 Supplementary files are available for this work. For more information about accessing these files, follow the link from the Table of Contents to "Reading the Supplementary Files".

# UNDERSTANDING THE PSYCHOSOCIAL DYNAMICS OF HIV/AIDS PREVENTION AND CARE IN THE COMMUNITY: BASE CASE MODEL FINDINGS AND IMPLICATIONS

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*A system dynamics model was built for the purpose of fostering a greater understanding about the psychosocial dynamics of HIV/AIDS prevention and care in the community over a twenty-year time horizon, from the epidemic's inception (circa 1981) to the present. In particular, the psychosocial dynamics of perceived stigma, complacency, and [dis]empowerment were studied in relation to the epidemiology of HIV/AIDS in Michigan. The study was informed by the results of an extensive qualitative research project that explored the current and emerging needs of persons living with HIV/AIDS (PLWHA) and by the insight and knowledge of a group of ten (N=10) core key informants from Michigan's HIV community. The underlying dynamics of the problem focus in the study were expressed in a set of five key causal processes. Initial feedback from members of Michigan's HIV community affirmed that the base case model has provided deeper insight into the phenomena of HIV/AIDS prevention and care.*

## INTRODUCTION

Twenty years have passed since the Centers for Disease Control and Prevention (CDC) reported the unsettling news of five deaths in Los Angeles from Pneumocystis Carinii Pneumonia (PCP) (CDC, 1981), the event that marked the beginning of a worldwide battle against Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS). Since then numerous, co-existing epidemics have emerged in throughout the globe – some of them highly volatile – all of them compromising the health and well-being of the communities they impact. *Sexual behaviors* (particularly unprotected sex between men), *substance use* (particularly injecting drug use), and distribution of *contaminated blood products* (particularly

within the hemophilia community) are events that carry a substantial amount of explanatory power with respect to understanding the genesis and expansion of these epidemics over time.

Yet these reasons alone do not adequately explain current patterns of HIV/AIDS burden. An epidemic is a dynamic process that, as (Doka, 1997) explains in the following passage, involves time, place, biology, and society:

Diseases are more than biological phenomena or individual catastrophes. They are profoundly social events. In many cases, the disease emerges and spreads because changing social conditions trouble the fragile balances that exist between humans and their diseases. In other situations, a disease is perceived or recognized in a distinct way, reflecting new social conditions and forces. In all cases, the ways in which a disease is spread and treated are strongly influenced by larger sociological considerations. And the emergence of new, or newly perceived, diseases is likely to change social institutions and perhaps society itself (p. xiv).

With respect to HIV/AIDS, *psychosocial* factors, namely *stigma*, *complacency*, and *[dis]empowerment*, need to be explicitly taken into consideration in the design of HIV/AIDS-related interventions (Aday, 1993; Doka, 1997; IOM, 2001; Mann & Tarantola, 1996). In particular, these factors have been associated with social context challenged by racism, homophobia/heterosexism, gender inequities, politics, religious intolerance, and poverty. The point to be made here is that interventions intended to address the problem of HIV/AIDS are not likely to be effective if they do not address the complexities of the psychosocial context in which the epidemic sits (Hart & Boulton, 1995; Rhodes, 1995; Treichler, 1991 (in press); Zierler & Krieger, 1997).

Despite these complexities, the actual nature, or character, of any given solution to the problem of HIV/AIDS, or any other epidemic for that matter, is simple. There are two general approaches, namely: (1) *prevention* and (2) *care*. Both have been proven to work if the right 'mix' is available (ACDP, 1999; CDC, 1997a; Jemmott, Jemmott, & Fong, 1992, 1998; Kegeles, Hays, & Coates, 1996; Valdiserri, Lyter, & Leviton, 1989). In general, we want to prevent new cases of HIV infection and we want to develop and make accessible treatments that sustain quality of life for those who may already be positive. There is a need to strike a good balance, to integrate preventative measures into care services and *visa versa*, to foster HIV/AIDS *prevention through care*, and *care through prevention* (Altman, 1994; CDC, 1999; Delor & Hubert, 2000; Doka, 1997; IOM, 2001; Labonte, 1994; Mann & Tarantola, 1996; Morin, Coates, & Shriver, 2000; Plumridge & Chetwynd, 1998). To begin to understand the challenge inferred by this statement, a review of the HIV/AIDS epidemic's *stages of intervention* is important to keep in mind. Reflecting on the relatively short history of HIV/AIDS, it appears that the norm for community intervention has been either prevention-focused or care-focused, but not an integration of both (CDC, 1993, 1997a, 1997b, 2000; Falck, Carlson, Price, & Turner, 1994; Morin et al., 2000; Schwartz, Dilley, & Sorensen, 1994).

### **Stages of Intervention**

Although a critical understanding of the meaning of our collective response to the HIV/AIDS crisis is just now emerging in the social sciences, a number of retrospectives have already been offered. So far, an historical unfolding of HIV/AIDS has been viewed in terms of three to four 'phases,' or stages, of societal reaction spanning a twenty-year period (1981 to 2001). For example, Mann and Tarantola (1996) have labeled three periods, namely: (1) the 'period of discovery' (1981-1984), (2) the 'period of early response' (1985-1988), and (3) the

‘current period’ (1989 to 1996). More recently, Rosenbrock et al. (2000) have labeled four periods, the first three of which more or less correspond to Mann and Tarantola’s. Rosenbrock et al.’s phases include the following: (1) ‘emergence of exceptionalism’ (1981-1986), (2) the ‘consolidation and performance of exceptionalism’ (1986-1991), (3) the ‘exceptionalism crumbling, steps toward normalization’ (1991-1996), and (4) ‘normalization, normality’ (since 1996).

To some extent, these stages can be seen as political in nature. Taking an historical perspective on health and healthcare, Levine and Levine (1970) would argue that, for example, the perceived need for deployment of preventative strategies over medical strategies to address the problem of HIV/AIDS could be explained largely in sociopolitical terms. In general, they have observed that there is a tendency to cycle between ‘environmental’ explanations and ‘person’ explanations of the causes of social problems and that these cycles typically coincide with current political sentiments. In their review of a wide range of community health issues, Levine and Levine (1970) observed that when the climate of the times is *politically liberal*, the environment, or the system, is held at fault and interventions emphasize prevention over care. In contrast, when the climate of the times is *politically conservative*, the person, or the individual, is held at fault and interventions tend to emphasize care, or treatment, over prevention.

**Discovery/Emergence.** ‘Exceptionalism’ emerged out of the quick realization that HIV/AIDS was a different kind of public health problem and therefore could not be effectively addressed through a traditional public health frame of reference (Rosenbrock et al., 2000; Rosenbrock, Friedrich, & Heckmann, 1995). At the start of the HIV/AIDS epidemic in the industrialized world, the attitude of the public health and medical establishment was that the age of infectious diseases had come to an end. The discovery of HIV/AIDS generated a climate of great uncertainty, which in turn motivated a very intensive period of exploratory research and development.

**Early Response.** During the second period, the ‘period of early response’ (1985-1988), institutional responsiveness became the primary focus. Individual risk reduction initiatives remained a key objective, but they were now supported by selected health and social services. In many cases, these new services were the foundation upon which national AIDS programs were developed, many of them fostered by the guidance of the World Health Organization’s Global Program on AIDS (WHO/GPA) (WHO, 1987). Also during this period came the development of the earliest treatment protocols, but they were viewed as clearly separate and distinct from preventative activities (Chesney, Morin, & Sherr, 2000; Fenton & Peterman, 1997; Mann & Tarantola, 1996; NASTAD, 2001).

**Normalization.** According to Rosenbrock et al. (2000), during the period of normalization (1991-1996) HIV/AIDS turned into a ‘chronic disease.’ Among most industrialized countries, including the United States, epidemiological trends appeared stable and the infrastructure developed to provide prevention and care services underwent a process of consolidation. By the end of this period, what was once unfamiliar and very frightening seemed less so, which tended to cause the rate of HIV/AIDS innovation in both prevention and care to level off. Over time, public attention waned and began to shift to other priorities.

Also during this period the grassroots organizers who had stepped up in the early years began to leave due to burnout, which often took the form of serious health problems and death – given that many of these pioneers were themselves living with HIV/AIDS (Bayer & Oppenheimer, 1998; Kleiber, Enzmann, & Gusy, 1995). Overall, the effect was that an exceptional ‘activist’ zeitgeist dissipated in many locations. It was at this time, however, that

Mann and Tarantola (1996), among others (Mane et al., 1996), stepped up initiatives to further extend care services to PLWHA and to renew commitment to the fight against HIV/AIDS. In particular, the Coalition began a campaign to call attention to the reality that current approaches were insufficient and that there was a need to go beyond traditional models of public health to address the societal dimensions of 'vulnerability' to HIV, such as poverty, stigma, and complacency.

**Medicalization.** The most salient process contributing to the complacency was arguably initiated by widespread access to new, relatively effective anti-retroviral drugs in 1995. For the first time in the history of the epidemic the health of PLWHA was improved. Until this point, HIV/AIDS exceptionalism had been more or less preserved by the fact that the biomedical model was 'on the defensive.' The positive impact of anti-retroviral treatments was cause to relax a little. As new drugs became available and combination therapies were developed and shown to be ever more effective, HIV/AIDS began to be portrayed as a chronic illness. The dropping mortality rates as well as self-reports by PLWHA about the health benefits of the new treatments were taken as firm testimony of this fact (Patella et al., 1998).

**Normalization.** Rosenbrock et al. (2000) describe the period from 1996 to 2000 as revealing of two processes of normalization: (1) normalization in the form of cutbacks and (2) normalization as a generalization of exceptionalism. With respect to normalization in the form of cutbacks, AIDS-related task forces and specific agencies continued to be cut back or (re)integrated in normal hierarchic, bureaucratic organizations (Cattacin, 1998). For Michigan, a case in point would be the placement of the Michigan Department of Community Health's HIV/AIDS Intervention and Prevention Section (MDCH/HAPIS) into a sub-department of the MDCH's Sexually Transmitted Disease unit (MDCH/STD). The combined division is now referred to as 'MCDH/STD&HIV-AIDS/HAPIS.' What once stood alone, is now under the oversight of a larger, pre-existing division. Here, as in other locations, efforts to be more reflexive and cost efficient have translated into reduced or level funding for prevention, surveillance, and research (Foster, Gregory, Niederhausen, Rapallo, & Westmoreland, 1999).

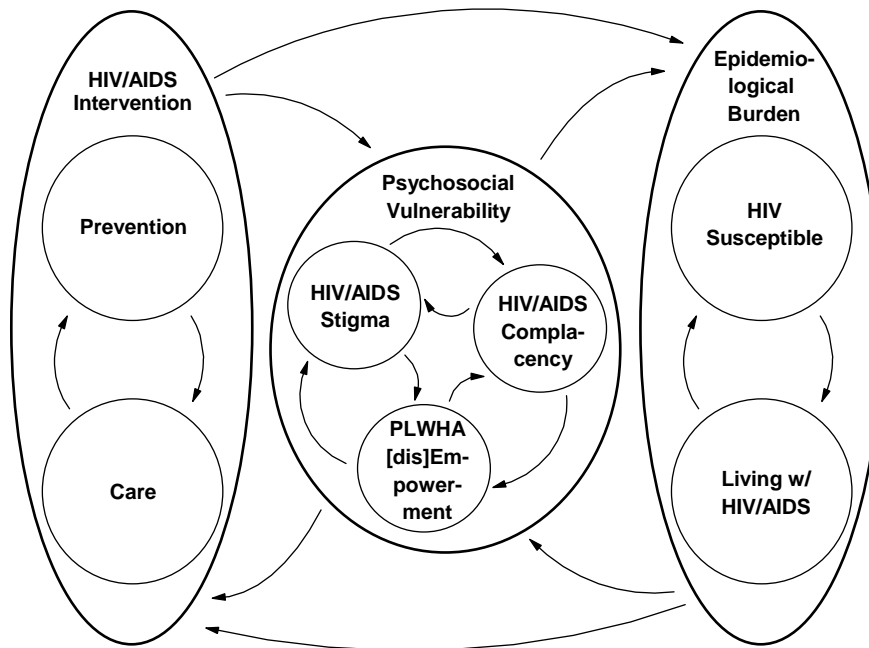
### **Overview of the Purpose and Methodology of the Study**

Attending to the full period of time covered by these various stages of intervention (circa 1981 to 2001), the purpose of the study was to work in a participatory manner with a small group of HIV/AIDS prevention and care advocates from Michigan to *build a model for understanding the psychosocial dynamics of prevention and care in the community*. The need to create such a model was articulated in a preceding, qualitative research project that identified and described the current and emerging challenges facing PLWHA in Michigan (Lounsbury, 2001). The small group of advocates involved in the study was comprised of persons who were familiar and active members of Michigan's HIV community (i.e., the community of persons involved in the design, delivery, consumption, and/or evaluation of HIV/AIDS prevention and care interventions in the state). The model that was build was intended to be of use as a policy analysis tool for Michigan's as well as other states' HIV communities. In general, the model was created to inform policy that could help achieve the following three overarching goals: (1) reduction of new HIV infections among all susceptible groups, (2) improved health and well-being among all PLWHA, and (3) increased efficiency and sustainability of HIV/AIDS-related services.

The study was qualitative in nature and applied a 'systems dynamics approach,' a research methodology explicitly intended to promote in-depth learning about dynamically complex problems (Ford, 1999; Forrester, 1961a, 1961b, 1971; Forrester, 1987; Sterman, 1994,

2000). The problem focus was defined in terms of trends in one or more constructs over a specified period of time. The dynamics of these trends were represented as a set of *causal loop diagrams*, which were then translated into a system of *interdependent mathematical structures* (i.e., the formal system dynamics model).

**Conceptual Framework.** Figure 1 places the three conceptual domains of focus in the current study (i.e., *epidemiological burden, HIV/AIDS intervention, and psychosocial vulnerability*) in an interdependent and dynamic context. The arrows linking the domains (and the sub-domains within each) indicate *dynamic interdependency* (i.e., behavior of one domain affects the behavior of others, either directly or indirectly, over time). Of particular focus is the *dynamic mediation* of psychosocial vulnerability as it interacts with prevention and care interventions and with epidemiological trends.



**Figure 1 - Conceptual framework for the current study**

**Applicable Works from the System Dynamics Literature.**

A search of the systems literature located a number of HIV/AIDS-related modeling projects, essentially all of which focused on epidemiological trend analyses and on the dissemination or adoption of a specific prevention or care technology (e.g., (Bernstein, Sokal, Seitz, Stover, & Naamara, 1998; Caulkins, Kaplan, Lurie, O'Connor, & Ahn, 1998; DeAngelis, 1998; Edwards, Shachter, & Owens, 1998; Garnett &

Anderson, 1996; Heidenberger & Roth, 1998; Kahn, Brandeau, & Dunn-Mortimer, 1998; Korenromp et al., 2000; Luboobi, 1994; Owens, Brandeau, & Sox, 1998; Paltiel & Freedberg, 1998; Porco & Blower, 1998; Rossi & Schinala, 1998; Van der Ploeg et al., 1998). In addition, (Taylor & Lane, 1998) provided a useful review of more than 50 simulation studies in the area of health care.

Only two studies of HIV/AIDS epidemiology addressed the integration of the dynamics of care with the dynamics of prevention. In the first of these studies, (Korenromp et al., 2000), simulated the effects of a “single-round mass treatment” of STDs to explore the potential impact on HIV incidence. In the second, Luboobi (1994), simulated the effects of providing increased medical care and health awareness interventions to sexually active, mature adults in Uganda. Notably, the work of Levin and Roberts (1976), who built a model of the dynamics of human service delivery, and Dangerfield, Fang, and Roberts (2001), who built a model of the epidemiology of HIV/AIDS and the consequences of HAART, were found to be substantively

and technically useful to the study's focus.

**Research Questions.** Considering the context of the complexity of the on-going HIV/AIDS epidemic in Michigan, the current study was used to research the following questions:

1. How does *stigma* caused by HIV/AIDS affect the dynamics of prevention and care in the community?
2. How does *complacency* caused by HIV/AIDS affect the dynamics of prevention and care in the community?
3. How does *[dis]empowerment* of PLWHA affect the dynamics of prevention and care in the community?
4. How does *care* affect the dynamics of prevention? [and/or] How does *prevention* affect the dynamics of care?

## METHOD

The problem focus in the current study addressed undesirable trends associated with the dynamic interaction of the three conceptual domains that were used to define the conceptual framework (i.e., *epidemiological burden*, *HIV/AIDS intervention*, and *psychosocial vulnerability*). In particular, the study was intended to promote critical thinking and deeper understanding about ways of addressing the detrimental effects of HIV/AIDS-related stigma, complacency, and [dis]empowerment on HIV/AIDS prevention and care interventions and on HIV incidence and AIDS mortality. To clarify the nature of these dynamic interactions, a number of important constructs were identified and defined by study participants from the HIV community in Michigan. These constructs were then structured into a set of *causal loops* that explicitly defined a given decision process over time. The ordering of the constructs that comprise each causal loop were also informed by the opinions and insight of study participants and by qualitative analysis of other sources of data that were accessible to the system dynamicist. In turn, the causal loops were then translated into a system of *interdependent mathematical structures* (i.e., the formal, base case system dynamics model).

The overarching objective of the system dynamics method is to discover, or *uncover*, a set of causal loops that describe the decision processes that have led to the problematic outcomes of concern in the study. In the study, a total of 13 causal loops were identified. In qualitative terms, each causal loop communicates a story, or *narrative*, about a substantive dynamic process related to the problem focus. In quantitative terms, each causal loop represents a set of stock-and-flow equations. Particular pairs of these causal loops share one or more of the same constructs.

In the current study, for the sake of understandability, the 13 causal loops were further organized into 5 *causal loop diagrams*. Although a single causal loop diagram with all 13 loops represented could have been drawn, it would have been difficult to understand. The five diagrams have been labeled, or titled, in a manner that references substantive, overarching processes of interest in the current study. Each of these diagrams is comprised of at least 2 of the 13 loops. Although these diagrams share some of the same constructs, none of them share the same loops. Simulation output was used to explore the dynamics of these overarching processes as well as to affirm the extent to which the base case model adheres to model validation guidelines.

## **Primary Data Sources**

Development of a system dynamics model for the study required data that described how change occurs within and between the three domains of the conceptual framework presented in Figure 1 (i.e., *intervention*, *psychosocial vulnerability*, and *epidemiological burden*). In particular, Michigan's Statewide Coordinated Statement of Need [SCSN] (Lounsbury, 2001) provided substantive information about each of these domains. Data sources for the SCSN included statewide and regional HIV/AIDS needs assessments, various service planning, evaluation, or policy documents, epidemiological surveillance reports, and key informant interviews. In total, 48 documents were reviewed and 34 key informants were interviewed about the service needs of persons living with and affected by HIV/AIDS in the state [see Appendix A for SCSN Human Subjects Approval, Informed Consent Procedure, and other data collection-related information; to review a complete list of SCSN documents and identifiable key informants (i.e., those persons who elected to speak 'on the record'), see the document on-line at <http://www.msu.edu/user/lounsbu1/scsn2001.html>].

In addition to information obtained and processed for the purposes of the SCSN project, useful data for the study was obtained from two other sources. These included MDCH epidemiological data (MDCH, 2000) and interview data from ten (N=10) core key informants from Michigan's HIV community.

## **HIV/AIDS-focused Peer-reviewed Literature**

The urgent and complex nature of the HIV/AIDS epidemic has motivated a wide range of basic and applied research initiatives. These efforts have generated a prolific number of peer-reviewed publications, a substantial portion of which is now referenced and summarized in carefully authored reviews. Examples of such works include (Mann & Tarantola, 1996) review of global trends in epidemiology and resource development, (Smith, 2001) encyclopedia of social, political, cultural, and scientific information, and the (IOM, 2001) critical analysis of factors affecting the on-going challenge of HIV prevention. These sources of data, as well as more than 400 individual articles on topics such as HIV disease progression, shortcomings and barriers to biomedical treatments, interventions to reduce risk-taking behaviors, health care service delivery innovations were also used to build and validate the study's system dynamics model.

## **Time Horizon**

A time horizon of 40 years was originally chosen (see Table 1). It started in 1971, ten years before the first cases of AIDS were detected in the United States, and continued through 2011, ten years from now. Based upon insights from (Mann & Tarantola, 1996) and (Rosenbrock et al., 2000) about hypothetical stages of response to the HIV/AIDS epidemic, the proposed time horizon was divided into six discrete phases. These phases were labeled as follows: (1) pre-discovery, (2) discovery, (3) mobilization, (4) medicalization, (5) normalization, and (6) remobilization.

It should be noted that the first period (pre-discovery) and the last phase (remobilization) were not included in the stages of response identified by either Mann and Tarantola (1996) or Rosenboch et al. (2000). The pre-discovery phase was added in order to account for the fact that disease progression from HIV susceptible to AIDS is estimated to be as high as 10 years. So, although



**Table 1 - Proposed six-phase time horizon**

<b>Name</b>	<b>Intervention Orientation</b>	<b>Period</b>	<b>Number of years</b>
Pre-discovery	Person-focused	1971 - 1981	10
Discovery	Community-focused	1982 - 1986	5
Mobilization	Community-focused	1987 - 1991	5
Medicalization	Person-focused	1992 - 1996	5
Normalization	Person-focused	1997 - 2001	5
Remobilization	Community-focused	2002 - 2011	10
<b>Time horizon (years)</b>			<b>40</b>

the first case of HIV was not detected until 1981 (CDC, 2001a, 2001b), a more valid simulation of the emerging epidemic ought to reach back about 8 to 10 years. The remobilization phase has been included in order to help core key informants think critically about the future dynamics of the epidemic. A period of just 18 years (1983 to 2001) was ultimately selected as the simulation period for the model developed in the study because it corresponded with currently available epidemiological surveillance data collected by MDCH's Bureau of Epidemiology (MDCH, 2000). This shortened time horizon allowed for a more straightforward model validation process.

### **Reference Modes**

Reference modes for key constructs are used to clarify the problem focus for the system dynamics study. The problem focus in the study suggested the need for four sets of reference modes, as follows: (1) HIV/AIDS prevalence, incidence, and mortality; (2) HIV/AIDS prevention and care funding; (3) HIV/AIDS prevention and care service system quality; (4) HIV/AIDS-related stigma and complacency. The curves presented in these figures capture, to the best knowledge available, the essential shape of change over time for a given construct of interest.

Data used to create the reference modes for HIV/AIDS prevalence, incidence, and mortality were obtained from quantitative data collected by MDCH from 1983 to 2000 (MDCH, 2000). Data used to create the reference modes for HIV/AIDS care and prevention funding were obtained from quantitative data collected by the Kaiser Family Foundation for fiscal years 1995, 1997, 1999 (Foster et al., 1999). Data used to create the reference modes for quality of HIV/AIDS prevention and care services and for HIV/AIDS stigma and complacency were based upon a number of studies and reports (Doka, 1997; Gilmore & Somerville, 1994; Herek & Capitano, 1993; Kowalewski, 1990; Letine et al., 2000; Lounsbury, 1997; Schag, Ganz, Kahn, & Peterson, 1992; St. Martin, 1996), some of a purely qualitative nature, about how communities have responded to the epidemic, as well as interview data provided by the study's core key informants. These reference modes show that HIV/AIDS-related stigma has stayed very high through the entire time horizon and that complacency about HIV/AIDS has dipped dramatically since the early years of the epidemic, but may be increasing somewhat now and in the near future.

### **Model Validation Procedure**

In general, the ultimate validation of the formal system dynamics model occurs gradually as it is found to be increasingly accepted by members of the target audience for which it was created in the first place (Forrester & Senge, 1980). Consistent with this premise, the process of

building and validating the system dynamics model in the current study was an exercise in packaging the collective intuition of the system dynamicist and his core key informants. At every step in the process of *modeling for understanding*, a review of available information about the model's structure and behavior was requested of one or more core key informants by the system dynamicist. Their feedback was then used to inform decisions about 'next steps' in the construction of the model.

It is important to note that system dynamics, as a methodology, allows tests about 'change' that are simply not possible, or reachable, with other types of models commonly used in the social sciences (e.g., correlational models, including multiple regression models, structural equation models, and other multi-variate statistical techniques). Moreover, standard hypotheses testing using inferential statistical methods is generally either inappropriate or, at most, supplemental to the work of understanding and interpreting the meaning of a given system dynamics model. In the current study, validation procedures developed by (Manni & Cavana, 2000) and by (Coyle, 1996) were found to be most useful and appropriate (see Tables 2 and 3). Note that these procedures are based upon the work of (Forrester & Senge, 1980) and (Coyle, 1983) regarding model validity.

**Table 2 - Categories of tests used for model validation**

No.	Validation test category
1	Verification tests, which are concerned with verifying that the structure and the parameters of the system have been correctly incorporated into the model.
2	Validation tests, which address the extent to which the simulated behavior of the model is like the actual 'real world' problem behavior it is intended to represent.
3	Legitimation tests, which affirm that the model follows commonly accepted principles or rules of system structure.

**Table 3 - Guidelines for model validation**

No.	Validation guideline
1	The behavior of the model must be plausible (i.e., it should generate output that is 'realistic').
2	The model must not produce nonsensical values, such as 'negative persons.'
3	The causal loop diagram must correspond to the statement of the problem.
4	The equations must correspond to the causal loop diagram (i.e., must match the qualitative representation of inflow and outflow).
5	The model must be dimensionally valid (i.e., the units of measurement or quantification of the constructs or variables on each side of the equation should be the same).
6	For material (i.e., physical) variables, the model should maintain 'conservation of flow.' (i.e., what enters the system should be accounted for at any point within the model's time horizon).

## MODEL CONSTRUCTS

Fifteen constructs were ultimately included in the base case system dynamics model. These constructs have been organized into three groups: one for each conceptual domain of focus in the study (i.e., *epidemiological burden*, *HIV/AIDS intervention*, and *psychosocial vulnerability*).

### **Epidemiological Burden Constructs**

The epidemiological burden domain includes two constructs: (1) HIV/AIDS epi burden and (2) HIV symptoms. HIV/AIDS epi burden (Construct A) was defined as the collective load, or pressure, experienced by communities affected by HIV/AIDS in Michigan. It was indicated by HIV/AIDS prevalence, incidence, and/or mortality, and represented by a vector of eleven (11) epidemiological stocks of persons, or subpopulations, living with HIV/AIDS and their associated flow through a process of disease progression and treatment. HIV symptoms (Construct B) was defined as the extent to which PLWHA manifest physical signs of their disease. It was represented by a vector of eight (8) epidemiological computations of the average number of HIV-related symptoms a given subpopulation of PLWHA is expected to endure given their disease stage and their access to care (i.e., treatment).

### **HIV/AIDS Intervention Constructs**

HIV/AIDS intervention domain includes four constructs: (1) Care system quality, (2) prevention system quality, (3) care resources, and (4) prevention resources. Care system quality (Construct C) was defined as the overall effectiveness of the services and infrastructure put in place to provide HIV/AIDS health care and support services (e.g., hospitals, clinics, community-based HIV/AIDS organizations). Specifically, it was the ability to meet the care needs of PLWHA and affected family and friends as described in Michigan's Statewide Coordinated Statement of Need (SCSN) (Lounsbury, 2001). It was represented by a single service stock. Prevention system quality (Construct D) was defined as the overall effectiveness of the services and infrastructure put into place to prevent new cases of HIV (e.g., informational campaigns, community interventions, access to condoms/clean needles). Specifically, it captured the ability to identify priority populations for HIV prevention services and to delivery effective services to meet the needs of the persons who comprise these populations as described in Michigan's Comprehensive Plan for HIV/AIDS Prevention (MHAC, 2001). It was represented by a single service stock.

Care resources (Construct E) was defined as material and human resources made available to HIV/AIDS care organizations throughout Michigan by a consequence of system change action on behalf of the care service system and a given level of funding for HIV/AIDS health care and support services. It was also represented by a single service stock. Prevention resources (Construct F) was defined as material and human resources made available to HIV prevention organizations throughout Michigan by a consequence of system change action and a given level of funding for informational campaigns, community interventions, access to condoms/clean need that will decrease HIV incidence. Represented by a single service stock.

### **Psychosocial Vulnerability Constructs**

The Psychosocial domain includes nine constructs. Six of the nine are *psychological* in nature. The remaining three constructs are *behavioral* in nature. The psychological constructs

include: (1) Satisfaction with care system quality, (2) satisfaction with prevention system quality, (3) perceived treatment efficacy, (4) perceived HIV-related stigma, (5) self-concept, and (6) system awareness.

**Psychological constructs.** Satisfaction with care system quality (Construct G) was defined as the extent to which members of each of the epidemiological subpopulations perceive that available health care and support for PLWHA is accessible and efficacious. It was represented by a vector of eight (8) psychosocial information stocks. Satisfaction with prevention system quality (Construct H) was defined as the extent to which members of each of the epidemiological subpopulations perceive that available HIV prevention services for all members of the community are accessible and efficacious. It was represented by a vector of eight (8) psychosocial information stocks. Perceived treatment efficacy (Construct I) was defined as the extent to which members of each of the epidemiological subpopulations believe that available clinical treatments, including the use of Highly Active Anti-retroviral Therapies (HAART), are able to manage, or control, the progression of HIV disease. Represented by a vector of eight (8) psychosocial information stocks. Perceived HIV-related stigma (Construct J) was define as the extent to which members of each of the epidemiological subpopulations shoulder a personal sense of being viewed by others as less worthy or less valuable (because they perceive that their community enforces stereotypical profiles of people thought to be at high-risk of HIV/AIDS, i.e., men who have sex with men, substance users, commercial sex workers, persons of color, persons living in poverty). It was represented by a vector of eight (8) psychosocial information stocks.

Self-concept [Empowerment] (Construct K) was defined as the first component of a 3-component, dynamic definition of psychological empowerment. It captured the extent to which members of the epidemiological subpopulations see themselves as self-assured, capable, respectable. It was similar to other psychological constructs such as self-esteem, self-efficacy. Also, may be thought of as the absence of depression. It was also directly influenced by both system awareness and system change action. It was represented by a vector of eight (8) psychosocial information stocks. System awareness [Empowerment] (Construct L) was defined as the second component of a 3-component, dynamic definition of psychological empowerment. It captured the extent to which members of the epidemiological subpopulations know about the state of prevention and care services in Michigan. Specifically, the degree to which they actually understand how to gain access and obtain prevention and care services for themselves and/or for others and how to effectively join and/or create settings for policy analysis, system advocacy, and direct services delivery. It was directly influenced by both self-concept and system change action, and ti was represented by a vector of eight (8) psychosocial information stocks.

**Behavioral constructs.** The behavioral constructs include: (1) System change action, (2) care complacency, and (3) prevention complacency. System change action [Empowerment] (Construct M) was the third component of a 3-component, dynamic definition of psychological empowerment. It was defined as the extent to which members of the epidemiological subpopulations actively engage in one or more efforts to improve the quality of the existing prevention and/or care infrastructure. It was directly influenced by both self-concept and system awareness, and it was represented by a vector of eight (8) behavioral information stocks. Care complacency (Construct N) was defined as the extent to which diagnosed (i.e., tested HIV-positive) PLWHA do not initiate and sustain health care and support services and adhere to prescribed treatments, including Highly Active Anti-retroviral Therapies (HAART). It was represented by a vector of four (4) behavioral information stocks. Prevention complacency (Construct O) was defined as the extent to which members of the epidemiological

subpopulations do not consistently execute safer-sex and safer-use behaviors to minimize the risk of further spreading HIV. It was represented by a vector of eight (8) behavioral information stocks.

Three other tables summarize other important information about each of the constructs in the model are presented here. Table 4 provides a breakdown of constructs by their generic mathematical structure. Table 5 compares the range of numeric values for each construct and specifies its unit of analysis. Table 6 details information about each constructs' initial value at time zero.

Figure 2 shows the final disaggregation of the Epi construct with estimated time delays. Note that the estimated time delays are not meant to be precise predictions of longevity, although they are in line with current averages reported by the CDC. By observation it can be seen that both receiving a late HIV positive test result and never actually learning about being HIV positive are associated with the fastest course of disease progression (6.5 years). In contrast, seeking testing soon after seroconversion and moving and staying in care is associated with the slowest course of disease progression (9.7 years). Recent treatment advances have added approximately 3 to 4 years of life, bringing the average total disease process from point of infection to AIDS-related death to 11 years (CDC, 2001c).

The structure of the Epi construct informed disaggregation of all other constructs quantified in *persons*. Conceptually important subpopulations included the following: (1) persons at-risk of contracting HIV, (2) persons who had tested positive but who were not yet in care, (3) persons who had tested positive and who were currently in care, and (4) persons who had tested positive who had dropped out of care. Note that although persons at-risk (i.e., persons not yet infected with HIV) are not included here as in independent stock variable, they are 'observable' in terms of changes in the HIV infection rate. For the purposes of the base case model, persons at-risk were operationally defined as the model's originating flow of persons entering the system (i.e., 10% of Michigan entire population, which was based upon U.S. Census information for 1970, 1980, 1990, and 2000).

**Table 4 - Constructs by generic mathematical structure**

Construct ID	Construct name	Construct abbr.	Generic structure
A	HIV/AIDS epi burden	Epi	Supply chain
B	HIV symptoms	Symptoms	Classical co-flow
C	Care system quality	CSQ	Self-limiting compounding process
D	Prevention system quality	PSQ	Self-limiting compounding process
E	Care resources	CR	External resource production process
F	Prevention resources	PR	External resource production process
G	Satisfaction with care system quality	SCSQ	Hines co-flow
H	Satisfaction with prevention system quality	SPSQ	Hines co-flow
I	Perceived treatment efficacy	PTE	Hines co-flow
J	Perceived HIV-related stigma	PHS	Hines co-flow
K	Self-concept (Empowerment)	SC	Hines co-flow
L	System awareness (Empowerment)	SA	Hines co-flow
M	System change action (Empowerment)	SCA	Hines co-flow
N	Care complacency	CC	Hines co-flow
O	Prevention complacency	PC	Hines co-flow

**Table 5 - Construct scale, Hines co-flow goal, and unit of analysis**

Variable nexus ID	Construct abbr.	Min value	Max value	Hines co-flow goal	Unit of analysis
A	Epi NI	0	Indef.	NA	Persons
A	Epi EHU	0	Indef.	NA	Persons
A	Epi MHU	0	Indef.	NA	Persons
A	Epi LHU	0	Indef.	NA	Persons
A	Epi ADU	0	Indef.	NA	Persons
A	Epi MHD	0	Indef.	NA	Persons
A	Epi LHD	0	Indef.	NA	Persons
A	Epi ADD	0	Indef.	NA	Persons
A	Epi MHDWC	0	Indef.	NA	Persons
A	Epi LHDWC	0	Indef.	NA	Persons
A	Epi ADDWC	0	Indef.	NA	Persons
B	Symptom	0	Indef.	NA	Symptoms/Person
C	CSQ	0	100	NA	System quality units
D	PSQ	0	100	NA	System quality units
E	CR	0	Indef.	NA	Resource units
F	PR	0	Indef.	NA	Resource units
G	SCSQ	0	100	80	Satisfaction units/Person
H	SPSQ	0	100	40	Satisfaction units/Person
I	PTE	0	100	60	Perceived treatment efficacy units/Person
J	PHS	0	100	70	Perceived stigma units/Person
K	SC	0	100	60	Self-concept units/Person
L	SA	0	100	30	System awareness units/Person
M	SCA	0	100	20	System change action units/Person
N	CC	0	100	50	Care complacency units/Person
O	PC	0	100	50	Prevention complacency units/Person

**Table 6 - Construct initial value and unit of analysis**

Var. nexus ID	Construct abbr.	Initial value									
		Epidemiological subpopulations									Global
		Early stage			Mid stage			Late stage			
		NI	EHU	MHU	MHD	MHDWC	LHU	LHD	LHDWC		
A	Epi	500	500	1000	2	1	45	2	1	NA	
B	Symptom	1	6	12	6	2	12	8	6	NA	
C	CSQ	NA	NA	NA	NA	NA	NA	NA	NA	1	
D	PSQ	NA	NA	NA	NA	NA	NA	NA	NA	1	
E	CR	NA	NA	NA	NA	NA	NA	NA	NA	1	
F	PR	NA	NA	NA	NA	NA	NA	NA	NA	1	
G	SCSQ	50	50	50	50	50	50	50	50	NA	
H	SPSQ	50	50	50	50	50	50	50	50	NA	
I	PTE	20	20	20	20	20	20	20	20	NA	
J	PHS	90	90	90	90	90	90	90	90	NA	
K	SC	50	50	50	50	50	50	50	50	NA	
L	SA	0	0	0	0	0	0	0	0	NA	
M	SCA	0	0	0	0	0	0	0	0	NA	
N	CC	NA	NA	NA	60	60	NA	60	60	NA	
O	PC	90	90	90	90	90	90	90	90	NA	

Note: 'NA' = Not Applicable; initial values for Epi ADU = 5, ADD = 0, and ADDWC = 0.

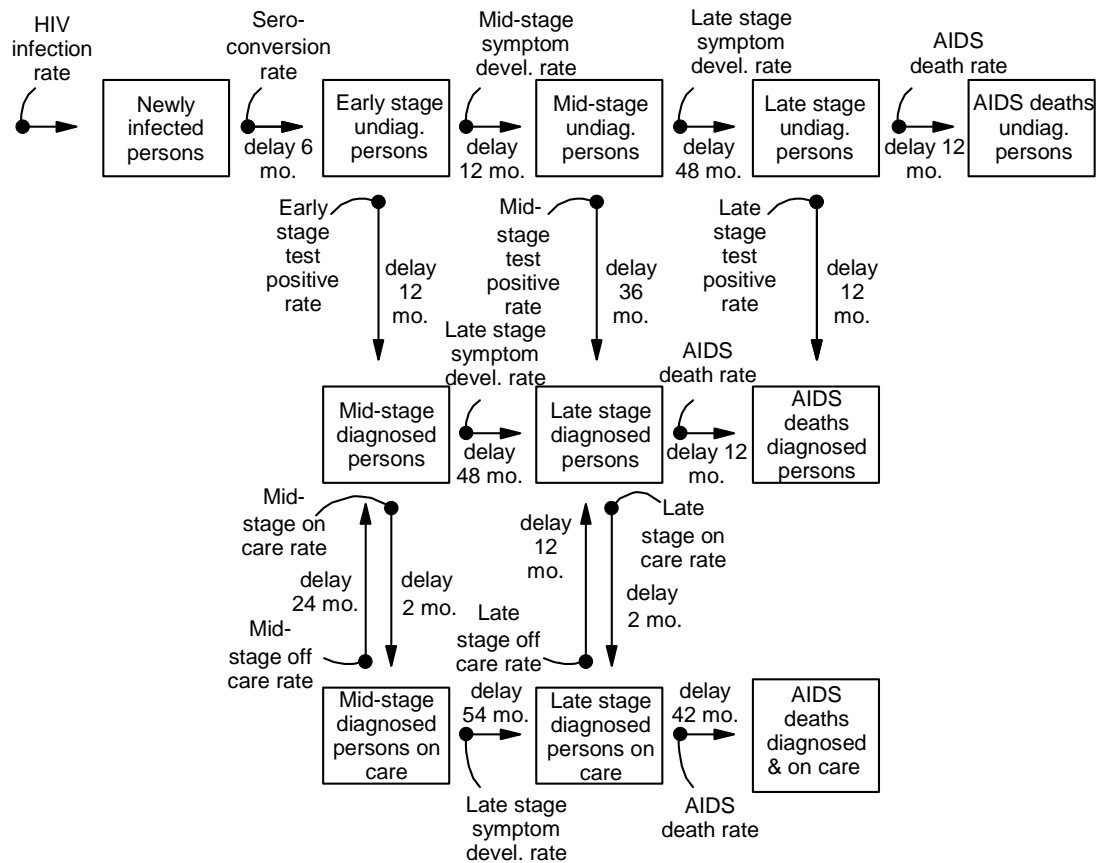


Figure 2 - Disaggregated stock-and-flow of HIV/AIDS epidemiological subpopulations

## RESULTS

Results of the study are presented in two parts. For the purpose of demonstrating model validity, the first part of this chapter provides a comparative analysis of the *simulated* to the *empirically grounded* reference modes for selected constructs used in the study. Recall that reference modes were developed for selected constructs within each of the study's three conceptual domains (i.e., *epidemiological burden*, *HIV/AIDS intervention*, and *psychosocial vulnerability*). The second part of this chapter provides multiple, in-depth perspectives on the dynamics of the study's problem focus. Causal loop diagrams and descriptive narratives of these diagrams are used to present the base case model's finalized system of feedback structures. In addition, simulation output for selected constructs from each causal loop diagram are used to present the model's behavior over time. Collectively, the results presented here are used to provide information about the extent to which the base case model adheres to validation guidelines and to clarify the nature of causal relationships among constructs included in the final base case model.

### Comparison of Simulated to Empirically Grounded Reference Modes

The comparative analysis of the *simulated* to the *empirically grounded* reference modes are presented below. Note that all graphical simulation results are expressed in terms of a count of months, from month 0 (i.e., January 1983) to month 216 (i.e., December 2001).

### Prevalence, Mortality, and Incidence

County-level HIV/AIDS surveillance data describing HIV/AIDS prevalence, mortality, and incidence in Michigan have been officially collected and analyzed by the MDCH Bureau of Epidemiology since 1983 (MDCH, 2000). Five figures and one table have been compiled to show the extent to which the dynamics of the base case model ‘fit,’ or correspond, to the dynamics of actual epidemiological data reported by the Bureau of Epidemiology.

**Prevalence.** Figure 3 presents the hypothesized (i.e., empirically grounded) and simulated reference mode for HIV/AIDS prevalence in Michigan from 1983 to 2001 (i.e., from month 0 to month 216). Note that, in the case of prevalence, data is not reported before month 36 (i.e., December 1986). The base case model shows a prevalence estimate from month zero (i.e., January 1983). In the model, prevalence was the sum of all 8 Epi stock variables representing PLWHA.

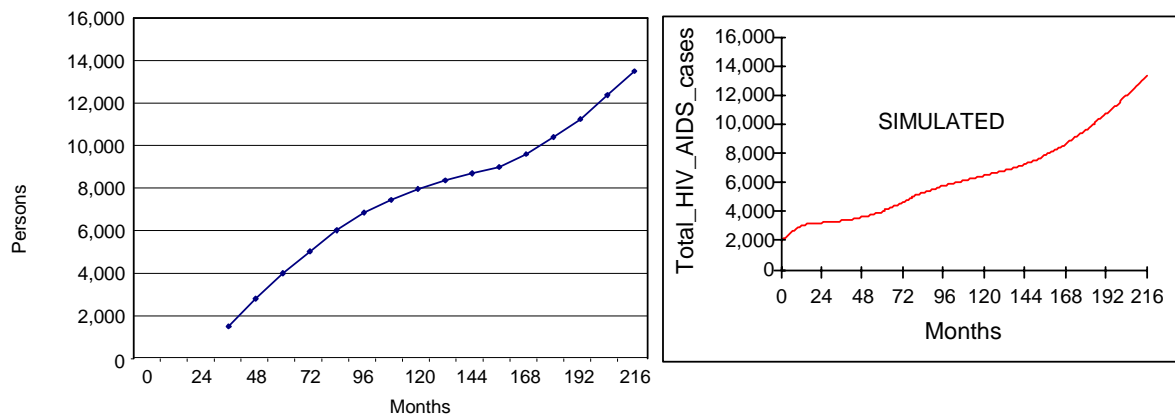


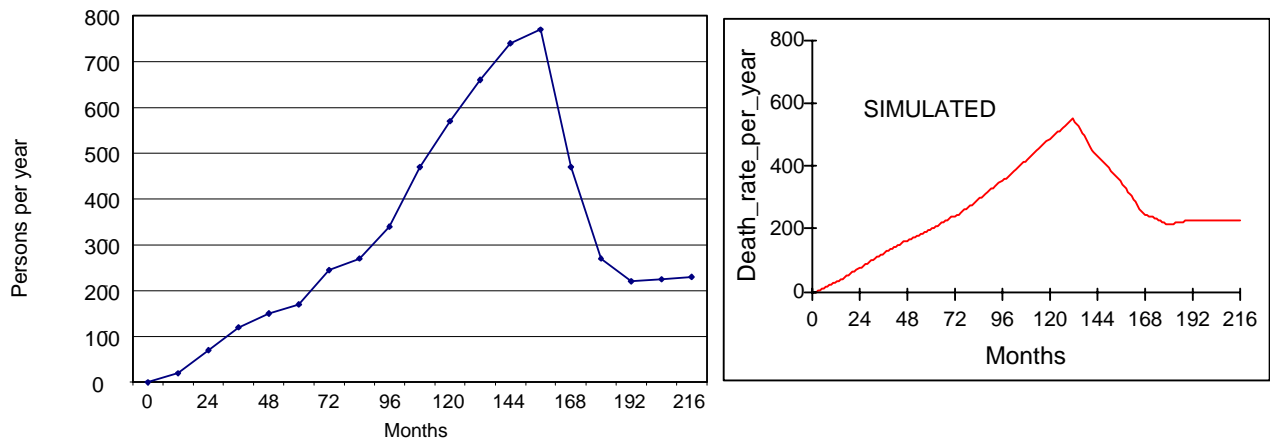
Figure 3 - Hypothesized and simulated reference mode for HIV/AIDS prevalence in Michigan, 1983 - 2001

Comparison of the two graphs indicated a close fit in terms of slope and magnitude beginning with month 48 (i.e., December 1987) and onward. Initial values for the Epi stocks were set to begin the simulation with 2,051 persons, reflecting the extent to which HIV/AIDS existed in Michigan in 1983. Although it may be argued that the simulated prevalence curve starts too high, taking into consideration the fit of its shape over the entire time horizon as well as the final simulated estimate of prevalence in 2001 suggests that an initial estimate of 2,051 persons was not unreasonable.

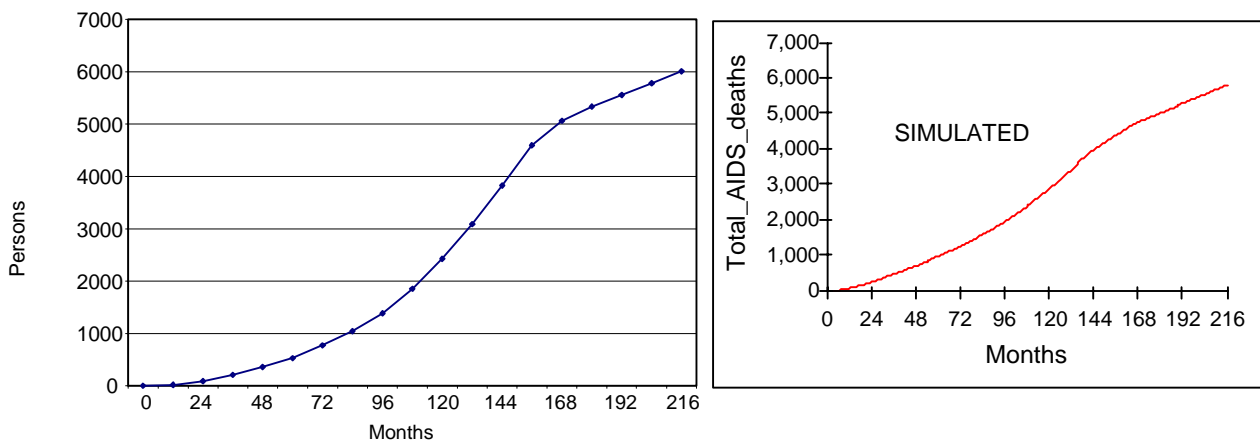
**Mortality.** Figure 4 presents the hypothesized and simulated reference mode for HIV/AIDS mortality per year in Michigan from 1983 to 2001. Mortality was computed as the sum of the three Epi stock variables of persons who had succumbed to AIDS-related. Comparison of the two graphs indicated a close fit in terms of slope, although the simulated curve peaks approximately 2 years earlier than the hypothesized curve, which hit a high at month 168 (14 years; December 1997). In addition, the simulated curve’s peak was lower in magnitude than the hypothesized curve by about 200 persons. By month 192 (16 years; 1999), however, both curves are essentially identical.

Figure 5 presents the hypothesized and simulated reference mode for HIV/AIDS cumulative mortality in Michigan over the same time horizon. Comparison of these two graphs indicated an extremely close fit in terms of both slope and magnitude. The simulated December 2001 value was 5,841 persons.





**Figure 4 - Hypothesized and simulated reference mode for HIV/AIDS mortality rate per year in Michigan, 1983 - 2001**



**Figure 5 - Hypothesized and simulated reference mode for HIV/AIDS cumulative mortality in Michigan, 1983 - 2001**

**Incidence.** Data reported for HIV incidence, or the number of new cases of HIV that occur within a given period of time, is a ‘best guess’ of the Bureau of Epidemiology. In fact, no estimates of incidence were even offered by the Bureau until December 1990. Figure 6 presents the hypothesized and simulated reference mode for HIV/AIDS incidence per year in Michigan from 1983 to 2001. The simulated curve starts out at approximately 1,250 persons per year, but drops precipitously within two years (i.e., 1985). It then begins to climb again, quickly, generating peak at month 72 (i.e., 1989) at approximately 1,000 persons per year, then dropping to about 800 persons by month 96 (i.e., 1991). Thereafter, the simulated incidence curve climbs steadily, reaching an estimate of approximately 1,600 new cases per year by month 216 (i.e., 2001). As of 1999, this rate appears to have dropped to just 825 persons (MDCH, 2001), a trend that is encouraging, yet inconsistent with recent epidemiological studies about the United States as a whole (IOM, 2001).

At first glance, the hypothesized and the simulated curves appear very different. Comparing the shape of the curve over the entire time horizon, one would have to assert that these two curves differ markedly in shape. Focusing on the dynamics of a narrower time horizon

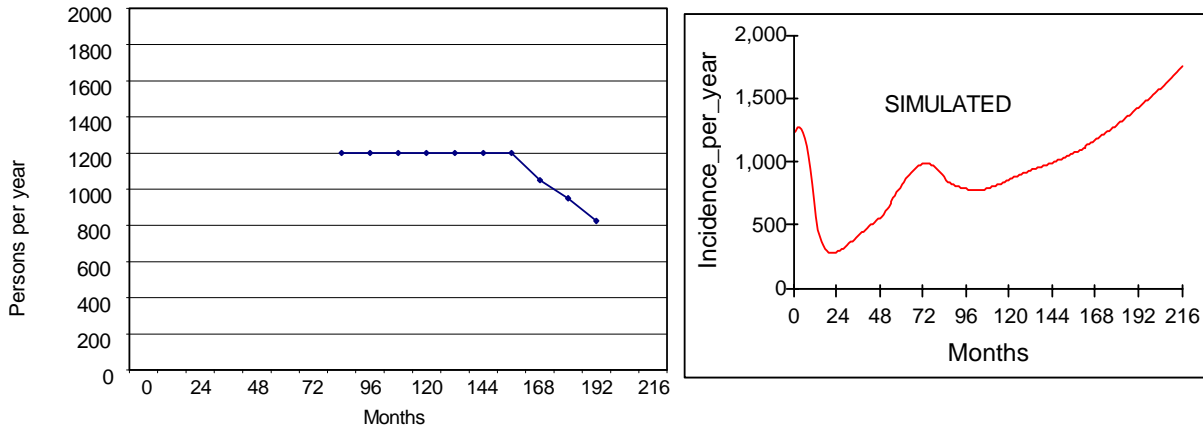


Figure 6 - Hypothesized and simulated reference mode for HIV/AIDS incidence per year in Michigan, 1983 - 2001

for which a report on incidence is available, (i.e., months 84 to 192; December 1990 to December 1999), it can be seen that the average number of new cases of HIV over that period was simulated to be 1,200 persons per month. This is still high if the December 1999 drop-off to 825 persons per year is considered, but more or less in line with MDCH reports if the time period is cut back to 1996. As Figure 7 shows, estimates of HIV incidence in Michigan were reported to be as low as 1,100 and as high as 1,200 persons per year from 1990 to 1996 (MDCH, 2000, 2001).

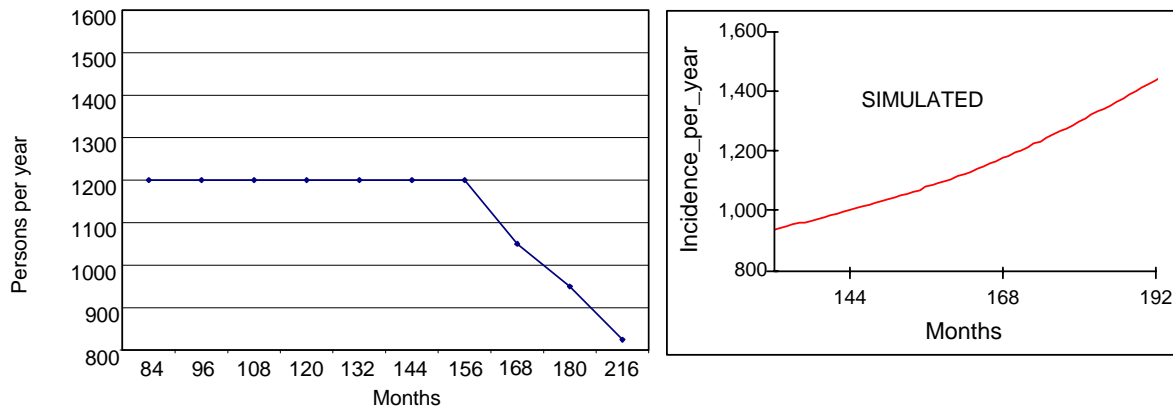


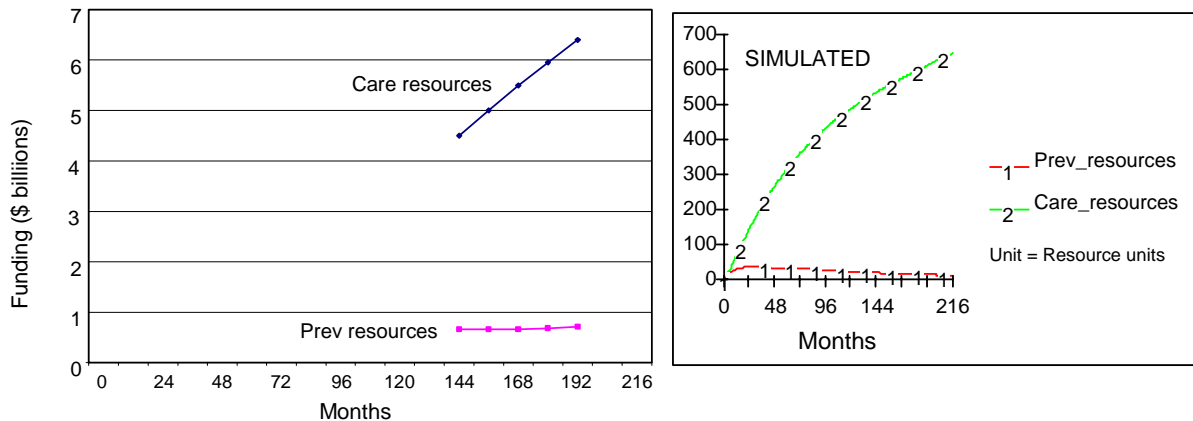
Figure 7 - Hypothesized and simulated reference mode for HIV/AIDS incidence per year in Michigan, 1990 - 1999

### Prevention and Care Funding

Data regarding actual allocations of care resources and prevention resources (i.e., funding) for HIV/AIDS was obtained from a report by (Foster et al., 1999) in a comprehensive analysis of the state of HIV prevention in the United States (IOM, 2001). As noted previously, detailed time series data on funding of prevention services relative to care services was not readily available, however it was reported that care funding in Michigan reached \$18 million in 2001, compared with \$6.6 million for prevention (personal communication, Debra Szwejd, November 14, 2001), revealing a funding difference that is more or less consistent with Foster's report. Moreover, the reference mode for HIV/AIDS funding in the United States was affirmed by core key informants to fit Michigan. Note that in lieu of reliable data expressed in dollars,

prevention and care resources are quantified in resource units. Resource units include funding as well as physical and human resources.

Figure 8 presents the hypothesized and the simulated reference mode for HIV/AIDS-related care resources (CR) and prevention resources (PR). Note that the y axis scales do not match. This is because the reference mode for the entire country is exhibited in the left-hand graph in terms of billions of dollars. Michigan's actual reference mode would be represented by only a small fraction of that total amount. Comparing the slopes of the hypothesized and the simulated reference modes over the period from month 144 to month 192 (i.e., December 1995 to December 1999), however, revealed a close match in terms of curve slope.



**Figure 8 - Hypothesized and simulated reference mode for HIV/AIDS-related care and prevention funding in the United States, 1983 -2001**

### Prevention and Care Service System Quality

The unit of analysis for prevention system quality (PSQ) and care system quality (CSQ) was system quality units. Quality units are defined as the extent to which care or prevention services are accessible and efficacious for persons and/or their communities. In general, core key informant interview data suggested the shape and magnitudes of the prevention system quality (PSQ) and care system quality (CSQ) was similar to the curves shown in Figure 9. Core key informant data also indicated that prevention system quality (PSQ) was higher than care system quality (CSQ) until the introduction of anti-retroviral therapies in 1994/1995. After that, care system quality (CSQ) was considered superior to prevention system quality (PSQ). Here again, it is concluded that the hypothesized and the simulated curves are comparable to each other in terms of shape and magnitude. Note, however, that simulated curve for care system quality (CSQ) begins a downward trend at month 180 (i.e., December 1998), a behavior that was not anticipated in the hypothesized reference mode.

### Stigma and Complacency

Perceived HIV stigma (PHS), prevention complacency (PC), and care complacency (CC) comprise the final set of hypothesized and simulated key reference modes to be presented for the base case model. Figure 10 compares the reference modes for all three of these constructs. With respect to perceived HIV stigma (PHS), the hypothesized reference mode goes very high very early, almost to its maximum, and then to remain high for the duration of the time horizon. HIV-positive core key informants strongly affirmed this trend, noting that the work of managing their

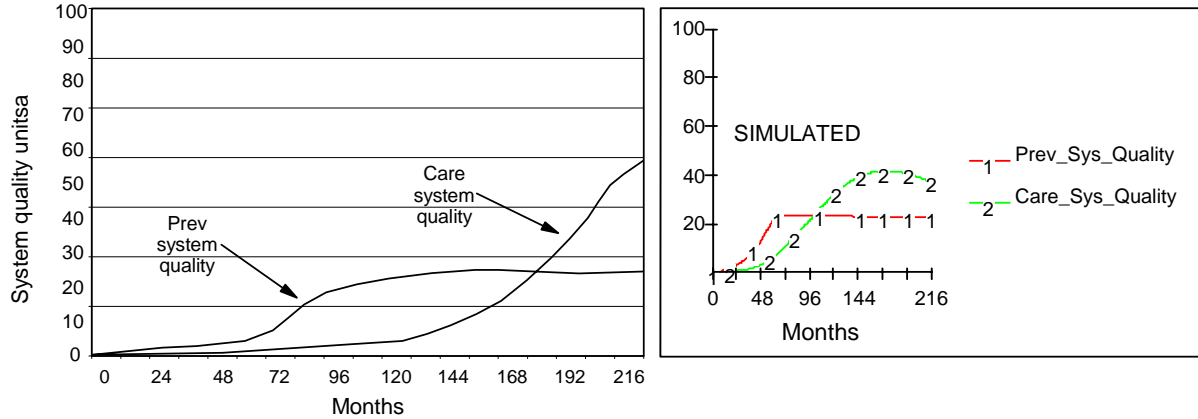


Figure 9 - Hypothesized and simulated reference mode for HIV/AIDS system quality in Michigan, 1983 - 2001

own sense of perceived HIV stigma was an on-going piece of work. By comparison, it is clear that simulated reference mode for perceived HIV stigma (PHS) reproduced the hypothesized curve closely, both in terms of shape and magnitude.

An assessment of the complacency reference mode is more complicated. Recall that, initially, 'complacency' was not theoretically separated into 'prevention' complacency and 'care' complacency. The need to distinguish between the two became clear during the latter part of the model building process. As a result, the originally hypothesized reference mode for complacency represents the overall trend for both types of complacency. As the model matured, prevention complacency (PC) became defined as the extent to which individuals, either HIV-positive or HIV-negative, engaged in behavior that would put them at-risk of being infected or of infecting another person. It also defined as an antecedent to the decision to take the HIV antibody test. Care complacency (CC) was second form of complacency, and it affected PLWHA only. Care complacency (CC) was defined as the extent to which persons who became HIV infected engaged the care system. It quantified their willingness and/or ability to engage the HIV care system and to adhere to best practices in HIV/AIDS treatment.

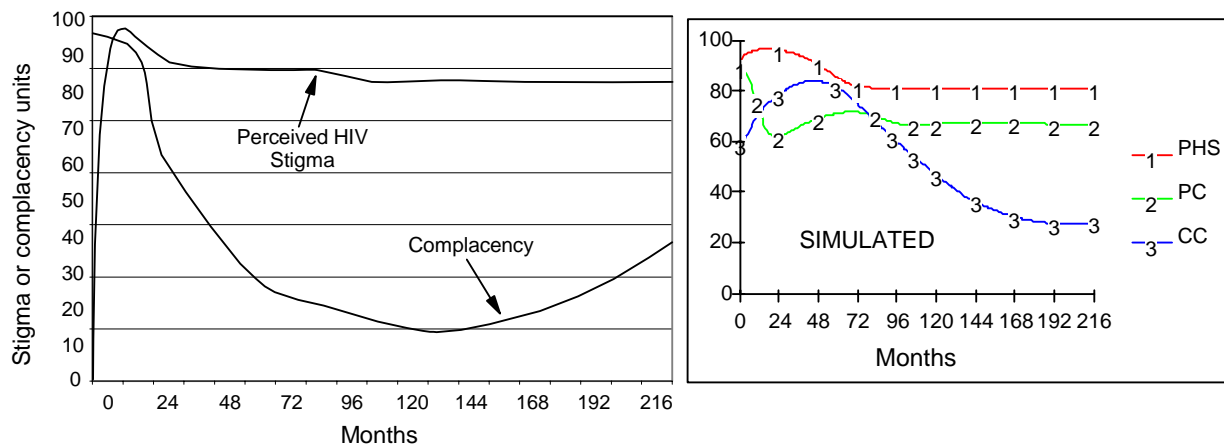


Figure 10 - Hypothesized and simulated reference mode for HIV/AIDS stigma and complacency in Michigan, 1983 - 2001

In the model, both prevention complacency (PC) and care complacency (CC) have a direct impact on HIV/AIDS epidemiological burden (Epi burden). Prevention complacency (PC) directly affects HIV incidence and HIV testing rates at three points (i.e., early, mid-, and late stage). Care complacency (CC) directly affects how many persons are in care and how long they may stay in care. Once tested, or diagnosed, persons typically move into a situation where they were receiving some level of HIV/AIDS treatment. However, care complacency (CC) affected decisions to drop out of care or to start care later, as well as decisions to restart care, had they dropped out at some point in the past.

Interestingly, the simulated reference mode for prevention complacency (PC) expresses a similar shape to the hypothesized reference mode, but not if the entire simulated time horizon is considered. In particular, the hypothesized curve shape was found to be ‘squashed,’ or horizontally shrunken, in the simulated reference mode over the time period from month zero to month 72 (i.e., January 1983 to December 1989). However, the simulated version of prevention complacency (PC) is much higher than the hypothesized reference mode across the entire time horizon. It is also interesting to note that if the dynamic average of the curves representing prevention complacency (PC) and care complacency (CC) is taken across the entire time horizon, the resulting curve does, in fact, approach the shape that was originally hypothesized for combined notion of ‘complacency.’ However, the curve still does not drop and recover as quickly as was expected. In conclusion, it is clear that the simulated curves for prevention complacency (PC) and care complacency (CC) do not fit the originally hypothesized complacency construct. Yet, there were parts of both the simulated curves that suggested that the qualitative idea of ‘complacency,’ *per se*, was correctly hypothesized.

### Key Causal Processes Identified

As the process of modeling was carried out, it became evident that the underlying dynamics of the current study’s problem focus could be expressed through a set of five key causal processes. These processes have been named as follows: (1) the perceived stigma process; (2) the care complacency process; (3) the prevention complacency process; (4) the community empowerment process; and (5) the resource allocation process. Collectively, the key causal processes offer insight into how stigma, complacency, and [dis]empowerment affect the dynamics of prevention and care in the community (i.e., research questions 1, 2, and 3). Similarly, the key dynamic processes offer insight into how goals of a ‘care system’ can work either for or against the goals of a ‘prevention system,’ and *visa versa* (i.e., research question 4).

A causal loop diagram of each process has been created. Table 7 presents a count of the number of loops and constructs that comprise each of these processes. As previously noted in

**Table 7 - Summary of key dynamic process loops and constructs**

Key dynamic process	Loops		Constructs				
	B	R	Total constr.	Model sector			
				Epi	Service	Psych social	Behave
Perceived stigma		2	8	1	2	3	2
Care complacency	1	1	7	2		3	2
Prevention complacency	1	1	7	2		3	2
Community empowerment	4	1	9		4	4	1
Resource allocation		2	7	1	4		2

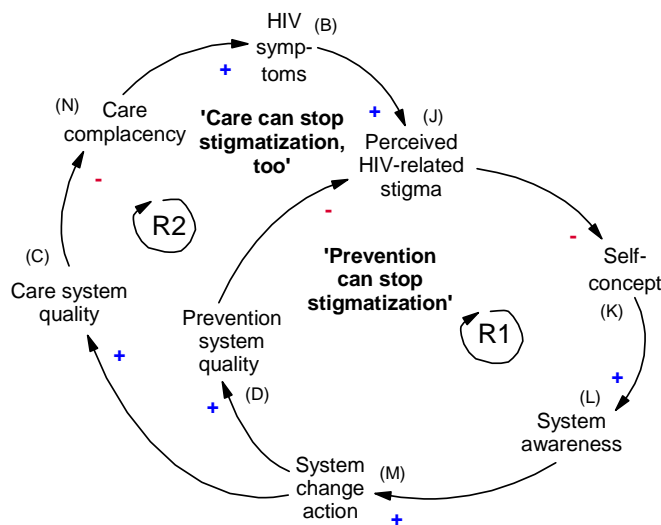
**Note: B = Balancing (negative feedback); R = Reinforcing (positive feedback).**

Chapter 3, there are a total of 13 causal loops, each of which represents a unique feedback structure in the model and each of which communicates a story, or *narrative*, about a substantive dynamic process related to the problem focus. Approximately half of the loops are balancing (i.e., feedback structures that are negative, goal-seeking, stabilizing, reducing, dampening) and half are reinforcing (i.e., feedback structures that are positive, growing, destabilizing, increasing, amplifying).

For easy reference, loops have been assigned a ‘loop ID.’ Loop IDs that begin with an R are ‘reinforcing;’ loop IDs that begin with a B are ‘balancing.’ In addition, constructs are referenced by their ‘construct ID.’

### Perceived Stigma Process

The causal loop diagram for the perceived stigma process is presented in Figure 5.9. It features two reinforcing loops (R1 and R2). As might be anticipated, the perceived stigma process was built around the perceived HIV stigma construct (PHS). Two constructs were directly antecedent to perceived HIV stigma (PHS), namely HIV symptoms and prevention system quality (PSQ). In turn, perceived HIV stigma (PHS) directly influenced self-concept (SC).



**Figure 11 - Causal loop diagram for perceived stigma process**

could be titled ‘prevention can stop stigma.’ This loop’s narrative might be read this way: An increase in the level of perceived HIV stigma (PHS) experienced by a particular subpopulation, or group [e.g., mid-stage HIV diagnosed persons in care (MHDWC)] of persons will tend to decrease, or dampen, their sense of self-concept (SC). As their self-concept (SC) dampens, so does their motivation to learn about, or become more aware of, what HIV/AIDS-related resources exist in the community, how to access them, and/or how easy or difficult it is to use them, etc. As a result of their lower system awareness (SA), they are also less likely to engage in any type of system change action (SCA), which could potentially make HIV/AIDS-related services more accessible or more effective for their community as a whole.

Note, however, that to the extent that this group of persons does not become involved in an effort to change the system, they have no effect on the quality of prevention services. Over time, the collective effect of their decreased system change action (SCA), in conjunction with the

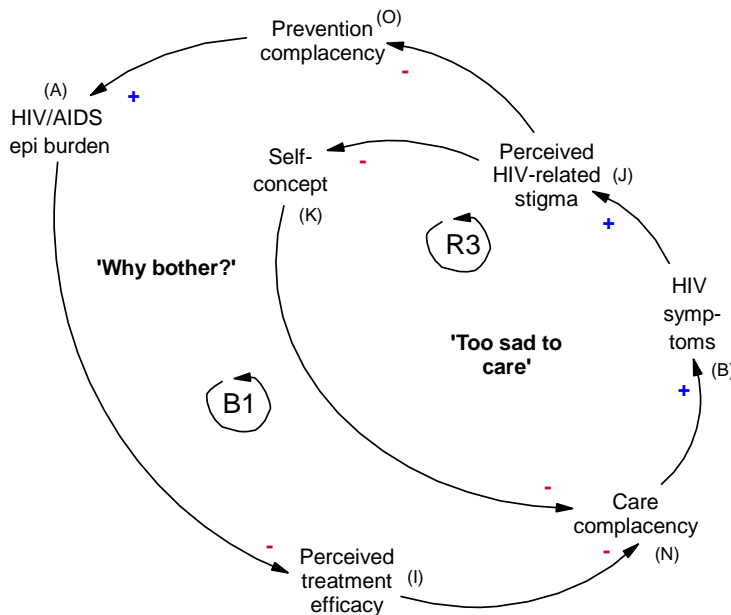
Loop R1 is comprised of five constructs. Following the causal pathway around the loop, one is taken through what has been previously defined as the model’s empowerment meta-construct [i.e., self-concept (SC) → system awareness (SA) → system change action (SCA)]. Given the potential effect of prevention system quality (PSQ) on perceived HIV stigma (PHS), the narrative associated with loop R1

effect of decreased system change action (SCA) attributable to other groups, would be, for example, that HIV/AIDS public service announcements were not run, activity groups or support groups in the community were not attended, concerned members of the community stopped attending regional HIV/AIDS prevention planning meeting, etc. Then, as the quality of the prevention system (PSQ) drops, perceived HIV stigma (PHS) would rise, further deflating self-concept (SC). Alternatively, as the quality of the prevention system (PSQ) increases, perceived HIV stigma (PHS) would decrease, which would begin to pump up self-concept (SC). This alternate ending to R1's narrative, therefore, is what suggested its title: 'prevention can stop stigma.'

Loop R2 reveals a similar set of dynamics as loop R1, but for the care side of the system. The narrative for loop R2 might be 'care can stop stigma, too.' Improvement in care system quality would likely address matters of care complacency (CC) among diagnosed PLWHA only, which would also likely reduce their personal symptoms of the disease. To the extent that any group of PLWHA is experiencing fewer HIV-related symptoms, they are likely to also experience a decreased sense of perceived HIV stigma (PHS). In this sense, R2 is, like R1, a substantive way to reduce levels of perceived HIV stigma (PHS).

### Care Complacency Process

The causal loop diagram for the care complacency process is presented in Figure 12. It features two loops, one balancing and one reinforcing (B1 and R3). Referring to the care complacency (CC) construct, it can be seen that psychosocial constructs directly influence care complacency (CC). These constructs are perceived treatment efficacy (PTE) and self-concept (SC). Care complacency (CC), in turn, influences the average level of HIV symptoms among persons who have been diagnosed, some of whom are actually in care, some of whom are



not. Keep in mind that care complacency (CC) was not quantified for subpopulations of persons who were undiagnosed (i.e., who had not yet received the results of a positive HIV antibody test). Care complacency (CC) pertains only to those four epidemiological subpopulations that have been diagnosed (i.e., tested and found to be HIV positive).

The narrative associated with loop R3 might be referred to as the 'too sad to care' effect. To the extent that self-concept (SC) drops, persons become depressed and motivated, and care complacency (CC) is likely to

**Figure 12 - Causal loop diagram for care complacency process**

increase. For example, persons receiving care for their HIV may become less willing to take their medication, keep doctors appointments, or do other things to take care of their health. Over time, increased care complacency (CC) will result in increased HIV symptoms. The symptoms, some



of which may be detectable by others around them, will tend to increase, or generate, stronger feelings of perceived HIV stigma (PHS). In turn, self-concept (SC) drops even further.

Loop B1 calls attention to a similar feedback process, but the trigger that reduces care complacency (CC) is perceived treatment efficacy (PTE). The narrative for B1 might be titled ‘why bother?’ Recall that perceived treatment efficacy (PTE) is defined as the extent to which members of each of the epidemiological subpopulations believe that available clinical treatments, including the use of HAART, are effective at managing or control the progression of HIV disease. Therefore, for PLWHA who are receiving care services, the stronger their perception that the treatments are working, the more they will follow doctor’s advice. The willingness to adhere to treatments can be expected to stay strong, unless there is an awareness of a growing number of treatment failures, either in their own lives or in the lives of others. For example, if AIDS-related deaths increased, perceived treatment efficacy (PTE) would be decreased. Over time, the loss of belief in the efficacy of available treatments could dampen care complacency (CC), which could exacerbate AIDS-related deaths, further decreasing perceived treatment efficacy (PTE). Alternative treatment approaches, not formally recognized by the care system, may be one way for PLWHA to turn. In any case, the effect would be to reduce treatment adherence to generally prescribed medical protocols. Over time, HIV symptoms would be likely to rise again, which would tend to further increase perceived HIV stigma (PHS). A subsequent reduction in prevention complacency (PC) would then be expected, which would likely have some degree of favorable impact on HIV/AIDS epidemiological burden.

### Prevention Complacency Process

The causal loop diagram for the prevention complacency process is presented in Figure 13. Note that it is essentially the complement of the care complacency process, with the care complacency (CC) construct being replaced with the prevention complacency (PC) construct. Like the care complacency process, the prevention complacency process features two loops, one balancing and one reinforcing (B2 and R4). Also like the care complacency process, the

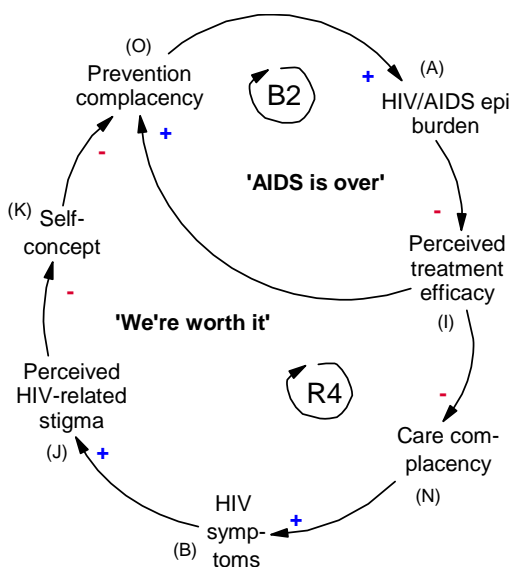


Figure 13 - Causal loop diagram for prevention complacency process

construct of focus, prevention complacency (PC), is directly influenced by both perceived treatment efficacy (PTE) and self-concept (SC).

There are two main differences between the prevention complacency process and the care complacency. First, the prevention complacency process affects all 8 epidemiological subpopulations, whether they are diagnosed or undiagnosed, in care or not in care. Second, the prevention complacency process affects the HIV infection rate as well as the decision to take an HIV test. In contrast, care complacency (CC) affects only the extent to which diagnosed persons choose to connect themselves to treatment offered through the care system.

Loop B2 shows how perceived treatment efficacy (PTE) affects prevention

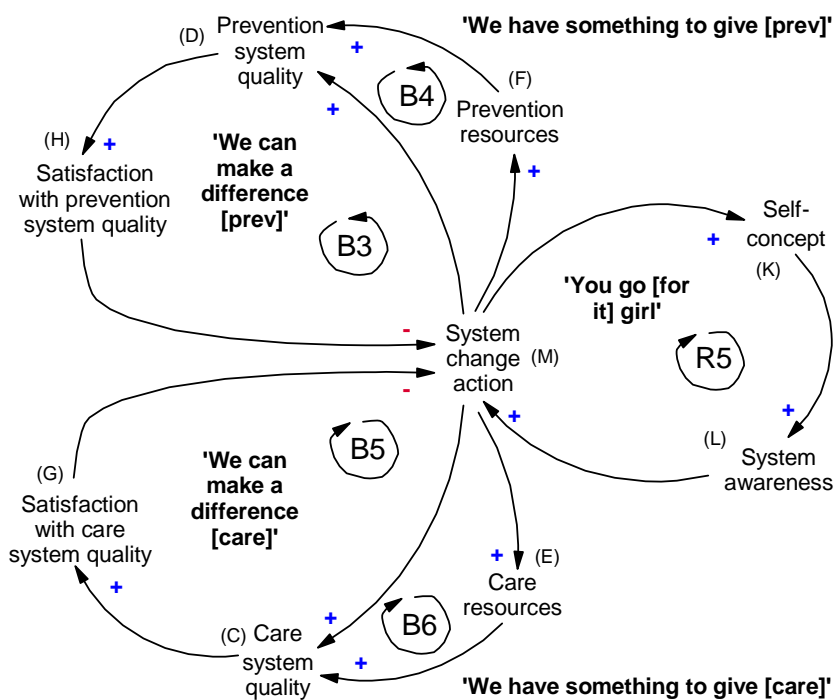


complacency (PC). This three-construct loop suggests that any subpopulation in the model would be likely to increase its level of prevention complacency (PC) by, for example, unprotected sex or drug use, as a result of an increase in their perception or belief that HAART and other available treatments are really working (i.e., are accessible and efficacious). The narrative for this feedback structure might be referred to as ‘AIDS is over.’ Strong perceived treatment efficacy (PTE) would suggest that people would be more willing to rationalize that (1) available treatments make HIV an easily managed health problem and/or (2) available treatments act as an effective prophylactic (e.g., condoms aren’t necessary).

Loop R4 taps into the idea that persons will not take risks regarding their personal chance of becoming HIV-positive because of a strong sense of self-concept (SC). The narrative played out here could be called ‘We’re worth it.’ In general, a strong or increasingly strong sense of self is going to have a prohibitive effect on risk-taking behavior and/or increase a group’s motivation to take the HIV anti-body test. In turn, fewer persons would be expected to contract HIV. However, if AIDS-related deaths increase in any discernable way, perceived treatment efficacy (PTE) is likely to diminish. Over time, care complacency (CC) is likely to increase as a result, bringing a higher burden of HIV symptoms and, naturally, higher levels of perceived HIV stigma (PHS).

### Community Empowerment Process

As its causal loop diagram suggests, the community empowerment process is, by far, the most elaborate dynamic structure discovered in the modeling process (see Figure 14). It is comprised of four balancing loops (B3, B4, B5, B6) and just one reinforcing loop (R5) that, diagrammatically, resemble a three-leaf clover. Loop R5 includes the three theoretical parts of the psychological empowerment construct, as defined by (Zimmerman, 1995), namely self-concept (SC), system awareness (SA), and system change action (SCA). Each of the balancing



loops (B3, B4, B5, and B6) address the dynamic relationship between satisfaction and system change action (SCA) for prevention (SPSQ) and care (SCSQ), respectively.

This structure’s only reinforcing loop, loop R5, might best be referred to as the heart of the community empowerment process. The title of the narrative for R5 is ‘you go [for it], girl.’ To the extent that self-concept (SC) is strengthened, system awareness (SA) is strengthened. In the

Figure 14 - Causal loop diagram for community empowerment process

model, either an improved understanding of the system (SA) or a strengthened self-concept (SC) could bring about action-oriented behavior (i.e., SCA).

R5, however, is affected by four balancing loops (B3, B4, B5, and B6). Collectively, these loops determine the extent to which system change action (SCA) increases, decreases, or stays flat over time. Loops B3 and B5 represent situations where members of a subpopulation personally get involved, or participate, in system change action (SCA). For example, these loops represent the extent to which subpopulations are working or volunteering as service providers to the community. B3 describes the level of such activity for the prevention side. B5 describes the level of such activity for the care side.

The title of the narrative for B3 and B5 could be ‘somebody’s got to do it’ or ‘we can make a difference.’ Note that what underlies the extent to which system change action (SCA) is reinforced or not is a function of the level of satisfaction with the system (SPSQ and SCSQ). As discussed previously in Chapter 4, HIV positive core key informants in the study, many of whom are service providers to the HIV community, described how it was often a profound sense of dissatisfaction with their circumstance and/or the circumstance of the community, that motivated them to get involved to make change.

Loops B4 and B6 represent similar dynamics to loops B3 and B5, although the action that is generated through B4 and B6 is more about participation in planning and/or advocacy to obtain greater resources on behalf of persons in need of prevention and/or care services. The good title of the narrative for these loops might be ‘we have something to say.’ System change action (SCA) would be expected to influence the level of resources allocated to address prevention and care in the community, for example. Here again, the reinforcing mechanism is dissatisfaction. To the extent that persons are content with the status quo, they would not be expected to instigate any appreciable level of change in the system.

### Resource Allocation Process

The resource allocation process is the fifth and final key dynamic process featured in the study. Its causal loop diagram is shown in Figure 15. The resource allocation process is comprised of just two loops, both of which are dynamically reinforcing (R6 and R7). It is a direct adaptation of the *systems thinking archetype* coined “Success to the Successful” by Senge

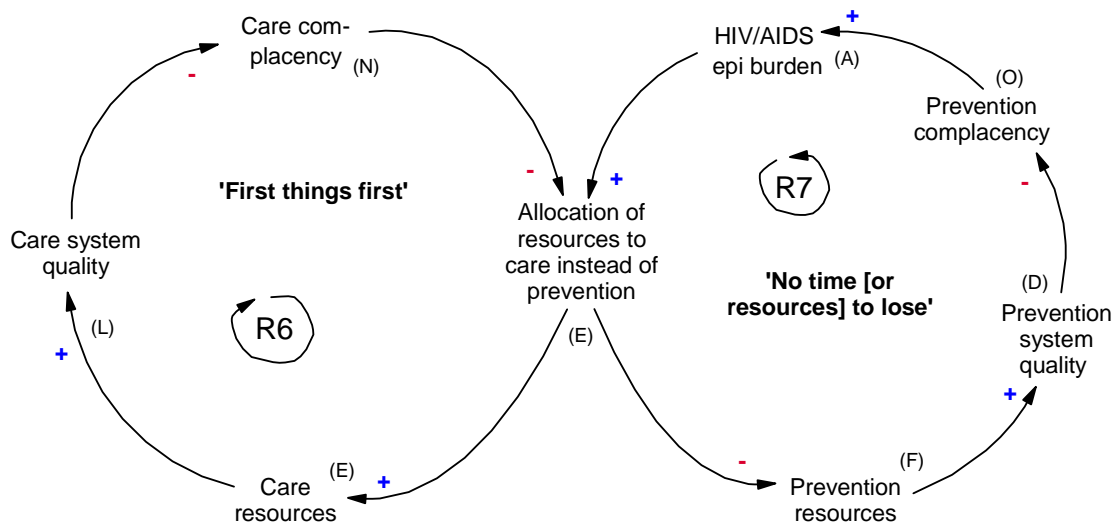


Figure 15 - Causal loop diagram for resource allocation process

(1990). In general, the archetype fits situations where two activities, or processes, compete for limited support, or resources. In Senge's words, "the more successful one becomes, the more support it gains, thereby starving the other" (p. 385). Note that the two loops shown in Figure 5.32 share the *allocation of resources to care instead of prevention* variable (hereafter abbreviated as 'care allocation'). Note that care allocation is not referred to as a construct. In the study, constructs are accumulation variables, or stocks. Instead, care allocation is an auxiliary variable. Nonetheless, it is a key variable in this key dynamic process. It was used to determine the proportion of total available resources that were slated for care services, as opposed to prevention services, in the community.

Loop R6 and R7 show how an increase in the number of newly infected persons in the system (Epi burden) initiated allocation of resources to care and, for the most part, away from prevention. The title of the narrative for R6 could be 'first things first,' reflecting the compelling circumstance of knowing that persons are testing positive and are in need of instrument assistance. Over time, the prevention side of the system suffers, probably reaching a point where funding and staffing levels are so bare bone that little or no prevention system quality remains.

R7's narrative title might be 'no time [or funds] to lose.' In this loop of the model, epi burden continues to rise because higher and higher levels of prevention complacency (PC) affect the HIV infection rate, which further accelerates a call for more care resources. Note that R6 could potentially operate to decrease funding allocations to care relative to prevention, but only to the extent that marginal increases in the quality of the care system (CSQ) do not effectively reduce care complacency (CC).

### **General Insights about Model Behavior**

Many simulations of behavior-over-time for various combinations of constructs were generated. A summary of general insights gained by analyzing the simulation output is presented here. By examination of the structure of the base case model, it can be seen that two behavioral constructs from the *psychosocial vulnerability* domain, namely prevention complacency (PC) and care complacency (CC), directly control the rate at which persons are entering (i.e., becoming infected with HIV) and exiting (i.e., eventually dying of complications due to AIDS) the *HIV/AIDS intervention* domain. To the extent that prevention complacency (PC) and care complacency (CC) can both be kept low, HIV/AIDS prevalence would decrease, or at least stabilize, over time, which would constitute a welcomed trend within the *epidemiological burden* domain.

Simulation results suggest a need to intervene more aggressively on the prevention side to reduce prevention complacency (PC). Overall, aggregate care complacency (CC) was the only construct that revealed a desirable, downward trend over the model's time horizon. Review of simulated output for disaggregated prevention complacency (PC) shows that all epidemiological subpopulations are exhibiting high levels of risk behavior. Interestingly, newly infected persons (NI), early stage undiagnosed persons (EHU), and mid-stage diagnosed persons (MHU) were shown to have the lowest levels of prevention complacency (PC). Subpopulations at the last stage of HIV disease who were receiving care services showed the highest levels of prevention complacency (PC) per person over time. This may be attributed to a belief that receiving treatments for HIV/AIDS reduces the risk of transmitting HIV to an uninfected person, hence rationalizing unsafe sexual or drug use behaviors.

Additional insight into how best to pursue a strategy that effectively lowers both

prevention complacency (PC) and care complacency (CC) is informed by the structure of the two key dynamics processes that are named after them (i.e., the prevention complacency process and the care complacency process). Comparison of these two key causal processes show that they are comprised of the same variables, but vary in their feedback structure. Perceived treatment efficacy (PTE) and self-concept (SC) are both antecedent to prevention complacency (PC) and care complacency (CC), but increasing perceived treatment efficacy (PTE) is shown to have an undesirable effect on prevention complacency (PC). In contrast, increases in self-concept (SC) over time have a desirable effect on both prevention complacency (PC) and care complacency (CC). Therefore, interventions that effectively boost self-concept (SC) may bring about the desired dynamic effect of simultaneously reducing prevention complacency (PC) and care complacency (CC).

Recall that self-concept (SC) is one of three constructs that comprise the empowerment meta-construct in the community empowerment process. To see how best to boost self-concept (SC), an appreciation of the challenges related to sustaining high community empowerment is needed. Simulation output from the base case model showed that self-concept (SC), system awareness (SA), and system change action (SCA) are relatively low for all undiagnosed persons. In contrast, they are substantially higher among late stage diagnosed persons (LHD) and late stage persons with care (LHDWC). These results may imply that ‘empowerment interventions’ could be informed, if not actually carried out, by members of these epidemiological subpopulations.

The finding that system change action (SCA) is driven by low levels of satisfaction with system quality suggests that living with HIV/AIDS is not easy, even when receiving appropriate care services. It is somewhat perplexing, however, that the same subpopulations (i.e., diagnosed persons and persons in care) can be credited with ‘seeing’ and ‘pressing’ for constructive change within the system can also be distinguished as showing the highest levels of prevention complacency (PC).

One explanation for low self-concept (SC), low system change action (SCA), and high prevention complacency (PC) is high perceived HIV stigma (PHS). In particular, recall that perceived HIV stigma (PHS) is directly antecedent to self-concept (SC). Although the HIV community has demonstrated an awareness of the negative effects of perceived HIV stigma (PHS), very high, sustained levels of this construct suggest that efforts to date have not been effective. In short, interventions that effectively impact prevention complacency (PC) and care complacency (CC) may require a direct effort to manage the dynamics of perceived HIV stigma (PHS).

## DISCUSSION

Results of the model validation process, as informed by six guidelines suggested by Coyle (1996), were favorable. A comparative analysis of *simulated* to *empirically grounded* reference modes showed that the base case model effectively reproduced trends in HIV/AIDS prevalence and mortality, prevention and care funding, prevention and care service system quality, and HIV/AIDS-related stigma. Questionable, yet plausible, model behavior was found for HIV incidence and complacency.

Although results support the validity of the base case model, additional tests focusing on finer aspects of structure and behavior will need to be carried out in order to fully assess the model’s soundness and usefulness as a policy tool. Recall that the

ultimate criterion of model validity, per Forrester and Senge (1980), is *confidence*, which is achieved as the model is applied and as output is reviewed and interpreted by members of its target audience.

Towards this end, initial feedback from members of Michigan's HIV community acknowledged that information from the base case model has already provided deeper insight into the phenomena of HIV/AIDS prevention and care. This sentiment was voluntarily reported to the system dynamicist at the conclusion of his presentation of the study's findings at a community meeting in mid-January 2002. The presentation was just one opportunity to dialogue about the implications of the behavior exhibited by the base case model. Additional meetings such as this one are essential if greater understanding and confidence in the model is to be affirmed. Based on findings from base case model simulations, a number of insights about possible policy experiments, or tests, for improved HIV/AIDS prevention and care have been identified. These are presented below.

### **Preliminary Policy Review**

Interpretation of simulation data suggested a number potentially compelling policy experiments. A review of model behavior from each of the five key causal processes was used to inform a preliminary assessment of policy implications for specific epidemiological subpopulations. These are presented below.

#### **Perceived Stigma Process**

Model simulations showed that perceived HIV stigma (PHS) affected undiagnosed persons most severely. These subpopulations included newly infected persons (NI), early stage HIV undiagnosed persons (EHU), mid-stage HIV undiagnosed persons (MHU), and late stage HIV undiagnosed persons (LHU). In comparison, diagnosed persons and persons in care were also impacted by perceived HIV stigma (PHS), yet being engaged with the care system as a PLWHA, even if the interface with the system was little more than obtaining an HIV antibody test, appeared to have the effect of dampening, or lowering, perceptions of being stigmatized due to HIV. Note that among these subpopulations, self-concept (SC) dropped to a low by month 24 (i.e., 1985), but then recovered rapidly for all groups. Mid-stage diagnosed persons (MHD) do not, however, recover to the level that late stage diagnosed persons or persons in care (MHDWC and LHDWC) do. This potential psychological 'buffering' effect of being in care was dramatically represented for persons at the later stage of HIV disease. In addition, the leveling off of prevention system quality (PSQ), which appears to have been a result of the 'medicalization' period during which attention and resources were reallocated away from prevention services, may have also played a role in keeping perceived HIV stigma (PHS) relatively high for subpopulations.

Generally, results indicated a need to address low self-concept (SC), particularly among undiagnosed persons, by either intervening to reduce perceived HIV stigma (PHS) or to boost self-concept (SC). If self-concept (SC) could be boosted sufficiently, system change action (SCA), in turn, could effectively strengthen prevention system quality (PSQ) and thereby effectively reduce perceived HIV stigma (PHS). In the meantime, strategies that are designed to encourage HIV testing so that persons who are undiagnosed can move into a care-receiving situation should be given priority. One way to do this may be to begin to aggressively promote

HIV prevention outreach by PLWHA, who are by definition known to be 'in care' [an example of system change action! (SCA)], to those who are positive yet undiagnosed.

### **Care Complacency Process**

By definition, the care complacency process directly affected diagnosed persons only [i.e., mid-stage HIV diagnosed persons (MHD), late stage HIV-diagnosed persons (LHD), mid-stage HIV diagnosed persons with care (MHDWC), and late stage HIV diagnosed persons with care (LHDWC)]. Because lower perceived treatment efficacy (PTE) appears to reduce care complacency (CC), causal dynamics associated with this process indicated a need for *care education programs* that help clients maintain a circumspect attitude about the potential benefits of existing treatments for HIV/AIDS. However, such education programs should be careful to not allow perceived treatment efficacy (PTE) to drop too low. Although prospects of effective treatments, even a cure, may be small, available treatments for HIV have been efficacious since the mid-1990s. In such situations, PLWHA may 'lose faith' in the system as a whole, which would reinforce higher care complacency (CC) up and, in turn, care dropout rates.

### **Prevention Complacency Process**

The need for effective prevention interventions is, in many ways, more salient today than ever before. Consistent with the common wisdom of HIV prevention experts, newly infected persons (NI) and early HIV undiagnosed persons (EHU) should be targeted to address relatively low levels of prevention complacency (PC), which the model indicates are still leading to HIV infection. Of course, the model clearly reminds us that HIV infection occurs only after exposure, through unprotected sex or drug use, to the virus in an already positive individual. For this reason, especially considering the continually growing number of PLWHA and considering the effect of the 'nothing to lose' phenomena identified in the model, all diagnosed persons as well should be involved in prevention complacency-reducing programs.

The 'nothing to lose' phenomena may be increasingly difficult to beat, particularly in the United States and other affluent, industrialized parts of the world, where HIV/AIDS has come to be viewed as a chronic illness (as opposed to an acute illness), which may have the effect of inflating perceived treatment efficacy (PTE). As a case in point, increasing rates of HIV infection have recently been observed among young gay men. (Valleroy, Secura, MacKellar, & Behel, 2001) found that, in a recent CDC-funded study conducted in six U.S. cities, one in ten gay and bisexual men (23 to 29 years of age; N=2401) was HIV-positive and that, among African American gay and bisexual men, one in three was HIV-positive. Of the 293 persons who were identified as HIV-positive in the study, only n=85 (29%) knew they were infected before they were tested for the purposes of the study. It was also found that n=66 (23%) of those who were HIV-positive were receiving medical care for HIV and that n=52 (18%) were taking anti-retroviral drugs. Moreover, during the past 6 months, 93% of the all men in the sample had had oral or anal sex with at least one other man. The prevalence of reported unprotected anal sex during this same, 6-month period was 46%. In the short run, before more effective, comprehensive prevention programs can be put into place, HIV/AIDS service providers should aggressively target newly (NI) and early stage HIV undiagnosed persons (EHU) with information about the how pervasive prevention complacency (PC) is among those who actually know they are HIV-positive.

## **Community Empowerment Process**

The community empowerment process, comprised of its three dimensions of system awareness (SA), self-concept (SC), and system change action (SCA), arguably revealed some of the most enlightening dynamics and potential for HIV/AIDS policy innovation relative to the four other processes. Model behavior showed that undiagnosed persons [i.e., newly infected persons (NI), early HIV undiagnosed persons (EHU), mid-stage diagnosed persons (MDU), and late stage HIV undiagnosed persons (LHU)], relative to persons who knew their HIV status and were receiving care, were shown to be highly disempowered with respect to creating any form of constructive change within the prevention and care systems.

The model suggested a need to promote greater *system change action* as a lever for *empowerment* of PLWHA. In particular, the model suggested a need for interventions that help undiagnosed persons learn about their serostatus and become engaged in a program of care as quickly as possible. Once within the care system, model behavior indicated that PLWHA appear to exhibit higher levels of system change action which, in turn, can dramatically improve the quality of both prevention (PSQ) and care (CSQ) over time. However, the dynamic structure that facilitates system change action was dependent upon high levels of PLWHA *dissatisfaction*, or frustration, with the quality of HIV/AIDS available services. With respect to this finding, it is suggested that future policy analyses explore ways of sustaining PLWHA system change action that are not dependent upon high levels *dissatisfaction* with services.

## **Resource Allocation Process**

Dynamics attributed to the final key causal process to be reviewed, the resource allocation process, indicated that all subpopulations in the model can have a potential impact on the unbalanced allocation processes that is so clearly at work in the HIV/AIDS epidemic. In addition, although service providers were not explicitly included in the model, they are implicitly included for intervention. In particular, there is a need to devise policy that generates constructive, tangible *demand for prevention services*. If an increase in demand for prevention services can be realized, the proportion of resources allocated to prevention system would increase over time, which ought to increase prevention system quality (PSQ) and, subsequently, decrease prevention complacency (PC). Care clients and providers may be the most effective facilitators of this initiative because of their first-hand knowledge about why prevention interventions have failed in the past.

The imbalance is evidently created by a combination of new treatments that have extended longevity for many persons living with HIV/AIDS (PLWHA) combined with continued addition of newly infected persons to the system. As the allocation process shows, this has rapidly increased the demand for HIV/AIDS-related care services and for the federal and state resources needed to cover them (Foster et al., 1999; IOM, 2001). Over time, the model shows that diminishing prevention system quality (PSQ), due to allocating to care (as opposed to prevention), will have the impact of increasing rates of new HIV infection, which would further increase demand for care, a point that many other community research projects have affirmed (Gibb, Ades, Gupta, & Sculpher, 1999; Gopal, 2000; IOM, 2001; Moore & Chaisson, 1997).

## **Conclusion**

Further analyses to identify the most effective ‘levers’ of change within the model and policy tests that explore how best to affect system performance to achieve the overarching goals

of (1) reducing new HIV infections among all susceptible groups, (2) improving health and well-being among all PLWHA, and (3) increasing efficiency and sustainability of HIV/AIDS-related services constitute important future work. Building upon the insight gained from the preliminary policy review of each of the key causal processes, future research will use the base case model to carry out ‘experiments in policy innovation’ of interest to the HIV community in Michigan as well as other communities affected by the epidemic.

The ‘systems approach’ used in this study represents a uniquely qualitative and participatory way of fostering in-depth thinking about HIV/AIDS prevention and care. It constitutes one effort to demonstrate how policy applications can be incorporated into the field of community psychology and how the underlying notion of *change* can be explicitly examined and interpreted, even in the context of highly complex problems. It is concluded that the process of *modeling for understanding* successfully generated an explicit picture of the dynamic complexity of the psychosocial context of HIV/AIDS prevention and care, opened a common space for the candid exchange of ideas about what can and ought to be done about it, and increased the potential of the community to work together in the future in a manner of enlightened collective action.



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