowledge <sup>116</sup>. The public acceptance of the technical basis of the claim gave doctors unquestioned legitimacy in the debate. Further, through creating and controlling a moral problem, physicians used the issue of abortion as a symbolic claim to superior moral status.<sup>116</sup> In contrast, women were precluded from any effective challenge to medical control of abortion because they were defined as self-interested parties whose vested interests in the outcome made them incapable of reaching an “objective” decision.<sup>116</sup>

Health-related stigma has functioned to strip individuals of their citizenship status in their communities. Gilman claims that societies have often considered that “healthy citizens are better citizens.”<sup>109</sup> In her work, Farrell explored the historical connection between body size and the notion of citizenship, noting that the link between weight and citizenship is illustrated quite literally in American cartoons of the late 19<sup>th</sup> and early 20<sup>th</sup> century depicting immigrant laborers as overweight, stupid and clumsy.<sup>115</sup> Not only were people with a disease not worthy of membership, but they also were thought to actively corrupt the rest of the state. Leung uses the metaphor of a “physically [and] socially corrupt body that threatened to pollute the healthy part of society” to characterize the attitude towards leprosy patients.<sup>105</sup> Leung argues that, to the rest of the world, leprosy in China embodied two “defects” of the Chinese race: its physical inferiority and the contagiousness of its disease.<sup>105</sup>

So strong was the fear, repulsion, and pity that the stigmatized provoked in others that it gave them a strange form of power in certain contexts. Leprosy sufferers in China formed groups



at the margins of society, and extorted money from others by refusing to leave from celebratory events or funerals unless they were paid, or worked for pirates and gangsters to retrieve ransom from families of kidnapped person.<sup>105</sup> At times, stigmatized diseases also served to inspire compassion in other people. An epileptic was “considered a poor wretch, deserving pity, compassion, and special consideration.” Beggars across Europe feigned epilepsy as early as the Middle Ages, prisoners feigned epilepsy to evade torture, and men feigned epilepsy to evade universal military conscription.<sup>106</sup>

### **Stigma and social structure**

Link and Phelan propose that stigmatization is contingent on a social structure in which there is differential access to social, economic, and political power that determines who is stigmatized by whom in a given society.<sup>117</sup> Castro and Farmer propose a framework for understanding stigma through the large-scale social inequalities rooted in historical and economic processes. Using the example of HIV/AIDS, they argue that social forces such as racism, poverty, gender inequality – termed structural violence - determine not only who is more vulnerable to disease but also who has access to health care and who ultimately suffers from stigma and discrimination.<sup>82</sup> Farmer’s ethnographic research showed that stigma in rural Haiti resulted from people’s belief that AIDS was an inevitable and fatal disease, a reflection and result of the complete lack of health care for the poor (AIDS and Accusations, Chapter 5, Haiti to Rwanda). Wolfe and colleagues found in Botswana that respondents who perceived that antiretroviral therapy was available had significantly lower odds of having stigmatized attitudes toward HIV/AIDS<sup>83</sup>. Farmer further states that HIV stigma has shaped the social response to AIDS by blaming the victims of AIDS and limiting further action. (AIDS and Accusations, Chapter 5, Haiti to Rwanda).

While social inequalities generate stigma, stigma continues to perpetuate and exacerbate these disparities. Yang and Kleinman describe stigma as a process that threatens social standing and the subsequent access to social resources, which they argue is what matters most to individuals in the local social context.<sup>118</sup> In China, an individual must cultivate the ability to engage in appropriate, reciprocal social exchanges in the family and community to be considered a full person. People with HIV/AIDS and schizophrenia are deemed no longer able to fulfill these interpersonal and intrapersonal obligations, and because fulfilling these norms of reciprocity define the moral status of the individual in the community, these individuals are treated as a non-person. These individuals face severe social sanctions and isolation from their families and communities – what they call a “social death.” Stigma has been found to profoundly limit the ability of the affected person to seek and maintain social resources in other settings as well. Disclosure is essential for people living with HIV/AIDS to receive social support. Yet, fear of becoming targets of stigmatization prevents them from disclosing their status to their social networks,<sup>26</sup> and the greater their shame and guilt, the more likely they are to avoid disclosure and interactions with others.<sup>71,72</sup> HIV stigma has been correlated with depression,<sup>28</sup> which may also limit their capacity for forming and maintaining social relationships. Takada and colleagues found that people living with HIV/AIDS who report experiences of discrimination and abandonment are more likely to lose their social support, consistent with the idea that friends and family members, who provide the bulk of social support, leave them because they become targets of stigma or are themselves sources of discrimination.

### **The lived experience of stigma**

Scholars have developed measures to understand the complex experience of health-related stigma for a variety of health conditions and adapted them for a range of cultural

contexts.<sup>111,119,120</sup> Among them are the scales used to study HIV-related stigma in the clinical epidemiology literature that conceptualizes stigma as composed of interpersonal and intrapersonal dimensions.<sup>26,28,29,50,121</sup> In these scales, enacted stigma refers to acts of discrimination and hostility directed at the stigmatized person because of his or her stigmatized status, normative stigma refers to the subjective awareness of stigma and the belief about the prevalence of stigmatizing attitudes among people in the local community, and internalized stigma refers to the extent to which an individual perceives stigma to be valid; in the case of stigmatized individuals, it is self-stigma, including feelings of guilt, shame, and worthlessness.<sup>50</sup> Each component is measured using its own scale. For example, the internalized stigma scale asks about feelings of guilt, shame, and worthlessness for being HIV-positive. Each of these dimensions have been shown to be related through other psychosocial factors that affect the wellbeing of people living with HIV/AIDS such as social support, depression, and disclosure avoidance.<sup>28,29,50,121</sup>

While these scales have been meticulously developed based on theoretical frameworks of stigma and exploratory qualitative interviews, then tested for construct validity, they cannot sufficiently capture the lived experience of stigma as well as autobiographical accounts that have been written by those who have lived with stigmatized conditions. These accounts of the fear, shame, loneliness and humiliation shows that living with stigma is an experience of significant suffering.

For Jamison, the diagnosis of bipolar disorder signified the loss of her sense of identity as a confident, self-reliant person. She vividly describes when she first sought diagnosis of her illness as being “paralyzed with fear and shame,” and “terribly shattered in all of my notions of myself.”<sup>122</sup> She lived in denial of her condition and was reluctant to adhere to her medications

for many years, despite being a clinical psychologist herself. Jamison's reluctance to disclose her conditions to others stemmed from her fear of the consequences it would have on her professional career, and her anticipation of rejection from colleagues and friends. In one instance, Jamison refused hospitalization for the fear that if it were to become known, she would lose her clinical responsibilities.<sup>122</sup> She encountered two heartbreaking rejections by her friends and family: first from her sister who was "disgusted" that Jamison relied on medication, and then from a close colleague who expressed he was "deeply disappointed" when she confided in him her diagnosis.<sup>122</sup>

Monette recounts the experience of caring for someone with AIDS in the mid-1990s United States, when the notion of AIDS had turned into "an inquisition in the gay community."<sup>123</sup> Monette describes his rollercoaster life, one moment filled with hope for the availability of a new treatment, the next moment facing the loss of his friends to AIDS and the possibility of his partner's impending death to the disease. Discrimination and social isolation were routine to the experience of living with HIV, from health care workers who reacted in horror and refuse to mention the word AIDS, to his partner's client who found out and left his partner's legal practice. Monette poetically calls the social isolation of living with HIV as being "exiled on the moon," an experience that cannot be fully understood except by those who are his "fellow exiles."<sup>123</sup> He and his partner's brother withheld information about his partner's diagnosis from his parents until his partner reached the later stages of AIDS and the disclosure became inevitable. Further debilitating was that Monette and his partner lived under a two-fold secrecy, a "double closet" of being homosexual and being HIV-positive.<sup>123</sup>

Sontag argues that society assigns meanings to diseases, and that these meanings lead to harmful assumptions about the person affected. Although she refrains from mentioning her

personal experiences, her account is perhaps colored by her experience of undergoing breast cancer treatment at the time of writing. Sontag describes that society believed that having a tumor was shameful. People with repressed negative feelings, who were “losers of society,” became affected by cancer, and as the person was dying of cancer, he or she was “robbed of all capacities of self-transcendence.” The language surrounding cancer captured these negative attitudes: cancer was associated with predatory and warlike terms such as “ruthless invasion” and “fight,” and itself has been used as a metaphor to signify political corruption. Ultimately, she argues that, “illness is *not* a metaphor, and that the most truthful way of regarding illness” is one without “metaphoric thinking.”<sup>110</sup>

## **STIGMATIZATION IN HEALTH POLICY**

Stigmatization operates explicitly or implicitly in public health campaigns that aim to discourage unhealthful behaviors. One of the most familiar examples is the American anti-tobacco campaign. In 1978, one of the earliest installments of American Cancer Society’s Annual Great American Smokeout Campaign championed the slogan, “Kissing a smoker is like licking an ashtray,” that remains in the memories of adults even today.<sup>124,125</sup> While more recent campaigns have been less explicit,<sup>126</sup> scholars and media alike nevertheless raise concern that anti-smoking policy in the United States has the potential to contribute to stigmatization by shaming smokers and sending symbolic messages of moral condemnation.<sup>111,125</sup> Stigmatization may have more impact in resource-poor settings with limited access to informational and educational resources: India, Khale and Dyalchand implemented a rural sanitation program that engenders a sense of shame regarding open defecation and encourages communities to address it themselves.<sup>127</sup>

Some argue that public health policies that reprehend health behaviors do not necessarily lead to stigmatization. Stuber and colleagues found that, despite wide-spread implementation of anti-smoking legislation in the US, less than a majority of American smokers perceive smoker-related stigma.<sup>128</sup> Evidence have suggested that the immediate social network matters more than policy: smokers who were exposed to smoke-free air laws reported lower levels of smoker-related stigma, while smokers whose friends and family found smoking unacceptable reported high levels of stigma.<sup>111</sup>

The effectiveness of these policies on health outcomes is mixed. Some public health approaches that stigmatize health conditions and behaviors have shown significant impact in reducing harmful health behaviors. Alamar and Glantz calculated a state-level social unacceptability index of smoking based on residents' support of smoke-free laws, and found a 10% increase in social unacceptability corresponded to a 3.7% decrease in cigarette consumption in the state.<sup>129</sup> While smokers who perceive devaluation engage in social withdrawal from non-smokers and keep secrets about smoking, they found that secrecy was correlated with a higher intention to quit smoking.<sup>128</sup> In Khale and Dyalchand's rural sanitation program, villages that used shame to discourage open defecation had on average a higher rate of toilet use compared to villages that used the traditional sanitation program based on the provision of sanitation hardware.<sup>127</sup>

In general, psychological research has found that using punishment tactics such as shame does not lead to lasting behavior change, and intervention research confirms this hypothesis. The weight bias literature overwhelmingly suggests that stigma contributes to psychological distress and unhealthy behaviors in both community and clinical populations.<sup>93</sup> For currently overweight and obese participants, experiences of stigmatization were all significantly related to greater

body image dissatisfaction, lower self-esteem, greater social anxiety, more depression, and less life satisfaction.<sup>130</sup> Stigma experiences and internalization of weight-based discrimination did not predict engagement in weight loss strategies and was found to be associated with higher frequency of binge-eating.<sup>131</sup>

HIV stigma is also a well-documented barrier to the health and well-being of people living with HIV/AIDS (PLWHA). HIV-stigma has been associated with delaying or avoidance of HIV testing,<sup>61,62</sup> poor adherence to HIV antiretroviral treatment,<sup>30</sup> and poor engagement with care.<sup>31</sup> In addition, PLWHA experience numerous mental and psychological sequelae of stigma, including stress, fear, anxiety, and depression.<sup>26-29</sup>

Even in rare situations in which stigmatizing interventions are medically justified, the public health benefits must be weighed with the consequences of discrimination. While isolation and quarantine were absolutely necessary in the control of SARS in Hong Kong, those quarantined became targets of discrimination and social isolation, leading them to lose employment opportunities, be denied essential services, and become isolated from relationships that provided emotional and financial support.<sup>132</sup> In enacting such public health interventions, Kleinman and Lee argue that it is critical to work toward limiting their negative social and psychological consequences as much as possible.

Lessons from the history of public health have shown that stigmatization of those who are already vulnerable exacerbates morbidity and mortality by erecting barriers between health services and those who are sick. The antivenereal disease campaigns by the United States during World War I resulted in justifying breaches in civil liberties in the name of public health, including the quarantine and incarceration of thousands of women who were suspected of

spreading venereal disease.<sup>133</sup> Despite these draconian efforts, they failed to serve as an effective public health measure, as the rates of disease remained high during the war. Furthermore, the military declined to distribute condoms for fear that it would encourage promiscuity, despite the evidence that they prevented infection. Brandt attributes the failure to the infusion of public health with the social hygiene movement of the 20<sup>th</sup> century, professing moral concern regarding sexuality and the notion of responsibility for contracting the disease, and that the best way to prevent infection was by adhering to a sexual ethic that made it impossible to acquire infection.

Public health approaches that stigmatize the individual for their health condition can be problematic for several reasons. By implying the individual has responsibility to change, these approaches neglect the complexity of health behaviors that are deeply embedded in social, cultural, and economic structures, as well as biological processes. This misplaced emphasis on individual responsibility may deny broader social responsibilities for health and disease.<sup>108</sup> Similarly, Becker contends that public health messaging about obesity “conflates health literacy with health agency,” assuming individual actors have responsibility, autonomy, and agency to manage behavior that is not entirely within the control of the individual.<sup>87</sup> This approach fails to take into account the psychological complexity of motivation, and the impact of the social environment and norms that create risk for stigmatized conditions. Moreover, stigmatization harms the health of those who are stigmatized by creating a barrier to health services, and causing social isolation and profound psychosocial distress. Ultimately, stigmatization must be addressed in health and social policy, not only for the wellbeing of those with stigmatized health conditions, but also to achieve positive public health outcomes.<sup>132</sup>

## **CONCLUSION**

Social psychologists describe stigma as originating from an unsympathetic interaction



between a person possessing a non-normative trait, and a cynical, authoritarian person who wishes to justify their social values. The stigmatizing response may have evolutionary roots in letting an individual detect people who pose fitness burdens. However, situating stigma in the social space reveals that health-related stigma is based on reductionistic explanations of disease causation, and is intimately tied to disparities in access to social, political, and economic resources. Furthermore, health policies that promote stigmatization not only fail to demonstrate outcomes in improving health, but also serve to harm those who are targets of stigma. Taken together, the use of health-related stigma in health and social policy represents a lack of acknowledgement of the social forces that shape the social distribution of disease as well as stigmatization. Further, the societal failure to acknowledge the suffering caused by stigmatization becomes in itself another form of suffering. Kleinman and colleagues argue that one may be unable to experience the pain of another because of the asymmetry of access to experiential knowledge, but this inability to experience pain is distinct from the inability to acknowledge their pain.<sup>134</sup> In this sense, the lack of acknowledgement of the suffering caused by stigmatization by policymakers in particular and society in general adds an additional layer of socially produced suffering to the experience of the stigmatized. Therefore, societies have a responsibility to be wary of enacting policies that stigmatize and normalize stigmatization, because they exacerbate the social and economic disparities that underlie stigmatization and cause unnecessary suffering to those who already suffer from their illnesses.

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