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SELF-CARE AGENCY IN GAY MEN WITH HIV INFECTION

by

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DISSERTATION

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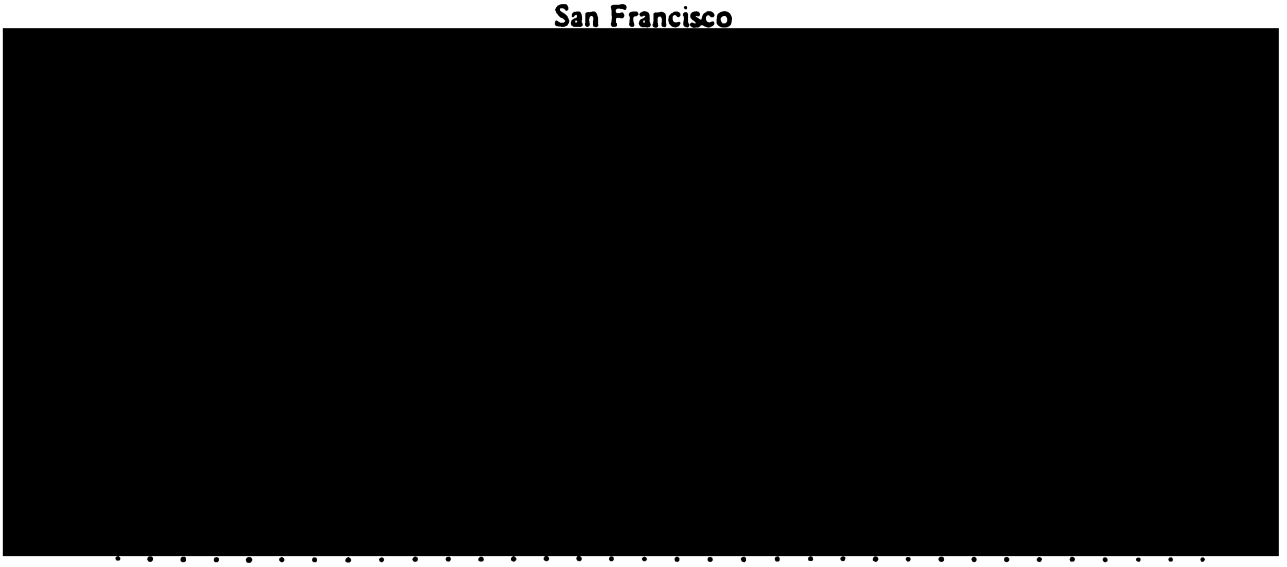

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Dedication

For Paul and Roland with all my love.
For the many who have lost their lives in the battle called AIDS.

Acknowledgements

There are many persons who have figured prominently in my development as a researcher. I wish to express my gratitude for the assistance and mentoring provided by Dr. Susan Gortner, the chairperson of my committee. In addition, I wish to express my appreciation to Drs. Marylin Dodd and Thomas Coates for their critiques of my written work during several formative stages of the dissertation process.

I remember many names who have fought the not-so-often good fight with AIDS over the years. Their memories continue to spark in me the hope that one day HIV infection will be manageable, or, better yet, cured. Their names must remain anonymous as I acknowledge them, but their legacies live even in these pages. They speak, and their voices will never be silenced.

Part of this work was funded by the Association of Nurses In AIDS Care/Burroughs-Wellcome Fellowship. I wish to thank the Board of Directors and management of the Burroughs-Wellcome Company for their continued support of nursing research in the care of persons with AIDS.

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Numerous colleagues, all who are more adept than I in evaluating self-care deficit theory, have provided critical appraisal of my thoughts. These colleagues include Dr. Jean Braun of the University of Missouri-Kansas City, Drs. Elizabeth Geden and Susan Taylor from the University of Missouri-Columbia, Dr. Jan Lee of U.C.L.A., Dr. Judith Saunders of City of Hope Medical Center, Dr. M. J. Denyes

of Wayne State University, and Dr. Maureen Frey of the University of Michigan. One weekend call to Dorothea Orem, who is now in retirement in Georgia, proved beneficial in further clarifying the direction that this research would take. I am indebted to her thoughtful analysis of self-care deficit theory. Indeed, this study would never have been were it not for her pioneering work in nursing theory development.

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In conclusion, I am forever grateful to my family--Paul, my life companion, Roland, our teenager, and the many friends and relatives who share our home. I have a good friend in Jane Lesher, a nurse colleague, who lends me her ear and listens from her heart. All of us travel this world well together. I cannot imagine the journey alone.

SELF-CARE AGENCY IN GAY MEN WITH HIV INFECTION

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ABSTRACT

Two constructs from Orem's self-care deficit theory formed the basis for this study of self-care agency and therapeutic self-care demand in gay men with HIV infection. The Self-as-Carer Inventory was used as the measure of self-care agency and the HIV-Specific Therapeutic Self-Care Demand Inventory, developed by the investigator, was employed to measure the therapeutic self-care demand. Three hundred-one subjects, aged 21 - 61, who had less than 200 T helper cells comprised the sample.

The study explored the relationship between one of the four component concepts of self-care agency--self-care operations--and self-care agency. It developed the empirical relationship between the basic conditioning factors and self-care agency. Self-care operations were measured by another paper and pencil instrument developed for the study, which was the HIV-Related Self-Care Behaviors Checklist.

A correlational design was used to relate demographic, therapeutic self-care demand, and self-care operations inventory scores to total and factor-specific self-care agency scores. In addition, a longitudinal design was used to capture the change in self-care operations in one case.

The longitudinal portion of the study was composed of 90 days of audio taped recordings of one subject's responses to questions about self-care operations. The analysis of the transcriptions from the audio tapes determined the congruence between factors that emerged from the HIV-Related Self-Care Behaviors Checklist and core categories from the transcribed data.

The two instruments developed for this study and the Self-as-Carer Inventory were analyzed using principal components analysis. Ten factors emerged from non-orthogonal analysis of the Self-as-Carer Inventory, accounting for 64.5% of total variance. Three factors were isolated from the orthogonal analysis of the HIV-Related Self-Care Behaviors Checklist, accounting for 63% of total variance. Two sub-scales from the HIV-Specific Therapeutic Self-Care Demand Inventory also produced orthogonal factor patterns accounting for 60% in total variance.

Combination of items from the HIV-Specific Therapeutic Self-Care Demand Inventory produced an operational definition for therapeutic self-care demand. Therapeutic self-care demand scores were negatively correlated (r = -0.38, p = <0.00) with self-care agency scores. Subsequent regression analysis of therapeutic self-care demand scores revealed that lower scores (i.e., less self-care demand) were predictors of higher levels of self-care agency--a finding that was consistent with the theory.

Susan R. Gortner, MN, PhD, Chair

Edward M. Freeman, MSN, RN, ANP

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CHAPTER 1

Introduction

Self-care deficit theory (Orem, 1991) is focused on the elaboration of human being and environment in relation to self-care. The theory maintains the perspective that human beings have achieved some degree of consciousness about the need to care for self. It also maintains that human beings share functional unity with their environments, such that in situations involving nursing care it is impossible to extricate the human being from the environment (Orem, 1991, p.143). The theory has been divided into several salient constructs that form umbrellas for component concepts: (a) self-care, (b) therapeutic self-care demand, (c) self-care agency, and (d) nursing agency (Orem, 1991).

Self-care agency (SCA) has been defined as "..the complex acquired ability to meet one's continuing requirements for care that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being" (Orem, 1991, p.145). Self-care agency, according to self-care deficit theory (Orem, 1991; Geden & Taylor, 1991), is related to self-care, which is composed of those behaviors that are enacted on behalf of self; it is related to the therapeutic self-care demand, which is the calculated need of an individual for assistance in achieving self-care requisites.

Self-care agency has been divided into three parts: (a) Phase I and Phase II self-care operations, (b) ten power components, and (c) foundational capabilities and dispositions (Orem, 1991). Measurement of the construct began in 1979 with the publication of Kearney and Fleischer's instrument, the Exercise of Self-Care Agency or ESCA (Kearney & Fleischer, 1979). It was soon followed by the doctoral dissertation of Denyes (Denyes, 1980), and her development of the Denyes Self-Care Agency Inventory (DSCAI) for use with adolescents. Numerous instruments that measured self-care agency followed these two and

have been reviewed in four critiques (Freeman, 1991a; Gast, et al., 1989; McBride, 1987; Weaver, 1987).

Self-care agency can be either adequate or inadequate. If it is adequate, it is said to be sufficient in amount to deal with the demands that are placed on self-care. But the adequacy of self-care agency has not been measured in prior studies. The theory maintains that the adequacy of self-care agency is to be "...measured in terms of the relationship of the number and kinds of operations that persons can engage in and the operations required to calculate and meet an existing or projected therapeutic self-care demand" (Orem, 1991, p. 147). Prior research in which self-care agency has been calculated has been limited by the lack of comparison of self-care agency with the therapeutic self-care demand. Therefore, it has been impossible in these studies to determine the empirical adequacy of self-care agency (Weaver, 1987).

Statement of the Problem

The development of the self-care deficit theory of nursing dates back to the year 1958 (Orem, 1991). However, as yet there have been few studies conducted to measure hypotheses generated from relationships between concepts within the theory (Frey & Denyes, 1989). Most attention in the nursing literature has been paid to the construct of self-care agency, which is one of four major constructs from the theory. Lesser attention has been paid to the theoretical relationships among the other three constructs of the theory: (a) self-care, (b) therapeutic self-care demand, and (c) nursing agency. There has also been little reported about the relationships between self-care agency and the other three constructs (Gast, et al., 1989).

In the past twenty years numerous researchers have created paper and pencil instruments to measure self-care agency. A full discussion of these researchers and their instruments is provided in chapter two. The instruments that

have been created to measure self-care agency include, but are limited to, the Adult Self-Care Agency Scale, the Self-as-Carer Inventory, and the Perception of Self-Care Agency Inventory.

As instruments to measure self-care agency have been created, researchers have provided construct validation by way of principal components analysis (factor analysis). But factor analyses using existing self-care agency instruments have been limited by two problems: 1) small samples, sometimes less than 250 subjects (Weaver, 1987), when 300 subjects are necessary to establish meaningful factorial groupings (Nunnally, 1977) and 2) orthogonal rotation of factors (Weaver, 1987). Kerlinger (1986), among others, determined that a minimum of 300 distinct units for measurement were necessary for reliable factor analysis. Lesser numbers have been associated with reduced reliability, especially in reference to second-order factor analysis. Second-order factor analysis is defined as principal components analysis that is performed on data after the initial analysis is completed.

Varimax rotation of factors in second-order analysis of self-care agency instrument data, an orthogonal rotation technique, has been criticized as inconsistent with the theoretical interconnectedness of power components (Weaver, 1987). Power components themselves have been hypothesized to be mutually inclusive in varying degrees of shared variance, based on Orem's conclusion that the power components need "...refinements and continued development with respect to their own structure..." (Orem, 1991, p.154).

Self-care agency instrument testing has been limited also by the almost total use of well samples or samples with varied illness characteristics (Gast, et al., 1989). The limitations of such samples are evident. First, self-care deficit theory proposes that self-care agency shifts in intensity and character according to the nature of the therapeutic self-care demand. There must be relatively little self-care demand among healthy subjects vis-a-vis ill subjects. Second, varying the illness

characteristics of the sample further splinters any conclusions to be drawn from self-care agency instrument data, since self-care agency will present differently for a patient with a bone fracture and a patient with a cold (Orem, 1991).

Several problems related to the development of empirical validation of hypotheses generated from self-care deficit theory are proposed for study here. The first problem is that the ten power components, identified in Orem's fourth edition text (1991), be used as latent variables for the purpose of factor analysis, and that an amply large sample size of similarly diagnosed ill patients be recruited for completion of a self-care agency instrument. Second-order analysis of factors will utilize statistical software that permits analysis based on the theoretical interconnectedness of the power components.

According to Orem (1991), unless self-care agency is accurately diagnosed, there is no rational foundation for critiquing real and potential self-care deficits, for determining scientifically derived methods of helping, and for prescribing the exercise of nursing agency (Orem, 1991, p. 147). In light of the introductory comments, self-care agency is construed both by its definition as well as by its adequacy. Therefore, the second problem to be studied is the empirical relationship between self-care agency and the real demands placed on a person in ill health. This becomes particularly meaningful to nursing practice because the measurement of adequacy has been proposed by the theory to be a judgment necessarily made by every nurse in the process of clinical decision-making (Orem, 1991).

The third and final problem is grounded in the measurement of self-care operations in a given ill sample. The interest in the measurement of self-care operations relative to the self-care management of a specific disease stems from the extent to which the change in self-care operations account for the variance in overall self-care agency scores. It has been the assumption of prior self-care

agency instrument testing that self-care agency has been measured according to isolated factors that are congruent with theoretical foundational capabilities or power components. From an exhaustive review of self-care agency instruments by Lee (1990) funded by the Self Care Institute, it was determined that no analysis of self-care agency from instrument testing has accounted for change in overall self-care agency scores according to fluctuations in self-care operations. Therefore, the measurement of self-care operations remains a problem for the proposed study to address.

Significance

The empirical study of self-care agency is in its infancy of development. Therefore, the significance of the proposed research is presented in this section. First in significance, the study has derived its research questions from theoretical relationships between two major constructs in self-care deficit theory, which are (a) self-care agency and (b) the therapeutic self-care demand. It has the potential to offer empirical evidence for the hypothesis that overall self-care agency scores either rise or fall according to the self-care demand of selected subjects. Second in significance is the determination of variance ascribed to self-care operations as they contribute to overall changes in self-care agency.

The third reason for the study's significance is the enrollment of large numbers of persons with similar illness characteristics. Few self-care agency empirical studies have enrolled large enough numbers from which factor analysis can be performed. Even fewer studies have to date measured self-care agency among subjects with potentially elevated therapeutic self-care demands. Therefore, there has been little chance to date to measure the adequacy of self-care agency in light of the self-care demand of subjects.

The fourth reason for significance of the study comes from the development of two paper and pencil measures of theoretical concepts. The

measure of the therapeutic self-care demand was developed after an exhaustive review of the literature of testing self-care deficit theory was completed. The second paper and pencil measure evaluated the enactment of the concept of self-care operations. Self-care operations, as measured by this instrument, were specific to the self-management of symptoms related to infection by the Human Immunodeficiency Virus (HIV). Prior to this study there had been few attempts made to measure the self-care operations that were specific to disease management by persons infected by HIV.

A final point has to do with methodological triangulation through the combination of paper and pencil measures with 300 subjects and analysis of transcribed audiocassette recordings obtained from one subject. This final strategy was used to determine (a) the changes in a longitudinal report of self-care operations, (b) whether the changes in self-care operations in the transcribed data were related to the factors that were to emerge from the paper and pencil measure of self-care, and (c) whether the self-care operations to emerge from the transcribed data could be used to add items to a paper and pencil measure of self-care operations. The significance of this methodology becomes evident in a brief presentation of the study design to follow.

The study design has been divided into two parts. In the first part, a correlational design was used to relate demographic, therapeutic self-care demand, and self-care operations inventory scores to total and factor-specific self-care agency scores. In the second part, a longitudinal design was used to capture the change in self-care operations in one case.

Two paper and pencil instruments have been created for this study. The instruments have been created from a close reading of available theory texts and from dialogue with nurse experts. However, it was of interest to determine

whether the recorded observations of one subject would support, challenge, or refute the changes obtained from the paper and pencil instruments.

CHAPTER 2

Review of Literature and Conceptual Framework

Introduction

Chapter two comprises the literature review and conceptual framework for this study. In the first section, the definitions of self-care agency, self-care, and the therapeutic self-care demand serve as anchors for the discussion of theoretical and empirical literature. The section is divided into literature pertaining to: (a) the measurement of self-care agency, (b) the measurement of the therapeutic self-care demand, (c) the measurement of self-care practices in HIV infected persons, (d) theory testing , and (e) substruction of two major constructs. The chapter concludes with the presentation of research questions and a chapter summary.

Conceptual Framework

Self-care deficit theory (Orem, 1991) is the conceptual framework that guides this study. Before an overview of the literature pertaining to the measurement of the major constructs of the theory is provided, two brief definitions will be required here. Orem (1991) has defined **self-care agency** as the power of a person to achieve the goals of self-care (p. 145). She defined **self-care** as the actions taken by persons each day to "...regulate their own functioning and development" (p. 3). Both definitions depict the action-oriented nature of the theory represented by the constructs.

Self-care agency has been divided by Orem (1991) into five concepts: (a) operational knowing, (b) knowing and doing capabilities, (c) sets of dispositions foundational for action, (d) power components, which are also called specific enabling capabilities, and (e) self-care operations. The five component concepts of self-care agency are hypothesized by the theory to be equally weighted. Therefore, the theory has suggested no greater emphasis on one

component over any other. However, Orem has maintained, as have other self-care deficit theorists (NDCG, 1979), that there are conditions, represented by operational knowing and by knowing and doing capabilities, that are prerequisites for the other three components. In short, a causal path has been suggested by the theory, such that the precursors known as (a) operational knowing and (b) knowing and doing capabilities precede in time the other three components of self-care agency. Neither of these precursors has been quantified in research pertaining to the theory, and will not be discussed further here.

The other three component concepts of self-care agency will be discussed next, beginning with self-care operations. Self-care deficit theory retains an equivocation in the relationship of the concept of self-care operations to the construct of self-care agency. Self-care operations, according to the capability of an individual to engage in their practice, are considered part of self-care agency as one of its three component concepts. However, Orem (1991; p. 151) uses the practice of self-care operations as the definition of self-care. Therefore, it is necessary to distinguish between the capability to engage in self-care operations (called "self-care operations") and the actual practice of them (called "self-care").

The second component concept of self-care agency for discussion here, the power components, was first developed by the Nursing Development Conference Group (NDCG, 1979). The power components received their name from their function within the construct, which was that they enabled the self-care agent or person (both terms used synonymously) to practice self-care operations. They were viewed as intermediate links between human capabilities to engage in self-care and self-care operations. Even as late as Orem's 1991 text there remains no clear relationship between the power components, which total ten in number, and the self-care operations. Refinement of the relationships between the power

components and the self-care operations is necessary even as the measurement of self-care agency proceeds (Orem, 1991, p. 154).

A list of the ten power components follows:

1. Ability to maintain attention and exercise requisite vigilance with respect to self. 2. Controlled use of available physical energy that is sufficient for the initiation and continuation of self-care operations. 3. Ability to control the position of the body and its parts. 4. Ability to reason within a self-care frame of reference. 5. Motivation (i.e., goal orientations for self-care that are in accord with its characteristics. 6. Ability to make decisions about care of self. 7. Ability to acquire technical knowledge about self-care. 8. A repertoire of skills adapted to the performance of self-care operations. 9. Ability to order discrete self-care actions into relationships with prior and subsequent actions. 10. Ability to consistently perform self-care operations (Orem, 1991, p. 155).

Foundational capabilities form the third component concept of self-care agency. Foundational capabilities include both the genetic and acquired abilities necessary for deliberate action (Backscheider, 1974; NDCG, 1979). The capabilities have been divided into (a) basic capabilities, such as learning, sensation, and perception, (b) knowing and doing capabilities, such as rational agency and operational knowing, (c) dispositions affecting goals sought, such as self-image, self-value, and self-understanding, and (d) significant orientative capabilities, such as orientation to time, health, and other persons (Orem, 1991, p. 153). It has long been advanced within self-care deficit theory that the list of foundational capabilities should be further developed through clinical use (Orem, 1991).

In addition to a discussion of the component concepts of self-care agency, self-care agency can be characterized as adequate or inadequate. The adequacy of self-care agency remains a theoretical principle, which is said to be "...measured in terms of the relationship of the number and kinds of operations that persons can engage in and the operations required to calculate and meet an existing or projected therapeutic self-care demand" (Orem, 1991, p.147). Yet

prior research in which self-care agency has been calculated has been limited by the lack of comparison of self-care agency with the therapeutic self-care demand. Therefore, it has been impossible in these studies to determine the empirical adequacy of self-care agency (Weaver, 1987).

Review of Literature

Instrument development to measure self-care agency began in 1979 with the publication of Kearney and Fleischer's instrument, the Exercise of Self-Care Agency or ESCA (Kearney & Fleischer, 1979). It was soon followed by the doctoral dissertation of Denyes (Denyes, 1980) and her development of the Denyes Self-Care Agency Inventory (DSCAI) for use with adolescents. Numerous instruments that measured self-care agency followed these two and have been reviewed in four critiques (Freeman, 1991; Gast, et al., 1989; McBride, 1987; Weaver, 1987).

Since the measurement of self-care agency is central to the empirical validation of self-care deficit theory and to the questions proposed for this investigation, a review of five instruments for measurement of self-care agency will follow. In turn, the Exercise of Self-Care Agency scale, the Denyes Self-Care Agency Inventory, the Perception of Self-Care Agency Scale, the Adult Self-Care Agency Scale, and the Self-as-Carer Inventory will be considered. Preference for the Self-as-Carer Inventory for the proposed study will be based on the reliability and validity studies conducted with the instrument in one ill adult sample to date.

1. The **Exercise of Self-Care Agency (ESCA)** was developed by Kearney and Fleischer (197. The ESCA consists of 43 items that represent five dimensions of self-care agency as it was perceived by the authors in interviews with their graduate 9)students. Items are rated in a five-point Likert scale.

Content validity of the ESCA was derived from the consensus of a panel of nurse experts. Construct validity was accomplished by way of a review of

literature, primarily using the 1973 document created by the Nursing Development Conference Group (NDCG, 1979). Construct validity was also addressed in the concurrent use of the Adjective Check List and the Internal-External Locus of Control Scale. Since the construct of self-care agency was in its infancy, it was considered impossible to determine concurrent or predictive validity with the ESCA (Kearney & Fleischer, 1979). Test-retest reliability and alpha coefficients from initial and subsequent use of the ESCA have remained high.

Six articles have emerged since initial publication of the instrument. Factor analysis of the data from initial testing of the ESCA was reported, with 84 nursing students and 153 psychology students forming the sample of a well population of young adults. Relatively high correlations ($r = 0.80$) supported the test-retest reliability of the ESCA (Kearney & Fleischer, 1979).

Factor analysis of the ESCA emerged from the report of Riesch and Hauck (1988), which isolated four factors with eigenvalues greater than 1.00. Factors were named self-concept, initiative and responsibility, knowledge, and passivity by a panel of theory experts. These factor names were congruent with those of Kearney and Fleischer (1979), thus adding to the construct validity of the ESCA. Riesch and Hauck (1988) recommended that the ESCA factors be studied according to the multitrait-multimethod proposed by Duffy (1987), because it was not clear whether the instrument measured the knowledge of self-care versus the act of self-care, or whether it measured the dispositional trait known as self-care agency.

McBride's (1987) use of the ESCA in 62 nursing students and 57 adult diabetics revealed similar test-retest reliability correlations to those of Kearney and Fleischer (1979). Theoretical congruence between readiness to learn, as measured by the Self-Directed Learning Readiness Scale, and the factors of initiative and knowledge from the ESCA did not reveal empirical significance,

however. McBride (1987) attributed the incongruence to the low levels of education in her adult diabetic sample. The significance of McBride's study was the use of the ESCA with an ill sample.

Geden and Taylor (1991) have concluded that the ESCA's operational definition of self-care agency is incongruent with the theoretical definition. Their conclusion is based on the fact that one of the factors identified by Kearney and Fleischer (1979) is passivity. Yet self-care agency, they contend, is action-oriented, based on the premise that self-care "...is a purposive goal or result seeking behavior" (Orem, 1985, p. 115). Furthermore, self-worth (factor 1) is actually a foundational capability of self-care agency and not one of the power components. A foundational capability would have no place in the measurement of the **exercise** of self-care agency (Geden & Taylor, 1991). These remarks parallel those of Gast, et al. (1989) in their comments about the ESCA.

2. The **Denyes Self-Care Agency Inventory (DSCAI)** was the product of Denyes' doctoral work (1980) in measuring self-care agency in adolescents. After theoretical review of the construct and early testing of 75 items that yielded content validity, Denyes arrived at a 22 Likert-type item instrument that she administered to 600 high school students. Factor analysis revealed six factors: 1) ego strength and decision-making capability, 2) relative valuing of health, 3) health knowledge and decision-making experience, 4) physical energy levels, 5) feelings, and 6) attention to health. The concurrent administration of a questionnaire on self-care practices yielded a strong relationship between self-care agency and self-care practices, a relationship predicted from the theory.

Construct validity based on hypothesized relationships between self-care agency and selected variables, such as autonomy, was addressed by Moore (1987) in her work with the DSCAI and the Personal Autonomy Scale. Theoretical arguments that linked personal autonomy to self-care agency were

used to formulate the hypotheses that Moore tested, since autonomy had been part of the definition of predisposing capabilities of self-care agency (Orem, 1985). Significant increases in subjects' self-care agency were noted along with increases in autonomy scores ($r = 0.20$; $p < .027$), thus confirming the hypothesis. Further evidence of construct validity of the DSCAI came from other studies (Campbell, 1989; Denyes, 1988).

Criticism of the DSCAI has been registered by Gast, et al. (1989) in a review article of existing instruments that criticized the DSCAI for its isolation of factors from foundational capabilities in the ten power components. One example of the isolation of foundational capabilities is the fact that ego strength (factor 1) is both a foundational capability as well as a power component. Small sample sizes, outside of the initial testing of the instrument with 600 subjects, have limited further factor analysis of the instrument.

In short, the DSCAI has become a useful instrument to measure self-care agency in adolescents. It has been demonstrated to have high measures of internal consistency (> 0.85 overall alpha), strong test-retest reliability, and evidence of construct validity. The applicability of the instrument across well and ill populations also supports its place as a useful tool. Limitations primarily remain in the cross-over of several factors of the DSCAI between foundational capabilities and the power components, as hypothesized by the Nursing Development Conference Group (1979) and Orem (1990). Further factor analytic studies involving the instrument are necessary (Gast, et al., 1989).

3. The **Perception of Self-Care Agency (PSCA)** was developed by Hanson and Bickel (1985) who specifically set out to measure the construct of self-care agency according to the list of ten power components first published by the Nursing Development Conference Group (1979). They reported that their development of the instrument was divided into three stages, beginning with item

pool development, progressing through the testing of the initial 120-item instrument, and culminating in a reduced format for the questionnaire that was later to be tested (Hanson & Bickel, 1985). Fifty-three items emerged from the longer form to comprise the shortened version of the instrument.

Five factors emerged from the factor analysis of the PSCA when administered to a 500-member study sample of non-hospitalized adults from the farmlands of central Missouri. These five factors accounted for 86% of the variance; each factor had an eigenvalue of >1.0. Applying a varimax rotation, the authors interpreted the factors as follows: 1) cognitive abilities, 2) negative cognitive abilities, 3) physical movement, 4) motivation, and 5) skills necessary for self-care.

Hanson and Bickel (1985) noted that the five factors did not mirror the ten power components, but that they seemed consistent with the construct of self-care agency when compared with the ten power components. The authors explained their understanding of the empirical construct overlap according to the theoretical overlap that is latent within the construct, largely based on personal communication between the authors and Orem (Hanson & Bickel, 1985, p. 275).

Weaver (1987) reported on the administration of the PSCA to 575 non institutionalized adults. The intent of his study was to apply LISREL factor analysis to the instrument responses returned from the original mailing of the instruments. Weaver concluded that the finding of only four of the ten power components in the original Hanson and Bickel (1985) research in instrument development could be attributed to the theoretically inconsistent factor analysis. Therefore, he used LISREL, a statistical software that did not require varimax rotation. Varimax rotation, as used by Hanson And Bickel (1985), does not allow intercorrelations between factors, a practice that would be necessary to analytically determine correspondence between factor analysis and the theoretical construct

(Weaver, 1987). Therefore, LISREL was considered to provide one means of establishing greater consistency between theoretical factors and second-order factor analysis from the PSCA.

One of Weaver's (1987) study aims was to compare the how well the ten power components fit the observed data from the independent data set. Weaver (1987) determined that the ten power components actually fit less well with the observed data than did the data set predicted from the data set observed from the research of Hanson and Bickel (1985).

4. The **Adult Self-Care Agency Scale (ASCAS)** was developed by Braun (1987). Derived from the DSCAI, the ASCAS is the adult version of the instrument. The ASCAS was developed simultaneously with the PSCAS and was the result of Braun's (1987) doctoral work. Questions that were peculiar to the adolescent population were not included in the ASCAS. The instrument consists of 46 7-point Likert-type items. The highest possible score was 322.

The only report of reliability and validity of the instrument comes from Braun (1987). 278 subjects were initially tested by the investigator. Construct validity was determined by contrasting the ASCAS with the Adjective Check List and the Multidimensional Health Locus of Control Scale to determine which of the three was best in classifying higher percentages of subjects according to answers to self-care behaviors and beliefs. The ASCAS was preferred at classifying subjects according to their responses to health practices and beliefs. Interitem reliability using coefficient alpha was 0.9255, thus supporting the conclusion that the ASCAS score variance could be attributed to signal variance.

R-type factor analysis was performed on the ASCAS. The factor analysis correlation matrix revealed no items were sufficiently intercorrelated to indicate redundancy. Again, Varimax rotation was used to isolate and extract factors. After removing factors with less than 0.70 squared multiple correlation,

Braun (1987) was left with five factors: 1) orientation to health/maintenance of health, 2) operational knowing, 3) self-care skills, 4) health decisions, and 5) consistent self-care actions.

No application of the ASCAS with an ill sample has been completed to date. Freeman (1991) is currently collecting data utilizing the ASCAS to determine the change in self-care agency over time as a predictive value of the instrument in measuring adaptation to a learned relaxation technique among ill and well samples. Results from the within-subjects, multiple serial measurement longitudinal design have revealed high alpha coefficients for overall instrument scores greater than 0.80 in both well and ill samples. Factor analysis has not been performed since study accrual is still in progress. Other than this study, there have been no further studies utilizing the ASCAS.

5. The **Self-as-Carer Inventory (SCI)** was developed by Geden and Taylor (1991). Initially the authors undertook a revision of the PSCAS for reasons that were identified in the summary discussion of the instrument earlier. Their guiding concern was that the items they constructed to measure self-care agency must also be linked somehow to the judgment that must be enacted before operationalizing self-care agency as ability. Their instrument is called the Self-as-Carer Inventory (SCI).

The instrument currently consists of 40 items and numerous revisions of wording have been enacted (Geden & Taylor, 1991). The same authors report on a recent study involving SCI (Geden & Taylor, 1990). The study enrolled 539 subjects.

Additional ratings of health state and amount of self-care rendered were added to the third version of the instrument, and were tested to see whether the ratings were related to total inventory scores, as was predicted by the theory. The ratings of health state were: 1) health in general, and 2) health at this moment.

Both were scored by the anchors of 1 = Healthy and 6 = Unhealthy, with the six points of the Likert scale representing evenly distributed intervals. The third measure asked the question "How much of your own self-care are you providing?" Anchors for the response to the latter question were 1 = All and 6 = None.

All correlations between summative scores from the inventory and the measures of health in general, health at this moment, and amount of self-care provided were significant at the 0.0001 level (Geden & Taylor, 1991). This finding was consistent with the theoretical relationship between self-care agency and its component concept of health state, as well as self-care rendered.

Test-retest reliability of the Self-as-Carer Inventory was conducted on an earlier and smaller sample, consisting of 56 students (Geden & Taylor, 1988). A correlation between testing dates one week apart revealed a coefficient of 0.85. No other reports of reliability were reported for this instrument prior to its use in this study.

Content validity for the instrument was conducted from the outset by consultation with self-care deficit theory experts. These judges were asked to measure each prospective item for "...content validity (present or absent) and to rate item clarity (clear = 1 to unclear = 3)" (Geden & Taylor, 1991, p. 48). Further content validation was conducted after items had been returned from the first item inquiry of the experts and after initial testing of the instrument in a sample of 10 English-speaking American adults. The second content validation was intended to separate out prospective items according to their relevancy to one of the ten power components. Geden and Taylor (1991) reported a content validity index (presumably an item to power components index) from the second round with the experts of 94%.

Principal components analysis was conducted on both the initial testing with 56 students and a subsequent testing of 518 health adults. Seven

factors emerged from the Varimax rotation of factors, accounting for 57% of score variance. After conducting an oblique rotation, eight factors emerged, which accounted for 55% of the variance. Seven of the eight factors reflected components of the self-care operations, such as antecedent knowledge, appraisal, and judgment. There was no report on the relationship between the factors and the ten power components, except to say that the ten power components were not isolated on a one-to-one factor to power component basis.

Subsequent principal components analysis of the third version of the inventory revealed four factors. These four factors accounted for 58% of the variance. The four factor names were: 1) Knowledge of Self, 2) Judgment and Decisions, 3) Attention and Awareness of Self, and 4) Physical Skills and Satisfaction with Self-Care. Each of the four factors had alpha scores ranging from 0.83 (Attention to and Awareness of Self) to 0.92 (Knowledge of Self). A cluster analysis was conducted after this oblique rotation to see whether a more concise pattern of factors might emerge. Cluster 1, by far the largest of the four factors to emerge from the cluster analysis, contained a total of 22 items, showing a cross-over from factor 2 to factor 1 from the oblique rotation of 7 items. Thus, fewer items were clustered with factors 2 to 4 according to this technique. The factor names were not reported as changed by the cluster procedure of analysis. Geden and Taylor (1991) have called for further validity studies by determining whether subscale values are congruent with data collected from a selected ill sample, and whether the data collected from the sample corresponded with the projections of an expert panel. Their caution is that further validity studies are warranted and necessary prior to widespread clinical applications of the instrument.

Research that Investigates the Therapeutic Self-Care Demand

As such, the therapeutic self-care demand has not been researched to date, because it has not been reduced to the level of empirical indicators as it is now presented for empirical validation by this study. The therapeutic self-care demand is operationalized by this study as the responses by subjects to a newly developed instrument, HIV-Specific Self-Care Behaviors. Factor analysis of these responses relative to the five results of the therapeutic self-care demand presented at the end of this chapter under the definition of the construct is presented in chapter four. More effort by self-care deficit theory researchers will be required to refine the construct for measurement purposes, and to clarify and develop instruments for the measurement of the construct.

However, numerous authors have both developed and critiqued instruments that measure concepts or behaviors related to self-care agency, frequently in relationship to self-care requisites (universal, developmental, and health-deviation self-care requisites). Dodd (1988) reviewed tools that measured self-care behaviors, and organized her review according to Orem's 1985 presentation of universal, developmental, and health-deviation self-care requisites. Dodd noted three problems that have arisen in the development of measurement instruments for the concept of self-care from the perspective of health-deviation self-care requisites.

First, according to Dodd, many instruments and studies in which self-care instruments are used have not clearly operationalized the concept of self-care. Second, the actual measurement of self-care as a concept is reduced to only a few questions in many instruments. Third, reliability and validity of self-care instruments are underreported. Finally, the measurement of self-care appears in instruments that have not been developed to measure the concept. The self-care measurement tools related to health-deviation self-care requisites reviewed by

Dodd were: (a) Klein-Bell Activities of Daily Living (ADL) Scale, (b) Self-Care Behavior Questionnaire, (c) Self-Care Behavior Log, and (d) Self-Observation and Report Technique.

Denyes (1980) identified the developmental self-care requisites of adolescents when she measured their self-care practices. Extrapolating theoretical guidance from major developmental theoreticians, such as Piaget, Erikson, and Kohlberg, Denyes developed lists of self-care strengths and limitations from each of the following domains of development for adolescents: psychosocial, cognitive, affective, and physical. Then, in combination with the development of items for her self-care agency scale, she also developed items for a self-care practices inventory that she later tested in her adolescent sample. Concurrent measurement of these self-care practices with her self-care agency instrument enhanced the construct validity primarily for the self-care agency instrument.

Evans' (1979) dissertation focused on the meeting of universal self-care requisites by assessing just one component of universal self-care requisites, which was the requisite for social interaction. Elderly subjects answered four items dealing with decision-making and action-taking behaviors connected with the phenomenon of social interaction.

Frey and Denyes (1989) were testing the relationships between the universal self-care requisites and health-deviation self-care requisites of a group of adolescent insulin-dependent diabetics. The authors conceptualized health-deviation self-care requisites as "...being aware of and attending to effects and results of illness...and carrying out prescribed therapeutic measures" (p. 71) [italics added]. Thus, their instrument to measure health-deviation self-care requisites (Diabetic Self-Care Practice Instrument) was based on this definition.

The definition of health-deviation self-care requisites stated by Frey and Denyes (1989) is almost identical to the definition of the therapeutic self-care

demand used by Orem (1991). According to Orem, the therapeutic self-care demand is composed of: (a) a self-care goal to be achieved, and (b) a normative course of action required to meet a particularized self-care requisite (1991, p. 135). It may be concluded that there is lack of agreement among some self-care deficit theorists and investigators as to the definition of the therapeutic self-care demand. The definition of the construct for this study follows the one used by Orem.

It is important to note that Frey and Denyes made it clear that the universal self-care requisites of their sample were correlated with the sample's health-deviation self-care requisites. They discovered a moderately strong positive linear relationship between the two ($n = 37$; $r = 0.62$, $P < .001$). This finding led them to postulate that the universal self-care requisites influence the methods used to treat health-deviation self-care requisites.

Saunders, Valente, and Travis (1989) developed a self-care practices tool to measure changes in self-care practices after knowledge of HIV serostatus is acquired. Known as the Self-Care Activities Report Scale (SCARS), the tool is based on the premise that overall elevated scores signify that self-care practices increase and change relative to the psychological distress experienced after knowledge of HIV seropositive status. In an indirect sense, the tool reflects the health-deviation requisites of persons who discover that they have been exposed to HIV.

Current research by Saunders (1992) using the SCARS to differentiate groups of men at risk for HIV infection, with mild, moderate, and severe HIV-related diseases, may substantiate that the SCARS is both a valid and reliable tool for measuring the changes in self-care practices of the sample across time. Correspondence with Saunders (1991) offered overall alpha coefficients for the SCARS of 0.87. In summary, empirical indicators for the therapeutic self-care

demand have not been developed in prior research involving the development and critique of self-care practices inventories.

Research that Investigates Self-Care in Persons with HIV Infection

Self-care operations, both Phase 1, intellectual and investigative operations, and Phase 2, initiation and continuation of self-care operations (Orem, 1991), have not been fully elucidated among persons with disease associated with infection by the Human Immunodeficiency Virus (HIV) who are symptomatic. Yet it is necessary to elucidate self-care operations, in general, in order to appreciate the contribution of self-care operations to overall self-care agency scores from an instrument. Without a clear picture of self-care operations it is unclear whether self-care operations have contributed to overall self-care agency scores from an instrument. This is to say that self-care operations contribute one of three dimensions to self-care agency, and that prior research involving instrument development has been limited by lack of assessment of the involvement of self-care operations to variance in scores (Geden & Taylor, 1991).

It is understood that the actual engagement in self-care operations is a distinct concept apart from the capability to engage in self-care operations (Orem, 1991). The engagement in self-care operations is self-care by definition of self-care deficit theory (Orem, 1991, p. 149). The capability to engage in self-care operations is one component of the definition of self-care agency. It is presumed by the theory that the capability to practice self-care operations cannot be assessed except as it is manifested in actual behavior. Refinement of self-care agency instruments is now at the stage where it is necessary to show correspondence between self-care behavior and self-care agency scores from instruments under development (Geden & Taylor, 1991).

Divided into three stages, self-care operations are composed of estimative, transitional, and productive types. The progression of the types of self-

care operations follows the decision-making pattern of investigation prior to enactment of the decision. Therefore, decision-making, according to the theory, is considered a rational endeavor (Orem, 1991).

No researcher has clarified a list of self-care operations of persons infected with HIV that is consistent with the theoretical components of self-care operations identified by Orem (1991). However, several researchers have begun the work of clarifying the role of self-care in health maintenance and restoration among persons infected by HIV.

Getty and Stern (1990) have characterized estimative type self-care operations of gay men infected by HIV. Their qualitative data were gathered through unstructured interviews with 34 gay men infected with HIV, from participant observations chosen from logs of subjects that characterized the interactions between nurses and subjects, and from fieldnotes of healthcare workers made during health education program offerings with HIV infected subjects.

Using a comparative analysis method, the authors gleaned a theoretical framework from the three sources of data. The framework, known as trusting, was identified as the basic psychological process that determined the manner in which gay men approached the disease process. It has been linked with the estimative process of self-care operations by this author because the qualitative approach used by Getty and Stern reveals one glimpse into the attitude of gay men toward their response toward AIDS, and attitude is one basis of the estimative type of self-care operations.

The evaluation of selected self-care operations among HIV infected gay men has been characterized by Lovejoy and Paul (1990). Their sample consisted of 162 seropositive gay men drawn from a treatment center in San Francisco. All of the sample was engaged in the same treatment at the center, a

factor that provided the researchers modest control over their otherwise self-selected sample. The purpose of the study was to describe the correlates of symptom-distress reported by the sample. Lovejoy had developed the HIV-Symptom Distress Scale in an earlier reported study (Lovejoy and Moran, 1988), and used it in the current study to determine its test-retest reliability at two and four weeks ($r = 0.6$), internal consistency (alpha = 0.9), and concurrent validity with the McCorkle-Young Symptom Distress Scale ($r = 0.7$).

It was determined that the HIV-Symptom Distress Scale might measure transient distress while the McCorkle-Young measured persistent symptom distress (Lovejoy & Paul, 1990). However, design limitations connected with the sampling technique severely limited even the conclusion that the instruments measured different kinds of distress, much less conclusions that were grander in scope. The study remains important to the proposed inquiry because it depicts the beginnings of knowledge regarding self-care operations of HIV seropositive gay men.

Both anxiety and depression, often mixed with anger and rage, have characterized responses to HIV infection (Miller, 1986, 1990; Wolcott, 1986). Decision-making in the estimative phase of self-care operations is limited by responses of these kinds. Therefore, it has become important to consider what is known about the influence of psychological states on decision-making by HIV seropositive individuals. Carnwarth and Miller (1986) have noted that all decisions of the HIV seropositive individual are influenced by knowledge of serostatus, indeed that the "...future life is predicated mainly on HIV" (Miller, 1990, p. 195).

If the future life is estimated mainly according to HIV serostatus, then knowledge regarding the transition from estimative self-care operations to productive operations must be forthcoming. It remains unclear how individuals infected by HIV evaluate their self-care operations prior to enacting them.

Moreover, it remains unclear how individuals at varying levels of symptom manifestation and symptom distress make the transition from estimative self-care operations to productive operations. The question f "how" in this case is one of "in what ways" and not according to what cause or "by what predictor."

One answer to the question of how individuals infected by HIV enact their decisions regarding self-care is presented by the few examples of coping literature with HIV infected subjects. Pivar and Temoshok (1989) documented the patterns of coping with HIV-related stressors in gay symptomatic subjects. Subjects were administered a semi-structured interview that was designed to elicit information about perceived HIV-associated stressors at three points in time nine months apart.

Perceived stressors were categorized as follows: (a) HIV and diagnostic testing, (b) severe symptom episodes, (c) treatment issues, (d) complications with family, work, school, or physical and psychological limitations and losses, and (e) general concerns about the future. Coping responses were also categorized: (a) 53% of subjects were "pro-active," thus accepting of responsibility, seeking social support, and prioritizing, among associated behaviors, (b) 22% of subjects exhibited a "control-denial" style centered on behaviors of avoidance and escape, and (c) 8% fell into a "taking care of self" response, by taking vacations, exercising, and meditating.

These categories of perceived stressors and categories of responses mirrored earlier findings (Namir, Wolcott, Fawzy, & Alumbaugh, 1987). Namir, et al. (1987) found that subjects with a "control-denial" response often exhibited higher levels of depression and lower levels of self-esteem, and were less likely to receive practical and social support with their disease management. Pivar and Temoshok (1989) discovered that self-destructive behaviors were characteristic of the "control-denial" response group, as well. Self-destructiveness was their

assessment of unsafe sex behaviors and drug-alcohol abuse practiced by the "control-denial" group.

For the purposes of the current study, knowledge of the transition from evaluation to action in the case of the "pro-active" response group corresponds with the theoretical transition from estimative to productive self-care operations as depicted in self-care deficit theory. In contrast with the "control-denial" group, the "pro-active" group successfully enacts self-care operations, such as seeking social support and reliable sources of information, after estimating the value and impact on themselves of these operations.

Weitz (1991) conducted semi-structured interviews with 37 men and women living with HIV disease in the state of Arizona. She noted that few of the persons she interviewed were passive victims of the infection, and most took a proactive stance toward their self-care practices. Lifestyle changes were apparent in the interviews with her sample, as self-care practices both increased in scope and number after knowledge of exposure to the virus. Such changes included eating more balanced meals, getting regular exercise and sleep, and avoiding tobacco and mind-altering substances (Weitz, 1991, pp. 85 ff.).

Empirical Validation of Nursing Models

Silva (1986) identified many problems with so-called theory testing using nursing theories as the theories tested. First, theories cannot be tested per se. Rather, hypotheses generated from the theories provide approaches to explaining and predicting real-to-life situations, such as are presented to the researcher for investigation. Second, Silva maintained that the only valid reason for theory-testing research is to examine the assumptions and propositions of a selected theory, and not merely to guide the researcher as a type of theoretical framework. In short, the theory must be considered in a comprehensive fashion for the hypotheses and the theory to be congruent.

Walker and Avant (1988) further defied theory testing research as placing the theory under review at risk for falsification. Falsification was dependent on the level of specificity of hypotheses generated from the theory, such that the more specific the hypothesis, the greater the likelihood of falsification.

Acton, Irvin, and Hopkins (1991) identified 15 criteria for evaluating theory-testing research. According to these authors, the comprehensiveness of theory-testing is dictated by following all of these criteria. The criteria are:

> 1. The purpose of the study is to examine the empirical validity of the constructs, concepts, assumptions, or relationships from the identified theoretic frame of reference.
> 2. The theoretic frame of reference must be explicitly described and summarized.
> 3. The constructs and concepts to be examined are theoretically defined.
> 4. An overview of previous studies that are based on the theoretic framework, or that clearly show the derivation of the concepts being tested, must be included in the review of the literature.
> 5. The research questions or hypotheses are logically derived from the definitions, assumptions, or propositions of the theoretic frame of reference.
> 6. The research questions or hypotheses are specific enough to put the theoretic frame of reference at risk for falsification.
> 7. The operational definitions are clearly derived from the theoretic frame of reference.
> 8. The design is congruent with the level of theory described in the theoretic frame of reference.
> 9. The instruments must be theoretically valid and reliable.
> 10. The theoretic frame of reference guided the sample selection.
> 11. The statistics are the most robust possible.
> 12. The analysis of data must provide evidence for supporting, refuting, or modifying the theoretic framework.
> 13. The research report must include an interpretive analysis of the findings in relation to the theory being tested.
> 14. The significance of the theory for nursing is discussed in the report.
> 15. Ideally, the researcher makes recommendations for further research on the basis of the theoretic findings (pp. 56-59).

The 15 criteria of theory testing depicted above guide this study. One approach to addressing the first eight criteria of theory-testing is the process

known as substruction (Hinshaw, 1979; Dulock & Holzemer, 1991). Substruction is defined as a process in which a researcher (a) clarifies constructs and concepts in a theory, (b) ascertains relationships between the variables derived from these constructs and concepts, and then (c) links the research method proposed to the relationships hypothesized. The goal of substruction is the creation of empirical measures of the lowest level of theoretical building blocks. The lowest level of theoretical building blocks is the sub-concept. The concept, in turn, is just above the level of the sub-concept in abstraction, and the construct is one level above the concept in abstraction. The highest level of abstraction is represented by the construct.

The process of substruction corresponds with criteria 1 through 8, because empirical indicators under review for the current study have been derived from constructs, concepts, and sub-concepts in self-care deficit theory. Particular emphasis has been placed on the substruction of two constructs, namely (a) self-care agency and (b) the therapeutic self-care demand.

Several new instruments have been developed expressly for this study and are first tested for reliability and validity in the course of the study. This process of instrument development corresponds with criterion 9 in the above list. Criteria 10 through 15 will be discussed in subsequent chapters, but without explicit mention of their numbering in the list printed above. The treatment of criteria 10 - 15 will be subsumed under the treatment of statistics selected, the research design, and the analysis and evaluation of data.

Testing Relationships Proposed by Self-Care Deficit Theory by Way of Substruction

Self-care deficit theory is a complex composite of theoretical constructs and concepts. The authoritative sources of the theory are few in number (NDCG, 1973; NDCG, 1979; Orem, 1990). But complete agreement

between authoritative texts regarding the operational definitions of constructs and concepts within the theory is yet to be achieved (Huch, 1991). For example, Huch (1991) noted that self-care is defined by Orem (1990) in at least four different ways in her latest text on the theory.

The four major constructs of self-care deficit theory, namely self-care agency, self-care, nursing agency, and therapeutic self-care demand, have acquired greater conceptual clarity throughout the span of the last thirty-five years, since Orem first developed the theory in 1958 (Orem, 1990). In this span of time, the Nursing Development Conference Group (1973; 1979), a group of nurse theoreticians convened for the purpose of developing the theory, and Orem have produced numerous revisions and developments of the theory. In addition, at least two international and multiple regional self-care deficit theory conferences have convened to address theory development by way of philosophical and empirical investigations. Therefore, the state of development of any one of the four major constructs must take into consideration the most recent texts before theoretical relationships are proposed for testing. This is the reason that Orem's fourth edition text of the theory (1990) has been used as the summary text for the generation of hypotheses for this project.

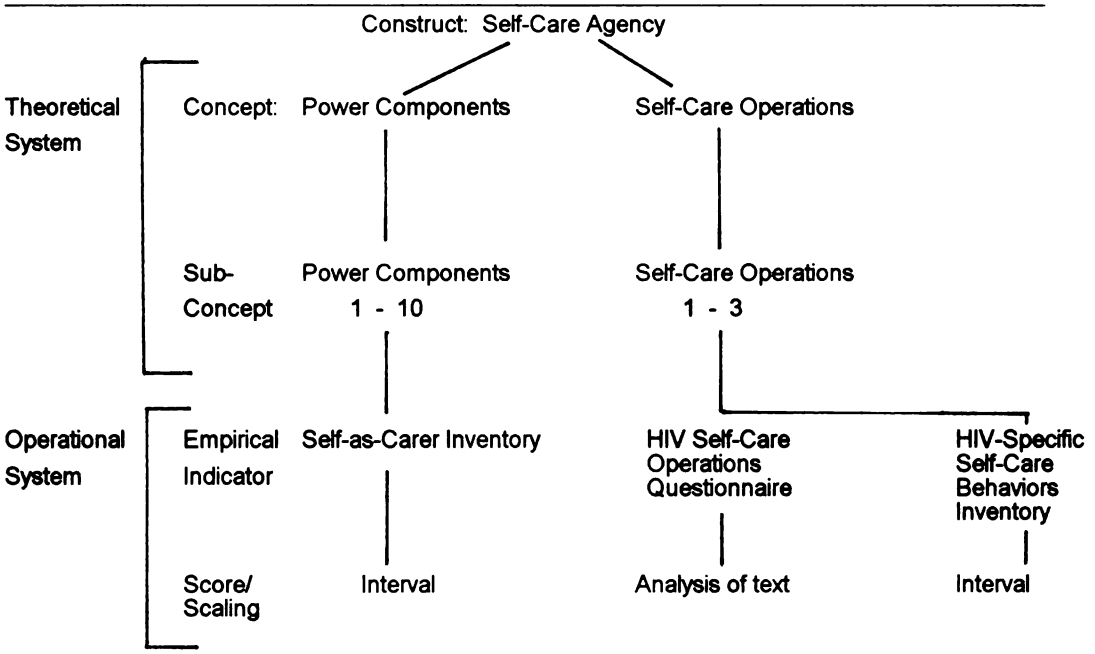
Substruction is used in this project to create diagrams of relationships between constructs, concepts and sub-concepts, and empirical indicators of concepts and sub-concepts generated from self-care deficit theory as gleaned from Orem's text. In subsequent paragraphs, self-care agency and the therapeutic self-care demand will be analyzed by way of substruction.

Self-care agency can be analyzed by way of substruction, and this substruction will produce five concepts. The five concepts are: (a) operational knowing, (b) knowing and doing capabilities, (c) foundational capabilities, (d) power components, and (e) self-care operations. But, for purposes of this study,

only (a) ten power components and (b) the three self-care operations will be completely analyzed through substruction, as represented in diagram 1.

Figure 1

Substruction of the construct of self-care agency



Emphasis has been placed on the power components because many questions remain whether existing self-care agency instruments actually measure the power components more than the other concepts of self-care agency (Geden & Taylor, 1991). Emphasis has been placed on self-care operations because there was nothing in the self-care deficit literature pertaining to persons with HIV infection that linked the theoretical relationships between self-care operations and self-care agency to empirical indicators. In diagram 1, therefore, the theoretical construct that underwent substruction was self-care agency. It was composed of

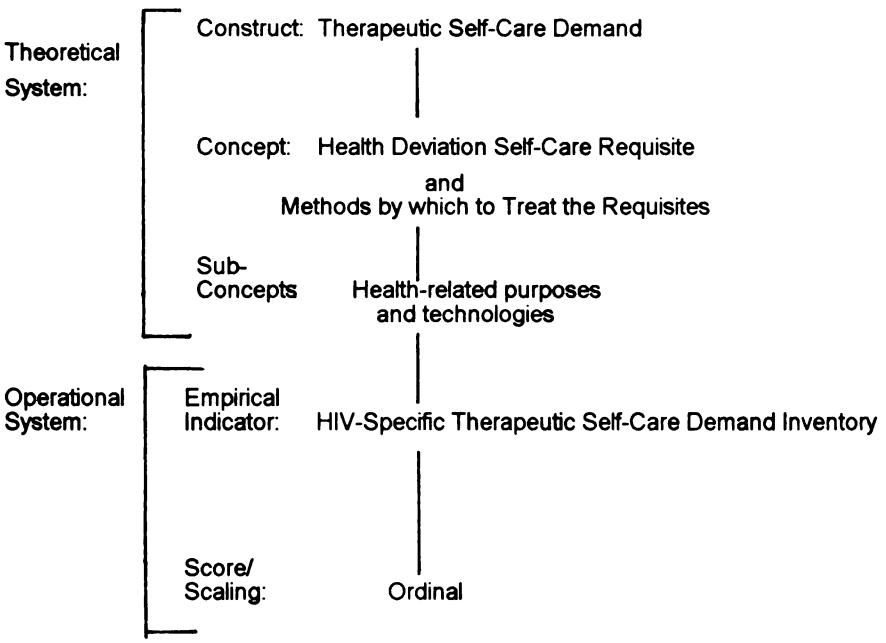
two concepts, which were the ten power components and three types of self-care operations.

The operational system of diagram 1 is composed of the empirical indicators and the types of scores and/or scaling that describe the empirical indicators. Diagram 1 depicts the ten power components as empirically indicated by the Self-as-Carer Inventory, which is an interval scale. The self-care operations have been empirically indicated by the interval scale, the HIV-Related Self-Care Behaviors Checklist, and the analysis of text from the HIV Self-Care Operations Questionnaire.

The emphasis applied to the ten power components and the three self-care operations does not diminish the importance of the other three component concepts of self-care agency. Rather, the emphasis applied in this study is merely the emphasis received from the research literature. Most research involving instrument development to measure self-care agency has focused on the factor structures of the instruments as the factors compare and contrast with the ten power components (Gast, et al., 1989). It is for this reason that the state of the science of testing hypotheses generated from self-care deficit theory is at present in its infancy (Lee, 1990). With maturity, the empirical science of validating hypotheses from self-care deficit theory will embrace other component concepts of self-care agency.

Figure 2

Substruction of the Construct Known as the Therapeutic Self Care Demand



The therapeutic self-care demand, like self-care agency, is a major construct in the theory known as self-care deficit theory. It has been defined as "...the totality of self-care operations to be performed for some duration in order to meet known self-care requisites..." (Orem, 1980, p. 40). The therapeutic self-care demand can be distinguished according to universal, developmental, and health-deviation self-care requisites. This is to say that the way to distinguish different kinds of therapeutic self-care demands is to characterize them as to the grouping of self-care practices dealing with universal, developmental, or health-deviation self-care requisites.

A self-care requisite is common to all people, and is defined as the requirement or requisite for a human being to achieve self-care. For example, the requisite for the consumption of water is one of the universal self-care requisites. While examples of each type of self-care requisite are considered more fully in

chapter two, the health-deviation self-care requisite must be considered here in the process of explaining diagram 6.

The health-deviation self-care requisite is defined as the acquired ability to ascertain a connection between illness or injury and the need to correct the problem or, at least, to do something about it. Orem (1991, p. 132) further characterizes the health-deviation self-care requisite as the link between the onset of disease or injury and the focus on self as the one who has become ill or injured. In short, the injured or diseased person recognizes self as diseased or injured. In addition, after recognition the human being must act, even if the action is only a decision to neglect the practice of behaviors that might correct the health deviation. For example, most people use the presence of a fever to signal the need to get added rest. In this example, the fever is recognized and the recognition leads to action, which is to seek added rest.

The actions to correct a health-deviation self-care requisite after T-helper cell depletion following a lengthy period of time of infection by HIV (variably considered among adults as 8 to 12 years after infection to reach a T-helper cell nadir of 200 cells or less) may be characterized in groups or kinds of actions (Lovejoy, Paul, Freeman, & Christianson, 1991). Actions that are similar may be grouped together to distinguish subjects according to one or more demographic, health state, or basic conditioning variables (Orem, 1991). Hence, in diagram 2, the health-deviation requisite therapeutic self-care demand has been operationalized as the composite of health deviation self-care requisites and methods used to treat them. The idea of the composite comes from the definition of the health-deviation self-care requisite, namely that there is recognition of the self as ill (health state) and the ill person performs deliberate actions to relieve the illness (self-care practices).

Research Questions

1. What is the congruence among theoretical components of self-care agency, the basic conditioning factors, and factors isolated from the Self-as-Carer Inventory (SCI)?

2. What are the relationships among T helper cell counts, self-care practices, and the total score from the HIV-Related Self-Care Behaviors Checklist?

3. What are the self-care operations of an HIV seropositive gay man with less than 200 T helper cells and how do these self-care operations change across time in serial measurements?

4. Can changes in the activation of self-care operations predict changes in Self-as-Carer Inventory (SCI) scores?

5. Is the calculated value of the therapeutic self-care demand correlated with Self-as-Carer Inventory scores?

Summary

The conceptual framework for this study is self-care deficit theory. Literature was reviewed that depicted the state of the definition of the major constructs and related concepts of the theory. In addition, progress in measuring the constructs of self-care agency and the therapeutic self-care demand was considered in the review of literature. Problems that have arisen in reference to measuring three of the five dimensions of self-care agency were addressed. Finally, literature pertaining to the measurement of self-care in persons infected with the Human Immunodeficiency Virus (HIV) was considered.

The process of substruction was introduced as one means of comprehensively testing the theory known as self-care deficit theory. Substruction was defined, and two constructs of self-care deficit theory were analyzed according to the process of substruction. The chapter concluded with a presentation of the research questions of this study.

CHAPTER 3

Design and Methods

Design

A two-part design was used in this study. In the first part, a correlational design was used to relate demographic, therapeutic self-care demand, and self-care operations inventory scores to total and factor-specific self-care agency scores. In the second part, a longitudinal time design was used to capture the change in self-care operations of a smaller sized sample than that used in the first part.

Research Setting

The research setting was a specialty unit of a local, private not-for-profit acute care hospital. The purpose of the specialty unit was to deliver aerosol pentamidine to persons infected by HIV. At the time of the data collection, 650 aerosol pentamidine treatments were provided through the unit on a monthly basis. Since the data collection came at a point in time after aerosol pentamidine was the universally preferred drug and route of delivery for preventing the opportunistic infection known as Pneumocystis carinii pneumonia (PCP), the average daily census for the unit had dropped from a high of 75 to 100 patients to 30 to 40 patients. Data were collected in the last two quarters of 1991.

The aerosol pentamidine unit had been engineered just for the delivery of aerosol pentamidine. It is placed on an HIV-designated unit of the hospital, located in one corner of the unit with doors separating it from the other parts of the unit. It was engineered with its own exhaust system, since numerous reports of health care worker soft tissue injury had been reported after exposure to the aerosolized drug (Montgomery, et al., 1989). The exhaust system formed an audible noise inside the treatment area. Since the unit was located on one end of

the building facing east and was surrounded by windows, there was always sufficient natural light in addition to fluorescent lights in use.

The treatment area proper for the room was surrounded by glass from floor to ceiling. Access into the area from the waiting room and central management desk was by way of sliding glass doors. An intercom system permitted communication between the respiratory therapists at the management desk (outside the partition) and the patients inside the partition.

The patients entered the treatment area and were seated for treatment on lounge chairs designed for reclining. Some patients reclined for therapy in a lateral recumbent position, while others were seated erect. The lateral recumbent position had been requested by the prescribing physicians of some of the patients, because it was believed that the prevention of apical pulmonic occurrence of the opportunistic infection was dependent on distribution of the aerosolized particles of the drug in the apices of the lungs. One respiratory therapist estimated that 30% of the patients maintained the lateral recumbent position, with the remaining patients seated erect.

The average duration of treatment was 30 minutes. Subjects had no prior knowledge or introduction to this study before entering the treatment unit on the day when the investigator approached them. However, all subjects were able to complete the study instruments during the 30 minutes of treatment. Informed consent was obtained in the unit's waiting area outside the partition. Then, the study subjects entered the treatment area where, they completed the study instruments.

Sample

Human subjects assurance.

The Human Subjects Committee of the University of California-San Francisco approved the study prior to recruitment of subjects. Study subjects were

approached by the study investigator prior to entering the treatment area. The study was explained, and informed consent was obtained. Questions were fielded at the time that informed consent was obtained, as well as during and after study instrument completion. The investigator's phone number was printed on the informed consent for questions to be addressed after the instruments were completed and returned to the investigator. The investigator was known by face and name to many of the subjects, since he was a research practitioner on the unit for many years prior to the administration of these instruments.

Nature and size of sample.

Three hundred HIV seropositive gay men with less than 200 T helper cells were recruited for the study. The 300 subjects were recruited from the patients reporting for aerosol pentamidine in a local pentamidine unit. The administration of pentamidine is dependent on the patient's number of T helper cells, since it is prescribed for HIV infected patients with less than 200 T helper cells. While the use of aerosol pentamidine was on the decline as primary and secondary prophylaxis for Pneumocystis carinii pneumonia, the selection of the setting provided a ready and convenient sample for the investigator. Confirmation of T helper status was acquired through patient report on the therapeutic self-care demand inventory.

Subject for completion of Self-Care Operations Inventory.

The one additional patient for completion of the self-care operations inventory was recruited from among the researcher's study subjects in other studies, but only after a three month search for one subject to begin the 90 days of data collection. Several subjects had agreed to perform the role of the one subject required for daily recordings, but left the study for personal reasons related to the amount of time required to complete the recordings.

This subject was recruited because he was well known by the researcher for reliability, health status, and follow-through with assigned tasks. Furthermore, his health history was also well known to the researcher, and the researcher had ready access to complete medical records for elucidation of study results. Limitations of the convenience sample are addressed under the limitations section of chapter five.

Criteria for sample selection.

The major criteria for sample selection were as follows: (a) male gender, (b) known infection by the Human Immunodeficiency Virus (HIV), (c) 200 or less T helper cells by self-report, (d) self-identified as gay, (e) ability to read and write in the English language, (f) at least 18 years of age, (g) presenting for aerosol pentamidine, and (h) ability to provide informed consent.

Data Collection Methods

Two techniques were utilized for data collection: 1) paper and pencil instruments, and 2) audio cassette recordings of verbal transmissions. The paper and pencil instruments were: 1) the Self-as-Carer Inventory, 2) the HIV-Related Self-Care Behavior Checklist, 3) the Demographics Inventory, and 4) the HIV-Specific Therapeutic Self-Care Demand Inventory. The verbal recordings on audio tape were responses by one subject to questions posed on the HIV Self-Care Operations Questions for Subject Response. Copies of the study instruments are located in Appendix E.

Instruments.

1. The Self-as-Carer Inventory was used to measure self-care agency (Geden & Taylor, 1991). Reliability and validity of the instrument were reported by Geden and Taylor (1991). The instrument consists of 40 items, which measure the "...perceived capacity to care for self" (p. 49). Items were developed by singling out concepts from the list of ten power components from self-care deficit

theory. One concept was isolated for each item developed. Instructions on the instrument requested subjects to identify how accurately the items described how they took care of themselves. A 6-point Likert-type scale was used to distribute responses between the equal interval anchors of 1 = Very Accurate and 6 = Very Inaccurate. All responses figured into a total, summative score for the instrument. The potential score range could be from 40 to 240; the lower the total score, the higher the perceived capability to care for self. The measure known as the Self-as-Carer Inventory used by this study is the third version of the instrument developed by Geden and Taylor (1991).

The mean summative score of 80.68 was achieved after administering the instrument to 585 subjects, with scores ranging from 40 to 239. Overall Cronbach's alpha was reported as 0.96 for the samples of both well and chronically ill adults. It was the intent of the authors to achieve stable factor structures given the increased variability of their samples, based on age, health state, and ethnicity. A comprehensive review of available reliability and validity data for the Self-as-Carer Inventory was reported in chapter two.

Power components were measured based on factors that emerged from the analysis of SCI data obtained. Analysis of the similarity between theoretical power components and the empirically derived factors from the SCI constituted the process of measurement of the power components for this study. The ten power components from self-care deficit theory are: (a) ability to maintain attention and exercise requisite vigilance with respect to self as self-care agent, (b) controlled use of available physical energy, (c) ability to control the position of the body, (d) ability to reason within a self-care frame of reference, (e) motivation toward self-care, (f) ability to make decisions about self-care, (g) ability to acquire technical knowledge about self-care from authoritative sources, (h) a repertoire of self-care skills adapted to the performance of self-care operations, (i) ability to order

discrete self-care actions into prior and subsequent actions with the goal of achieving regulatory goals of self-care, and (j) ability to consistently perform self-care operations (Orem, 1991, p. 155).

2. One subject's self-care operations were measured by way of the HIV Self-Care Operations for Subject Response Interview, which was based on the investigator's extrapolation of questions pertinent to persons infected with HIV that were derived from the list of self-care operations in Orem's fourth edition text (Orem, 1991, pp. 150-151). No reliability information was available regarding the questions. Since the literature involving the measurement of self-care of persons infected by HIV is in its infancy, the researcher had to rely on his many years of experience in the management of HIV disease to create questions for the instrument that both (a) addressed the three stages of self-care operations from the theory (Orem, 1991, pp. 150-151), and (b) reflected the kinds of information accrual, decision-making, and planning for action that are associated with the daily lives of persons infected by HIV.

The questionnaire consisted of nine categories of questions that followed the phases of the self-care operations outlined by the theory. For example, under the estimative type of self-care operations, the theory described the investigation of internal and external conditions and factors significant for self-care (Orem, 1991, p. 150). The result of enacting this operation would be empirical knowledge of self. The questionnaire asked the subject to describe the sources of information obtained with emphasis on information about HIV disease, to identify whether the information was new, and to predict ways that the information will or will not get incorporated into daily self-care practices. A copy of the questionnaire is found in Appendix E.

Expert validity was obtained by compiling the comments of three nurse experts regarding the congruence between the generic list of self-care operations

from the theory and the list of HIV-specific self-care operations provided by the investigator. The generic list of self-care operations was mailed to these three experts with the request that the raters identify (a) whether the items were congruent with the self-care operations proposed by the theory, and (b) whether the items were consistent with self-care operations of persons with HIV disease. The experts were chosen according to their expertise in the management of persons with HIV disease and according to their expressed knowledge and interest in self-care deficit theory.

A second instrument to measure self-care operations was developed by the investigator. Completion of the HIV-Related Self-Care Behavior Checklist, a Likert-type six-point 15-item scale, constituted a measurement of self-care operations as well. On a scale of 1 (never) to 5 (at least once a day), subjects were asked to rate the frequency of such self-care behaviors as "Take vitamins or herbs for your health" and "Take AZT/ddI/ddC, alone or in combination." Items that were not applicable were scored with a 6. A summated score was created from the scale.

It was necessary to create a summated score because subjects needed to be rated according to their overall enactment of self-care operations. In turn, the overall rating of self-care operations was used to substantiate proposed theoretical contributions of self-care operations to self-care agency. Thus, higher scores on the instrument were considered representative of greater levels of the concept of self-care operations (Kerlinger, 1986).

This second instrument was necessary because only one subject completed the interview format, whereas all subjects completed the Likert-type self-care behavior instrument. The instrument received expert panel review prior to testing. Content validity for instrument items was achieved by literature review with a primary question guiding the review of literature. Items were formulated from the

literature based on the question of what was known to date regarding the pattern of health-maintaining practices followed by persons who were HIV seropositive who had 200 T helper cells or less. The review of literature about standard self-care practices was presented in chapter two. No indices of reliability were available prior to the instrument's use in this study.

3. Demographics were measured using a Demographic Inventory developed by the investigator for this study. Demographic forms used by the investigator in following subjects enrolled in drug studies for persons with less than 200 T helper cells were utilized in the development of the demographic inventory for this study, because of their standardization among many more subjects than have been enrolled in any other kind of study involving the population of interest. The demographics inventory provided data regarding the following variables: 1) age, 2) educational status, 3) employment status, 4) occupation, 5) ethnicity, 6) living arrangements (e.g. living along, living with lover or spouse, etc.), and 7) other demographic variables as needed. Additional demographic-like data were obtained by way of the HIV-Specific Therapeutic Self-Care Demand Inventory. A complete discussion of these additional items appears under the presentation of the therapeutic self-care demand in the next section of this chapter. The Demographics Inventory is located in Appendix E.

4. HIV-Specific Therapeutic Self-Care Demand was assessed by an instrument developed by the investigator for this study, which was the HIV-Specific Therapeutic Self-Care Demand Inventory. The instrument is divided into two parts. In the first part, there are nine questions involving the subject's HIV-related illnesses along with questions about current drug, vitamin, and other therapies. In the second part, 14 items that measure intervening variables of the therapeutic self-care demand that were not included in the demographic inventory

are presented. A copy of the HIV-Specific Therapeutic Self-Care Demand Inventory is available in Appendix E.

Table 1

Items Used to Measure the Therapeutic Self-Care Demand

Construct Name	Inventory used to measure construct	Items from the inventory
Therapeutic Self-Care Demand	HIV-Specific Therapeutic Self-Care Demand Inventory	**Health Deviation Self-Care Demand** Item 7: Year first identified as HIV seropositive? Item 8: Last T helper cell count Item 12: History of opportunistic infections **Methods of Treatment** Item 10: PCP prophylaxis Item 13: Hospitalizations Item 14: Medications **Total Score** Items 7 + 8 + 12 + 10 + 13 + 14

Nine items from the first part of the scale measured the health-deviation self-care requisites of the sample with HIV disease along with their associated treatments or diagnostic tests. For example, one item asked "When were you first diagnosed as HIV positive after testing?" The following item, "Last T helper cell count," was considered a diagnostic test strongly associated with years since

infection. The response to the latter item was considered nominal data, with possible entries of subjects ranging from 0 T helper cells to 200 T helper cells.

Because T helper cells decline across time in serial measurements of persons with HIV infection, the date of the last T helper cell count was noted in the following item as nominal data. Two items measured the drugs taken by subjects to prevent infection by a common opportunistic protozoan, Pneumocystis carinii, and to treat active infections, including infection by the retrovirus HIV. These were also scored as ordinal data. Absence of the drug was scored as zero, and presence or use of the drug was scored as one. The items asked, " Which of the following do you use to prevent getting PCP? (Check all that apply)" and "What are the medications that you use? "

At the time that the instrument was developed in early 1991, there was no definite ruling from the Centers for Disease Control and the World AIDS Federation that the diagnostic category of AIDS would be defined according to absolute T helper cell counts. Therefore, one of the questions asked "Do you have an AIDS diagnosis?" The question was later obviated by the change in the definition of AIDS, which as of January of 1992 was the presence of an absolute T helper cell count of 200 cells. At the time that data were collected in the Fall of 1991, many of the subjects recruited for the study had already learned about the change in the definition. It was not assessed which subjects knew of this change, nor was it assessed whether subjects knew that the date of the change in the diagnostic definition was slated to occur in 1992 and not at the time that they were completing the instruments.

A total score was developed from the items listed in table 1. This score was considered the operational definition of the therapeutic self-care demand for purposes of this study. Each item counted equally in weight in the calculation of the total score for the therapeutic self-care demand. The six items measured: (a)

health deviation self-care requisites (three items), and (b) methods used to treat the self-care requisites (three items).

The intervening variables, known in self-care deficit theory as **basic conditioning factors**, have been hypothesized to create variance in both the total score of self-care agency and the therapeutic self-care demand. The basic conditioning factors include: (a) age, (b) gender, (c) developmental state, (d) health state, (e) sociocultural orientation, (f) health care system factors, (g) family system factors, (h) patterns of daily living, (i) environmental factors, and (j) resource availability and adequacy. The basic conditioning factors have been linked to items used to measure them in table 2.

Table 2

Basic Conditioning Factors, Instrument of Measurement, and Item Descriptor

Factor Descriptor	Instrument	Item
Age	Demographics Inventory	Item 1: Age___(fill in your age in years)
Gender	[Study eligibility required male gender]	[All subjects were men]
Developmental State	HIV-Specific Therapeutic Self-Care Demand Inventory	Item 6: In which of the following arenas have you been out of the closet about your sexual identity?
Health State	Self-as-Carer Inventory (not part of total score for self-care agency)	Two items: a) How would you rate your health at this moment? b) How would you rate your health in general?

Sociocultural Orientation	Demographics Inventory (DI) and HIV-Specific Therapeutic Self-Care Demand Inventory (TSCD)	DI: Item 2: Educational level Item 3: Occupation Item 4: Years in occupation Item 5: Ethnicity Item 6: Living arrangements TSCD: Item 1: City of origin Item 2: How long in Bay Area? Item 3: Make-up of neighborhood?
Health Care System Factors	HIV-Specific Therapeutic Self-Care Demand Inventory	Item 15: How many times have you seen your physician? Item 16: Do you use the services of other providers?
Family System Factors	HIV-Specific Therapeutic Self-Care Demand Inventory (TSCD) and Demographics Inventory (DI)	TSCD: Item 4: How many friends do you have? Item 5: Have you experienced gay spousal living or heterosexual marriage? DI: Item 6: Living arrangements
Patterns of Daily Living	HIV-Specific Therapeutic Self-Care Demand Inventory	Item 22: Identify which activities are patterned in your daily life [Interval scale]
Environmental Factors	HIV-Specific Therapeutic Self-Care Demand Inventory	Item 23: What is the effect of the following factors on your health? [Interval scale]

Resource Availability and Adequacy	Demographics Inventory (DI) and HIV-Specific Therapeutic Self-Care Demand Inventory (TSCD)	DI: Item 7: Your income last year TSCD: Item 20: Does your income cover your health care needs? Item 21: If no (to 20), how much more do you need? Item 17: Use of community services Item 18: Community service of preference Item 19: Rate the community service of preference

Age was measured with one question, which provided nominal data. The data were converted into categorical scores for purposes of grouping. The scoring of age data used measures of central tendency for categories. The **gender** of subjects for the study was male only.

Developmental state was only considered in reference to self-identification as gay for purposes of this study. Therefore, one instrument item asked the question "In which of the following arenas have you been out of the closet about your sexual identity?" Responses were scored as ordinal data with 0 = variable not present and 1 = present. The descriptors for the item are included in the HIV-Specific Therapeutic Self-Care Demand Inventory, copy of which is found in Appendix E.

Health state was measured by way of two items from the Self-as-Carer Inventory. The scores from the items were not combined, but rather left independent of each other for purposes of this study. The two health state items were Likert-type scales.

Sociocultural orientation was measured by a large number of items. Items to measure the variable of sociocultural orientation appeared on either the Demographics Inventory or the HIV-Specific Self-Care Demand Inventory. The items were scored separately from each other.

Health care system factors were measured by way of two questions from the HIV-Specific Therapeutic Self-Care Demand Inventory. Both items addressed the use of services provided by established disciplines of health care providers.

Family systems were measured by way of two variables on this instrument and by one variable from the Demographics Inventory. The two items from this instrument were: 1) "How many friends do you have that you can call at any hour of the day or night to ask for help?" and 2) "Have you experienced (been part of) one of the following?" The second question asked whether the subject had been part of 1) 1 = heterosexual marriage, or 2) 2 = gay or lesbian lovers (spousal). The one item from the Demographics Inventory was "Living arrangements (check as many as apply)." A copy of the Demographics Inventory is included in Appendix E.

The use of the **health care system** was measured by the items listed in table 2. Scores from an ordinal scale were used to assess frequency of use of services rendered by the subject's physician. The question asked "How many times in the past thirty days have you seen your physician or other health care provider who provides you with primary health care?" One other health care system use item was "Do you routinely use the services of any of the following health care professionals?"

The variables of **patterns of daily living** and **environmental factors** from the HIV-Specific Therapeutic Self-Care Demand Inventory were developed as interval subscales of the instrument. The patterns of daily living variable consisted of 23 items in response to the question: "Of the following activities of daily living,

identify which activities are patterned in your daily life." Evenly distributed intervals between a 6-point Likert scale ranged from 1 = very strong pattern to 6 = no pattern at all. Items were developed according to the idea that they would be patterned in the lives of most people. A copy of the subscale is included in the HIV-Specific Self-Care Demand Inventory in Appendix E.

A summative score was developed for the subscale with possible total scores ranging from 23 to 138. A lower total score suggested the presence of stronger patterns of daily living for the subject. A higher score reflected the absence of strong patterns in activities of daily living measured by the subscale.

The variable of environmental factors also became a subscale of the larger inventory known as the HIV-Specific Therapeutic Self-Care Demand Inventory. It consisted of 20 items and, like the subscale above it on the instrument, was a six-point Likert scale. The question for the subscale was "What is the effect of the following factors on your health?" The items were considered evenly distributed across the six intervals. Items emerged from the literature and from expert panel review, and reflected prevailing beliefs about the relationships between the impact of the subject's environment on health. Examples of the scale are: 1) how much money you have, 2) a clean, neat house, and 3) shopping located close to home.

A summative score was developed for this subscale. Total scores could range from 20 to 120. A lower total score was representative of the overall impression that the items created a great effect on health. A higher score suggested that the items mentioned had little or no effect on health. No data transformation was completed since the data was from a Likert-type scale.

Resource availability and adequacy was measured by the item from the Demographics Inventory: "Your income last year." Income was scored as ordinal data. The variable of income was measured again in the index from the HIV-Specific Therapeutic Self-Care Demand Inventory. The item asked "Does your

income each month combined with your health insurance benefits cover your health needs in a given month (30 days)?" An answer of No to this question requested an answer to the following question: "On the average, how much more money in a given month do you need to cover your health care costs?"

Community services also figured into measurement of the variable of resource availability and adequacy. The item asked "Which of the following community services have you used at any time in the past to deal with HIV infection?" A summative score of services was created from the tally of services used.

The community service of preference from the list of services selected under the prior question was an item that asked "Of the services that you checked under question #18 above, which service have you used most often?" The number of the service from the preceding question was to be recorded in the blank after the question.

The adequacy of the service of the community preference was scored on an ordinal scale. The question was "Just considering the service that you have used most often, rate the adequacy of this service according to the following."

No reliability and validity data were available for the HIV-Specific Therapeutic Self-Care Demand Inventory. Again, expert validity was obtained from the panel of nurse experts convened to provide expert review for all of the instruments developed for this study. The panel of three nurse experts were asked to identify in this instrument (a) whether the items on the instrument were representative of the basic conditioning factors from the theory, (b) how they would change the wording and/or approach to item development if they disagreed with an item, and (c) whether the HIV disease markers of the inventory and their associated symptom management items were consistent with the experts' understanding of the phenomenon measured.

Responses from the experts required the substitutions of three items for items proposed, and required substitutions within the last two subscales: (a) patterns of daily living, and (b) effects of the environmental factor on health. The three items that required substitutions were: (a) adding the wording, "...do you have that you can call at any time of the day or night" to the question "How many friends do you have?"; (b) adding HIV antibody status prior to 1985 to the item that asked "When were you first identified as HIV positive after testing?"; and (c) adding drugs to treat Mycobacterium avium intracellulare and Mycobacterium tuberculosis to the list of medications. These added drugs were Lamprene, Myambutol, I.N.H., Rifampin, and clorithromycin. Items added to the measure of patterns of daily life were: (a) drinking alcohol and (b) practicing a hobby. Items added to the effects of the environment were: (a) how much debt you have, (b) access to alternative health care, and (c) feeling accepted as a gay person.

Procedure

The investigator alone collected all data for this study, thus ensuring uniformity in data collection. No discussion of the instruments was part of the data collection, except when necessary to explain an item that was unclear to the subject.

Subjects who entered the pentamidine unit were offered the Self-as-Carer Inventory, the demographics inventory, the HIV-Related Self-Care Behavior Checklist, and the HIV-Specific Therapeutic Self-Care Demand Inventory in a study packet that was stapled together. A cover sheet in the data collection packet briefly described the study and the criteria for entry into the study. Subjects were asked to read the cover sheet and to ask questions of the investigator. Following satisfactory answers to the questions of the subject, the investigator invited the subject to read and sign the informed consent.

Those not interested or not eligible to complete the packet were asked to return the packet to the investigator. Anonymity of subjects was protected by separating the informed consents from the study packets and by reminding study subjects that they should not identify themselves in any fashion on the study packet.

The one subject for comprehensive follow-up using the self-care operations inventory and a microcassette recorder over 90 days was recruited from among subjects well known by the researcher from other studies conducted by the researcher. The subject was approached by personal interview within the context of office visits with the investigator. First, the study was explained and questions were fielded from the prospective subject. Then, the subject received a standard study packet, which included: 1) the Self-as-Carer Inventory (SCI), 2) the Self-Care Operations Inventory, 3) the Demographics Inventory, 4) the HIV-Related Self-Care Behavior Checklist, and 5) the Therapeutic Self-Care Demand Inventory. The study packet also contained a cover sheet identical to that used with the 300 subjects. When the subject agreed to participation, an informed consent was obtained.

After signing the informed consent, the subject was trained in the use of the microcassette recorder and was provided microcassette tapes, batteries, and printed instructions for maintenance of the unit. The subject also received a phone number by which the subject could reach the investigator should problems arise with the unit. Instructions in returning used cassettes and completed instruments also were provided.

Data Analysis

Since this study attempted to clarify the empirical relationships between constructs and concepts from study questions derived from self-care deficit theory,

the procedures for analyzing data were determined by the nature of the data obtained (e.g. whether it was nominal, ordinal, or interval) and by the manner in which the constructs were related to each other according to the theory. Procedures for analyzing data to identify these relationships are presented below, according to the order of the study questions as they were presented in chapter two.

Research Question One

What is the congruence among theoretical components of self-care agency, the basic conditioning factors, and factors isolated from the Self-as-Carer Inventory?

Not all component concepts of the construct known as self-care agency were isolated for data collection by this study. Instead, only the concepts of self-care operations, the power components, and the basic conditioning factors were examined as contributors to the overall scaled score of self-care agency from the Self-as-Carer Inventory. Therefore, there were three variables examined under the first research question. They were: 1) self-care agency, as scored by factor and total scores on the Self-as-Carer Inventory, 2) self-care operations data obtained from two sources, the HIV-Related Self-Care Behavior Checklist and the transcribed data from the verbal transmissions, and 3) the basic conditioning factors as measured by the individual items from the HIV-Specific Therapeutic Self-Care Demand Inventory and health state from the Self-as-Carer Inventory.

Pearson Product-Moment Correlation was used to identify relationships between total scores on the Self-as-Carer Inventory and total scores from the HIV-Related Self Care Behavior Checklist. Analysis of transcribed data of self-care operations was done according to methods identified by Strauss (1987). Themes that emerged from the analysis of transcribed data were used to further elucidate the factors that emerged from the paper and pencil instrument, the HIV-Related Self-Care Behavior Checklist. The relationship between the themes from

the transcribed data and the factor scores will be discussed under study question number 3. Again, the factor scores and total scores from the HIV-Related Self-Care Behaviors Checklist were the measurement of self-care operations.

Forward stepwise multiple regression was employed to determine the relative contribution to the summated score from the Self-as-Carer Inventory from component concept of self-care agency that were investigated by this study. The concept was **self-care operations**, as quantified by the summated score from the HIV-Related Self-Care Behaviors Checklist.

The relative contributions of this concept to the overall self-care agency score was distinguished from the contribution to the overall score from the basic conditioning factors. It was necessary to distinguish the concept from the basic conditioning factors because self-care agency has been theorized to vary according to the basic conditioning factors.

Congruence between the factors to emerge from the Self-as-Carer Inventory and the power components from the theory was examined. The congruence between the two was determined by the development of a table that compared each power component with corresponding factors isolated from the principal components analysis of the Self-as-Carer Inventory.

Factor analysis of the Self-as-Carer Inventory was carried out using both varimax and oblique methods of factor rotation. The intent of using both rotations was to determine the ability of either method to relay latent variables that approximate a structure similar to the ten power components, which is the second of the two component concepts of self-care agency identified for study here.

Research Question Two

What are the relationships among T helper cell counts, self-care practices, and the total score from the HIV-Related Self-Care Behaviors Checklist?

Descriptive and inferential statistics were used to analyze this question. Measures of central tendency and frequency tables first were used to analyze the total score to the instrument called the HIV-Related Self-Care Behaviors Checklist.

The instrument used to measure self-care practices had not been used prior to this study. The initial analysis of the instrument involves the report of Cronbach's alpha to measure the internal consistency of items from the instrument. Factor analysis using a Varimax rotation of factors was then used to identify factor clusters. CRUNCH version 4.0, a statistical package for the personal computer, was used for factor analysis. Factors that emerged with Eigenvalues greater than or equal to one were accepted (Nunnally, 1977), and were analyzed for their congruence with the literature on the self-care practices of this population.

Because the health state of subjects can be grouped according to absolute number of T helper cells, with 50 T helper cells used as the discriminator between subjects who tend to be more symptomatic (with less than 50 T helper cells) and those who are less symptomatic (with more than 50 cells), subjects have been grouped accordingly. There were no subjects with exactly 50 T helper cells. One group included subjects with less than 50 T helper cells, and the other group included all those with more than 50 T helper cells. Therefore, the data from the HIV-Related Self-Care Behavior Checklist were analyzed first with Pearson Product Moment Correlation to identify the relationship between summated scores from the instrument and actual T helper cell counts.

Research Question Three

What are the self-care operations of an HIV seropositive gay man with less than 200 T helper cells, and how do these self-care operations change across time in serial measurements?

Self-care operations have been measured by way of two instruments in this study. Analysis of text using a categorical approach was already mentioned under question one, and it was the approach used to identify self-care operations from the transcribed data of one subject. However, it is under this third question that there was a full elucidation of the categories from the transcribed text as they reflected the three kinds of self-care operations proposed by self-care deficit theory. The categories that emerged from the transcribed recordings were consistent with the transition from knowledge to action proposed by the theory, because the questions that guided the recordings were generated from the theory as mentioned above.

Transcribed data were analyzed according to the techniques of dimensional and constant comparison analysis. Such an analysis ensures that conceptualizations emerge from data to specify and define the context and consequences of the phenomena under review (Strauss, 1987).

Open coding, the first step in the analysis of the transcribed text, began following the first thirty days of recorded sessions. According to the method, data collection and analysis must occur simultaneously and continuously to demonstrate early congruence and divergence with self-care deficit theory.

Open coding of the data collected for this research revealed several repetitive themes or concepts. A partial list of the early concepts gleaned from the first thirty days of transcribed data included: (a) the sources and places for information gathering, (b) the conditions under which information can be acquired, (c) the knowing body, (d) caring for self, (e) determining the

usefulness of information, (f) monitoring self-care behavior, (g) activities on days off versus days at work, (h) conditions for information accrual and behavioral change, and (i) "let me just be and not be sick today."

The researcher asked what was going on in the data as the next step of the method. Categories began to be formed based on these early codes. During this phase of the analysis, sets of actions and their interactions were identified. These were related to conditions, conditional categories, and intervening conditions. Over time, as the open coding continued, the contexts of the conditions formed new linkages between emerging categories. Then, consequences and further conceptual linkages for categories themselves became defined.

Early categories of the data included the following: (a) learning and the readiness to learn, related to place and day of the week, (b) learning not always with intent to learn, (c) useful information, (d) routine for self-care, and (e) conditions for altering the routine for self-care.

Numerous memoranda (memos) were recorded during the phases of open coding. One early memo noted that the subject had knowledge of his own body that was superior in one instance to the expert knowledge of his ophthalmologist. The subject remarked that he had been screened for a routine visit with his ophthalmologist and that it was possible that he had a recurrence of retinitis caused by cytomegalovirus infection. The memo read:

> Wonder if he has stopped paying attention to his Amsler grid just because he can now visualize his computer screen at work without any curvature to lines.

In fact, subsequent observations of the code that was identified as "the knowing body" revealed that the subject had ceased to attend to the so-called diagnosis of recurrence. Later his ophthalmologist concurred with the assessment. There had been no recurrence after all.

As the categories became expanded and revised, other memos emerged. For example, with reference to the category of day of the week, one memo read:

> He needs time just to be without the vision of himself as sick. No mention of work; he's going to play hard.

The memo revealed the time consciousness of the subject with reference to how and when information was acquired. It also suggested that he might not seek out information on his days off because he does not see himself as HIV-infected and sick on the weekends.

Analyzing data and placing it side-by-side with self-care deficit theory with regard to context, condition, action/interaction, and consequences of action was the next step of the analysis here. Thus, the analysis of data at this stage processed the categories according to a greater world of meaning that was inherent in the questions from self-care deficit theory that had been the frame for the questions posed to the subject.

Categories were examined, expanded, merged, and finally clarified by the process of writing and analyzing memos. New questions emerged from the data after each level of memos were written and later re-examined. Questions that were left to the researcher at this point were fielded in discussion with colleagues who were experts in (a) HIV disease management, (b) self-care deficit theory, or (c) the method of textual analysis used for the study. The discussion of these questions further clarified and expanded the codes and categories.

The core categories were selected over other competing categories for their ability to differentiate the variation in the data. The core categories to emerge were: (a) Learning at Work, (b) Flexible Self-Care, and (c) Every Day a Well Day.

When the sufficiency of both category saturation and depth of conceptual linkages were reached, the analysis of the data were concluded. The analysis of

data determined the congruence between the self-care operations of this one subject and the generic list of self-care operations that appeared in the fourth edition of Orem's text (1991) on self-care deficit theory.

Research Question Four

Are changes in the activation of self-care operations correlated with changes in Self-as-Carer Inventory scores?

The total scores from the Self-as-Carer Inventory instruments completed by the one subject who completed daily recordings have been analyzed for test-retest reliability on an item-by-item basis using the Pearson Product Moment Correlation. It was necessary to analyze the instruments on an item basis because all four times that the Self-as-Carer Inventory was completed the same total score was obtained. Therefore, any variation between instruments had to have occurred on individual items.

Changes in the item scores and total scores of the one subject's responses to the HIV-Related Self-Care Behavior Checklist have also been correlated with Pearson r's with item scores on the Self-as-Carer Inventory. Finally, the core categories from the transcribed data were compared with the factors to have emerged from the factor analysis of the HIV-Specific Self-Care Behavior Inventory.

Research Question Five

Is the calculated value of the therapeutic self-care demand correlated with Self-as-Carer Inventory scores?

The self-acknowledgment of health-deviation self-care requisites and the methods used by research subjects to respond to these requisites is the definition of the **therapeutic self-care demand** used by this study. The definition was operationalized as the composite score of paper and pencil items used to measure the health-deviation self-care requisite relative to HIV infection and the methods

used to treat the health deviation self-care requisites. These six items appeared on the HIV-Specific Therapeutic Self-Care Demand Inventory. The six component items of this variable were presented at length in the discussion of the definition of the concept earlier in this chapter.

This definition of the therapeutic self-care demand guided the researcher in formulating the paper and pencil instrument called the HIV-Specific Therapeutic Self-Care Demand Inventory. Particular health-deviation self-care requisites of the person infected by HIV and with less than 200 T helper cells were gleaned from the literature of opportunistic infections. Methods used to combat these requisites were also gleaned from the same literature. Combined self-care requisites and methods for treating opportunistic infections comprised the questions pertaining to the therapeutic self-care demand.

No total score of the therapeutic self-care demand was available prior to the use of the instrument in this study. Therefore, descriptive statistics for the composite score were first analyzed to determine the range of scores, as well as measures of central tendency.

The total score of the therapeutic self-care demand was correlated with the summated score from the Self-as-Carer Inventory to determine the direction of the relationship and the significance of the relationship. Nesting the two parts of the sample according to T helper cell count was applied to the data as a secondary analysis.

CHAPTER 4

Results of the Study

Introduction

Three hundred one (301) subjects were enrolled in the study. All but one of the subjects were approached for participation in the pentamidine unit of a local medical center. The remaining one subject was selected by the researcher according to his ability and willingness to complete the daily audio recordings for the study.

This chapter is divided into three sections: (a) sample characteristics, (b) reliability and validity of study instruments in the sample tested, and (c) the reports of findings relative to the study questions. Both tabular and narrative reports have been used to clarify the analyses from the study.

Sample Characteristics

The sample was characterized according to age, education, occupation and years in job, ethnicity, living arrangements, income, city of origin, duration of time having lived in the geographic area of the study, make-up of the neighborhood of residence, family system factors, developmental factors, and the use and adequacy of health-related services. All of these characteristics were summarized from data on the Demographics Inventory and the HIV-Specific Therapeutic Self-Care Demand Inventory. The sample characteristics are equated with the basic conditioning factors of self-care deficit theory.

Table 3

Measures of Central Tendency for Age

Variable	Mean	Median	Mode	Range
Age	39.5	40.0	40.0	21-61

n = 301, SD = 5.9

The average age (Table 3) for the sample based on responses to the Demographics Inventory was 39.5 years, with a median age of 40 and a range of 26 to 61 years. A frequency graph of age revealed the largest percentiles of groupings of age in the 32 to 33 year category, the 39 to 40 category, and the 43 to 44 year category. Age was recorded without category as a continuous variable. Age was later categorized for purposes of analyzing the study questions. The categories were: (a) less than or equal to 27 years, (b) 28 to 33 years, (c) 34 to 41 years, and (d) 42 years of age or more. These categories were based on the frequency groupings reported here.

Education, a categorical variable on the Demographics Inventory, was classified as follows: (a) grammar school, (b) high school, (c) some college, (d) associate degree, (e) four year degree, (f) graduate degree, and (g) technical school. Subjects were asked to rate themselves according to the highest level of education completed. The mean of 4.58 and median of 5.00 provided the finding that the sample was college-educated for the most part. Sixty-two (20.67%) sample members had achieved graduate degrees.

Years in job, a categorical variable from the Demographics Inventory, was categorized according to the grouping of years. A score of one corresponded with less than one year on the job; 2 represented one to two years; 3 was two to five

years; and 4 was greater than five years. The mean score was 3.67, with a median

Table 4

Occupations of the Sample

Category of occupation	Frequency	Percentage
Professional, technical		
architects, computer specialists, librarians, scientists, health professionals, teachers, writers, artists, and entertainers	116	41.28%
Manager, administrator, sales		
retail and wholesale buyers, health administrators, office managers, public administrators, restaurant managers, sales representatives, advertising agents	80	28.47%
Clerical		
bank tellers, bookkeepers, cashiers, estimators, file clerks, insurance adjustors, library assistants, mail carriers, receptionists, secretaries, ticket agents, proofreaders	29	10.32%
Service Workers		
bartenders, cooks, waiters, health aides, practical nurses, airline flight attendants, hairdressers, child care workers, fire fighters, police, guards	20	7.12
Other Categories: (Craftsman, Equipment Operator, Transport Operator, Farmer, and Laborer)	36	12.81%

n = 281
no response = 19

score of 4.00. Greater than five years represented the greatest percentage of responses (221; 76.7%), followed by two to five years (66; 16.67%), less than one year (12; 4.17%), and one to two years (6; 2.08%).

Occupation (Table 4) was classified as nominal data on the Demographics Inventory, which requested subjects to write their job titles on a blank line. Data were then categorized according to groupings of occupations as follows: 1) professional, technical (e.g., architects, teachers, artists), 2) manager, administrator, sales (e.g., retail buyers, office managers, health administrators), 3) clerical (e.g., bank tellers, cashiers, secretaries), 4) craftsman (e.g., mechanics and repairmen), 5) equipment operator (e.g., garage workers, packers and wrappers), 6) transport operator (e.g., bus drivers, delivery people, and taxi drivers), 7) service worker (e.g., bartenders, cooks, police, and firefighters), 8) farmer/ farm laborer, 9) laborer (e.g., construction helpers, vehicle washers, and warehouse workers), and 10) retired or out of work.

. One hundred sixteen (116; 44.96%) were categorized as professional, technical in occupation. The frequency scores were then distributed among manager, administrator (80; 31.01%), clerical (29; 11.24%), and service worker (20; 7.75%). Fewer than eight responses appeared in each of the 5 remaining categories, which accounted for the five remaining responses.

There were eight categories for ethnicity (Table 5) on the Demographics Inventory: 1) American Indian, 2) African American (Black), 3) Hispanic, Latino, 4) South Pacific Islander, 5) Southeast Asian, 6) Caucasian, 7) Taiwanese, Mainland Chinese, and 8) Other. The largest percentage of responses were Caucasian (232; 77.33%), followed by Hispanic, Latino (33; 11%), and African American (18; 6%).

Table 5

Ethnicity of the Sample

Ethnic category	Responses*	Percentage
Caucasian	232	77.33%
Hispanic, Latino	33	11%
African American (Black)	18	6%
Other categories: Southeast Asian, South Pacific Islander, Native American, Taiwanese/ Mainland Chinese	17	5.67%

n = 300

* one subject for audio recorded data were Caucasian

There were five or fewer responses for each of the remaining categories, each comprising 1-5% or less of the sample.

Table 6

Living Arrangements

Category of living arrangement	Responses	Percentage
Live alone	125	41.67%
Live with lover/spouse	96	32%
Live with roommates	76	25.33%
Other categories: Live with parents/siblings, Live with children	4	1%

n = 291

no response = 10

The variable of living arrangements (Table 6) on the Demographics Inventory asked whether respondents 1) lived alone, 2) lived with roommates, 3) lived with lover or spouse, 4) lived with parents or siblings, or 5) lived with children. The inventory asked respondents to check as many as applied. However, all respondents checked only one category each. The largest majority of responses were to the category of live alone (125; 41.67%), followed by live with lover or spouse (96; 32%) and live with roommates (76; 25.33%).

The variable of income (Table 7) on the Demographics Inventory was also categorical. It asked responses according to the instructions: Your income last year (just your income; check one). Possible responses were 1) was enough to live comfortably in the Bay Area, 2) was enough to live in the Bay Area, but you were not comfortable, 3) was not enough to live in the Bay Area; you needed public or private assistance, and 4) no response.

Table 7

Income

Income category	Responses	Percentage
Was enough to live in the Bay Area	212	71.14%
Was enough to live in the Bay Area, but was not comfortable	48	16.11%
Was not enough to live in the Bay Area	27	9.06%
No response	11	3.69%

n = 298
no response submitted = 3

The first category accounted for 71.14% of the sample. This was followed by 48 responses to category 2 (16.11%) and 27 responses to category 3 (9.06%).

Eleven chose no response (3.69%). The sample included at least two respondents who drove to the Bay Area from distances of more than 100 miles just to receive their medical treatment. This information was gleaned from data written into the margins of the inventory.

The remaining demographic data appeared on the HIV-Specific Therapeutic Self-Care Demand Inventory, because they were pertinent to the assessment of basic conditioning factors, which were variables from the theory

Table 8

City of Origin, Length of Time in the Bay Area, and Composition of the Neighborhood

Variable category	Responses	Percentage
City of origin		
Urban	163	55.82%
Semi-urban	88	30.14%
Small town/Rural	41	14.04%
Length of time in the Bay Area		
More than 5 years	215	72.15%
2 to 5 years	55	18.46%
6 months to 2 years	28	9.40%
less than 6 months	1	<1%
Composition of the Neighborhood		
Mixture of heterosexual and gay	191	64.09%
Mostly heterosexual	66	22.15%
Mostly gay and lesbian	40	13.42%

under review. Basic conditioning factors include all of the demographic variables from the Demographics Inventory as well as the responses to the following items from the HIV-Specific Therapeutic Self-Care Demand Inventory.

Nominal data were obtained for responses to the query city or town of origin. City of origin (Table 8) was considered one of the measures of sociocultural orientation from the list of basic conditioning factors. Nominal data were converted to categorical data based on the following formula: (a) urban environment with 100,000 or more population based on the 1950 census, (b) semi-urban environment with less than 100,000 but greater than 20,000 population based on the 1950 census, and (c) less than 20,000 population based on the census from 1950. All subjects were born in the United States. The mean score was 1.58, with a median of 1.00 and mode of 1.00. Urban responses formed the majority of the responses (163; 55.82%), followed by semi-urban (88; 30.14%) and rural or small town (41; 14.04%). The 1950 census was used because it was taken at the time that the majority of the sample was born based on the average age for the sample.

The length of time residing in the Bay Area (Table 8) varied among respondents. Length of time residing in the Bay Area was considered one measure of sociocultural orientation from the basic conditioning factors. The categorical responses included: (a) less than 6 months, (b) 6 months - 2 years, (c) 2 - 5 years, and (d) greater than 5 years. There were no responses to less than 6 months. The mean score was 3.62, with a median of 4.00 and a mode of 4.00. The majority of responses were to the category "greater than 5 years" (215; 72.15%). In descending order of frequency, the responses were 2 - 5 years (55; 18.46%) and 6 months - 2 years (28; 9.40%).

The composition of the neighborhoods of the respondents (Table 8) was included under the basic conditioning factor known as environmental factors.

Composition was defined as the perceived predominance of heterosexual or homosexual neighbors in the neighborhood. Thus, the item from the scale asked, "How would you characterize the make-up of your neighborhood?" Response s were categorized according to: (a) predominately gay and lesbian, (b) predominately heterosexual, and (c) a mixture of the two. The majority labeled their neighborhoods as a mixture of the two (191; 64.09%), followed by predominately heterosexual (66; 22.15%) and predominately gay and lesbian (40; 13.42%). The mean score was 2.51, with a median of 3.00 and a mode of 3.00.

Table 9

Measurements of Family Systems

Category of the family system	Responses	Percentage
How many friends do you have?*		
4 or more	99	33%
3	95	31.67%
2	80	26.67%
1	21	7%
None	5	1.67%
Have you been part of the following?		
Gay lovers/spousal	258	96.99%
Heterosexual marriage	8	3.01%
	n = 266	
	no response = 35	

*How many friends do you have that you can call at any time of the day or night to ask for help?

Family system (Table 9), as a basic conditioning factor, was measured by the variables of friends and spousal partnerships on the inventory. The question

about friends asked, "How many friends do you have that you can call at any hour of the day or night to ask for help?" The categorical responses were: (a) none, (b) one, (c) two, (d) three, and (e) four or more. The mean score was 3.87, with a median score of 4.00 and a mode of 5.00. The majority of responses were from the end of the scale with three or more friends. The largest percentage of responses came to the qualifier of four or more friends (99; 33%), followed by three friends (95; 31.67%), two friends (80; 26.67%), one friend (21; 7.00%), and no friends (5; 1.67%).

The second of two measures of family system (Table 9) was the question, "have you experienced (been part of) one of the following?" Responses called for selecting between (a). heterosexual marriage and (b) gay or lesbian lovers (spousal). The question was intended to generate information from respondents about either one or the other. Involvement in both was precluded by design and intent. However, eight respondents answered that they had experienced both of these family arrangements. Their responses were not included in the totals that follow. The majority of responses were to the category of gay lovers (258; 96.99%), with only eight (3.01%) identifying their involvement in heterosexual marriages. No response to this item presumed that there was no prior or current involvement in one of these partnerships. There was no response from 27 subjects.

Table 10

Disclosure of Sexual Orientation to Family, Friends, Co-Workers, and Supervisor

With whom the disclosure has been made	Responses	Percentage
with parents	237	78%
with some friends; not with all	72	24%

with all friends; not all acquain.	104	35%
with all friends, all acquaintances	122	41%
with co-workers, not the boss	67	23%
with co-workers and the boss	155	52%
not out of the closet with anyone	4	1%

The final measure of basic conditioning factors and the final measure of demographics for the sample to be reported here was the question, "In which of the following arenas have you been out of the closet about your sexual identity (check all that apply)?" The question was created as a measure of the basic conditioning factor known as developmental state. Arenas in which the inventory categorized the variable of being out of the closet included: (a) with parents, (b) with some friends but not with others, (c) with all friends but not with all acquaintances, (d) with all friends and acquaintances, (e) on the job with some co-workers but not with the boss, (f) on the job with all co-workers and with the boss, and (g) not out of the closet with any of the above.

Most respondents reported being out of the closet about their sexuality with their parents (237; 78.40%). These responses were paired with various other responses. But the pairing of responses that discriminated the sample was the combination of being out of the closet with (a) parents, (b) all friends and acquaintances, and (c) all co-workers and the boss (81; 23.70%). The frequency of responses was as follows: (a) on the job with all co-workers and the boss (155); (b) with all friends and acquaintances (121); (c) with all friends but not with all acquaintances (106); (d) with some friends but not with others (72); (e)

on the job with some co-workers but not with the boss (67;, and (f) not out of the closet with any of the above (4).

Instrument Reliability and Validity

Self-as-Carer Inventory.

Normative data for the Self-as-Carer Inventory are presented in table 8. The Self-as-Carer Inventory was examined for internal consistency reliability according to item and total score analysis using Cronbach's alpha. All 40 items of the instrument were summed to produce the total score. The range of total scores was from 40 to 124 with a mean of 66.4, a median of 63.5, and a mode of 54. The overall alpha coefficient for the instrument was 0.91, with item alphas ranging from 0.91 for two items (I relate my self-care actions to one another to reach my health goals, and I have the physical balance I need in order to take care of myself) to 0.92 (I plan my self-care according to the energy I have).

Such high alphas are usually considered as evidence that the instrument's items are discrete in their measurement, thus revealing a high degree of internal consistency, which means that the item intercorrelations are low (Nunnally, 1977). This finding was consistent with the reported reliability of the instrument in the testing of 585 respondents in one study (Geden & Taylor, 1991), in which the authors reported a total inventory alpha of 0.96.

Construct validity was determined using a principal components analysis with an oblique factor rotation. Eigenvalues greater than or equal to one were considered retainable. Initial examination of the factors to emerge from the oblique rotation was paired with examination of the oblique factor loading plots obtained from the analysis. The examination of the plots was made necessary by the initial appearance of 11 factors with eigenvalues greater than one. Prior testing of the instrument had revealed only four factors (Geden & Taylor, 1991). Results

of the rotated factor pattern from this study's sample are contained in table 11, which is located in Appendix A.

Ten factors were retained after oblique rotation of principal components. One of the original eleven factors contained only a single significant component. After two of the factors were merged into one, ten factors were left, which accounted for 64.5% of the total score.

Naming the factors was done according to the principle that the name for the factor should represent the contents of the instrument items that appeared as grouped within the factor (Burns & Grove, 1987). After the factors were named, the investigator compared these names with key words that appear in each of the ten power components and with the three types of self-care operations. In the case of one factor name (Factor 5), the investigator changed the name after reviewing the self-care operations from the theory.

Factor 1. **Physical Strength and Setting Priorities for Self-Care** consisted of six items, that covered assessment factors related to the subject's physical strength in addition to setting priorities about self-care practices. Items that represented the factor included: "My strength is adequate," and "The way I take care of myself is consistent with what I consider important in my life." The eigenvalue for the factor was 10.9, and it carried 25% of the cumulative variance. Cronbach's alpha for the factor was 0.77.

Factor 2. **Information Seeking** consisted of six items that covered attending to signals from self to care for self and the pursuit of information pertaining to health and well-being. Representative items from the instrument included: "I know where to find good information I need to help me take care of myself," and "I consider health information in choosing solutions to problems in caring for myself." The eigenvalue was 3.26. It contributed 7.4% to the overall variance. The factor alpha was 0.69.

Factor 3. **Taking Responsibility for Self** was composed of four items; these were clustered around the theme of follow-through with decisions for self-care. For example, items included: "I follow through on health care," and "I follow through with decisions I make." The eigenvalue for factor 3 was 2.96. The factor accounted for 6.7% of overall variance. Cronbach's alpha was 0.57.

Factor 4. **Knowledge of Self** consisted of seven items that presented the theme of knowledge about information needed, physical energy required, and consequences of decisions enacted. Examples of items were "I know the resources I need," "I know when I have enough energy," and "I know which actions to do first to best accomplish my self-care." The eigenvalue for the factor was 2.48. The factor accounted for 5.6% of overall variance. Cronbach's alpha was 0.77.

Factor 5. **Transitional Period of Decision-Making** contained four items and was named according to the transitional stage of self-care operations proposed by the theory. Examples of the factor were: "To make a decision about my self-care, I look at the pros and cons," and "I plan my self-care according to the energy I have." The eigenvalue was 2.16. The factor's contribution to overall variance was 4.9%. The alpha was 0.76.

Factor 6. **Adapting the Self-Care Routine** consisted of three items and was named according to the "fit" of self-care activities with other patterns of living, such as family and social life. Representative items were "How I take care of myself fits with my family life," and "My self-care routine fits in with other parts of my life." The third item was a curious anomaly, however. It read "My joints are flexible enough for me to take care of myself." Its item composite score was 0.58. The eigenvalue for factor 6 was 1.85. Its unique contribution to overall variance was 4.2%. The factor alpha was 0.62.

Factor 7. **Environment as the Exigency in Self-Care** was named by the role that environment had on the alterations in self-care decisions. It consisted of

three items. The attention paid to the environment had an effect on self-care decisions according to the item "I am aware of things around me that affect my ability to take care of myself." Another item was "I judge how much energy I need to take care of myself." The eigenvalue for factor 7 was 1.73. It accounted for 3.9% of overall variance. Cronbach's alpha was 0.69.

Factor 8. **Flexibility in Self-Care** consisted of three items and was named by the approach to self-care from alternative perspectives. Representatives of the factor were the items "I do my self-care in a variety of ways," and "I explore several alternatives before I make a decision about my self-care." Factor eight's eigenvalue was 1.56. It accounted for 3.6% in overall variance. The factor alpha was 0.43.

Factor 9. **Help Seeking** consisted of only two items, but these items had such high composite scores (0.69 and 0.78) that it was impossible to cluster them with other factors. The recognition of authoritative information combined with problem-based decision-making were the characteristics of items that comprised this factor. For example, there was the item: "I use information from authorities to help me." The eigenvalue for the factor was 1.4. It accounted for 3.2% in overall variance. The factor alpha was not calculated due to the small number of items to be correlated in the matrix.

Factor 10. **Hearing and Vision**, was comprised of one item, which was number 27 on the instrument: "My hearing and vision are adequate to allow me to care for myself." Its high composite score of 0.78 was far higher than the next highest composite score under factor 1, which was 0.23. Therefore, it stood apart from all other factors, and was considered a separate factor composed of one item. The eigenvalue for the factor was 1.29. The factor accounted for 3% of overall variance. The alpha for item number 27 was 0.91 when it was correlated with all 40 items from the Self-as-Carer Inventory in the correlation matrix.

Table 12

Comparison between factors isolated from the Self-as-Carer Inventory and the Theoretical Power Components

Factor Number and Name	Power Component (PC)
Factor 1: Physical Strength and Setting Priorities for Self-Care	PC 3: Ability to control the position of the body
Factor 2: Information Seeking	PC 7: Ability to acquire technical knowledge about self-care
Factor 3: Taking Responsibility for Self	PC 5: Motivation and goal-orientation toward self-care
Factor 4: Knowledge of Self	PC 4: Ability to reason within a self-care frame of reference
Factor 5: Transitional Period of Decision-Making	PC 6: Ability to make decisions about care of self
Factor 6: Adapting the Self-Care Routine	PC 10: Ability to integrate self-care activities into living on a consistent basis
Factor 7: Environment as the Exigency in Self-Care	PC 1: Ability to maintain attention and vigilance to inner and outer forces
Factor 8: Flexibility in Self-Care	**
Factor 9: Help Seeking	**
Factor 10: Hearing and Vision	**

** No one power component is congruent with the factor

Table 12 presents one interpretation of the correspondences between the factors from the Self-as-Carer Inventory and the list of 10 power components from self-care deficit theory (Orem, 1991, p. 155). It is clear that there is not an exact match between the empirical factors and the power components. However, it is important to note that, while there is not an exact correspondence between the two, there is a heuristic value to comparing the two in a list side-by-side. The heuristic value of the exercise is this: the Self-as-Carer Inventory is measuring more than the ten power components, but it is reasonable to conclude that most of

the ten power components correspond with one or more of the factors isolated from the Self-as-Carer Inventory.

HIV-Related Self-Care Behavior Checklist.

The HIV-Related Self-Care Behavior Checklist was an instrument used to measure the concept of self-care operations. There was no use of this instrument prior to the current study. Cronbach's alpha was used to measure reliability of items. The alpha scores ranged from 0.57 (Take vitamins or herbs for your health, item # 3) to 0.63 (Make changes in your medications based on how you feel, item # 1). After removing the lowest alpha scores of 0.57 and 0.59 (Participate in physical activities, item # 6), there were 13 items remaining in the instrument with reliability scores greater than 0.59.

A summative score was calculated from the items. The summative scores ranged from 31 to 67, with a mean value of 53.7, a median of 55, and a mode of 57. Cronbach's alpha for the summative score was 0.34 with both item number 3 and number 6 part of the summative score. However, when these low alpha items were removed, the alpha for the summative score was raised to 0.47, which was still far lower than the average item alpha of 0.62.

HIV-Related Self-Care Behavior Checklist

Principal components analysis with varimax (orthogonal) rotation was performed with the data as the measure of construct validity. Table 13, Appendix D, depicts the factor analysis. Six factors emerged initially; these required analysis to see whether six factors were required, since items had been distributed into aggregate groupings of few items each. Further analysis reduced the factor total to three. The results of the factor analysis were as follows.

Factor 1. **Maintaining Wellness** consisted of six items. Each item is reported next along with its component factor score in parentheses. The items were: (a) Eat what you consider to be a nutritious diet (.63); (b) Do leisure

activities (.72); (c) Plan activities to fit with your plans for self-care, such as rest (.58); (d) Participate in physical activities (.44); (e) Seek out entertaining things to do (.70); and (f) Meditate or pray (.29). Variance for factor 1 items was 2.291. Factor 1 accounted for 26.2% of overall variance for the retained factors, based on retaining factors with eigenvalues greater than or equal to 1.0.

Factor 2. **Taking Medications and Vitamins** consisted of four items. The items were: (a) Take AZT/ddI/ddC, alone or in combination (.65); (b) Take vitamins or herbs for your health (.62); (c) Take medications to prevent PCP (.45); and (d) Take medications that you obtain from a source other than a doctor or other legal prescriber (.44). Factor 2 inter-item variance was 1.96. Factor 2 accounted for 19.8% of the variance.

Factor 3. **Modifying Self-Care Practices** consisted of four items. They were: (a) Make changes in your medications based on how you feel (.69); (b) Use aerosol pentamidine (.68); (c) Get enough sleep at night (.34); and (d) Talk with your friends/family about your health (.39). Factor 3 variance was 1.65. Factor 3 accounted for 16.7% of the overall variance.

Retaining 3 factors accounted for a total of 63% of the total scale variance. One item was dropped from the factor analysis. It was "Snack between meals to maintain/regain your weight." Without factor rotation the composite factor score for this one item was 0.45; with varimax rotation, it was 0.15. Both with and without rotation, the item did not group with other items in another factor, leaving it as the sole item for one factor in both cases. Therefore, the item was dropped from the final factor analysis. Had the fourth factor containing just one item been retained, it would have contributed only 1.7% to the overall variance to amount to a total of 65.4%.

HIV-Specific Therapeutic Self-Care Demand Inventory.

Reliability measures for the third tool were limited to the interval scales of the tool that measured patterns of daily living and effects of individual items on health. There were 23 items in the subscale that measured patterns of daily living, and 20 items in the subscale that measured the effects of the environment on health. The subscale that measured patterns of daily living was assigned the number 22 on the HIV-Specific Therapeutic Self-Care Demand Inventory. The subscale used to measure the effects of the environment was numbered 23 on the same Inventory.

The mean Cronbach's alpha for the measure of patterns of daily living was 0.75, with a low of 0.67 (item: "shopping for food") to a high of 0.81 (item: "eating meals"). The mean Cronbach's alpha for the measure of effects on health was 0.80, with the lowest alpha recorded for two items ("how much debt you have" and "peace in the world": 0.69) and the highest (0.82) for the item: "supportive friends/family."

Principal components analysis with varimax (orthogonal) rotation was applied to the two scales within the tool. Component scores greater than 0.4 were considered meaningful for the grouping of an item within a factor. These scores were combined with an examination of the Scree plots for the factors prior to making final decisions about groupings. Once items had been grouped in factors, and after using the rule that factors with eigenvalues greater than one would be used, factors were then named according to their composite items.

Patterns of Daily Living from the HIV-Specific Therapeutic Self-Care Demand Inventory.

Table 14, Appendix B, depicts the factor analysis of the patterns of daily living from the HIV-Specific Therapeutic Self-Care Demand Inventory.

Factor 1. **Eating Well and Practicing a Hobby** included three items from the scale of patterns of daily living, which were: (1) "Eating foods to promote health" (0.78), (2) "Practicing a hobby" (0.76), and (3) "Taking vitamins/herbs/supplements" (0.68). It exhibited the largest variance of the factors of 2.405. The eigenvalue for the factor was 4.09, and it accounted for 19% of the overall variance. Cronbach's alpha for the factor was 0.69.

Factor 2. **Communicating** involved four items from the scale. The four items were: (1) "Socializing with friends" (0.72), (2) "Talking with friends" (0.65), (3) "Praying and meditating" (0.53), and (4) "Talking with relatives" (0.53). All four items shared the common characteristic of communication. Therefore, the factor was named accordingly. Factor variance was 2.116. The eigenvalue for the factor was 2.54. It accounted for 12% of the variance in the total score. Cronbach's alpha for the factor was 0.63.

Factor 3. **Sedentary Pastimes** included two items. They were: (1) "Watching TV" (0.78) and (2) "Reading leisurely" (0.70). Since the two items were leisure in nature, it was necessary to distinguish them from factor 7 below, which also contained leisure items, such as exercising. The clear distinction between the two factors was the amount of activity required for one factor and not the other. Hence, the identifier of "sedentary" was applied to this factor, since most times one is seated to watch television and to read. Factor variance was 2.00. The factor eigenvalue was 1.87, and the factor accounted for 8.5% of the variance. The alpha for the factor was 0.59.

Factor 4. **Gathering Resources for Living** involved three items, which were: (1) "Cooking meals" (0.77), (2) "Shopping for food" (0.67), and (3) "Working at place of employment" (0.60). Factor variance was 1.88. The eigenvalue was 1.54. It accounted for 7% of the of overall variance. Factor alpha was 0.59.

Factor 5. **Upkeep of Body and Home** was the combination of three items. They were: (1) "Snacking between meals" (0.86), (2) "Doing yard work" (0.56), and (3) "Cleaning house" (0.53). Factor variance was 1.68. The eigenvalue for the factor was 1.42. It accounted for 6.4% of the overall variance. Factor alpha was 0.55.

Factor 6. **Other than Daily Activities** was the combination of "Paying bills" (0.48) and "Doing laundry" (0.76). It was the assumption in naming the factor that neither activity is part of the average subject's daily behavioral pattern. Factor variance was 1.678. The eigenvalue was 1.22. It accounted for 5.6% of the overall variance. Factor alpha was 0.39.

Factor 7. **Diversions** was the combination of three items: (1) "Drinking alcohol" (0.83), (2) "Attending religious services" (0.56), and (3) "Exercising" (0.41). The subject's mood can be affected by participating in any one of the three activities represented by the items. Therefore, the grouping of the items was considered meaningful in light of the characteristic change in mood after participating in a religious service, exercise, and consumption of alcohol. Factor variance was 1.663. The eigenvalue was 1.09. The factor accounted for 4.9% of overall variance. Factor alpha was 0.50.

Factor 8. **Regular Time Every Day** combined two items: (1) "Taking prescribed medications" (0.83) and (2) "Eating meals" (0.64). Often, the consumption of medications and meals occurs at the same time every day. This may be due to the conventional wisdom that drugs are absorbed better on a full stomach. Because medications and meals are consumed at regular intervals on a daily basis, the factor was named on the basis of this shared characteristic. Factor variance was 0.83. The eigenvalue was 1.05. The factor contributed 4.8% to the overall variance. Factor alpha was 0.38.

In summary, there were eight factors to emerge from the Likert-type scale that measured patterns of daily living. The eight factors together accounted for 69% of the overall variance in the score. All eight factors were named according to the meaning ascribed to the items that had clustered beneath each factor.

Environmental Effects on Health from the HIV-Specific Therapeutic Self-Care Demand Inventory.

Table 15, Appendix C, provides the factor distribution for the principal components analysis of the Likert-type scale called Environmental Effects on Health, which is part of the HIV-Specific Therapeutic Self-Care Demand Inventory.

Factor 1. **Choice of Physician and Leisure** was composed of five items, which accounted for 25% of overall variance. The five items were: (1) "Physician whom you like" (0.82), (2) "Physician whom you respect" (0.81), (3) "Money/time to take vacations" (0.50), (4) "Regular vacations" (0.50), and (5) "Free time to do what you want" (0.49). The shared characteristic between items was getting what one wanted. Thus, the items to group under factor 1 shared the characteristic of choice. It needs to be stated again that subjects enrolled in this study were part of a private medical center's population, in which all patients had the choice of their physicians. Factor variance was 2.432. The eigenvalue was 4.76. The factor alpha was 0.76. The factor accounted for 25.1% of the overall variance.

Factor 2. **Home and Neighborhood** was composed of three items: (1) "A gay-friendly community" (0.75), (2) "Supportive family" (0.74), and (3) "Orderly home life" (0.65). Factor variance was 2.1. The eigenvalue was 1.9. Cronbach's alpha for the factor was 0.65. The factor accounted for 10% of the total variance.

Factor 3. **Balance of Work and Leisure** was comprised of three items: (1) "Balance of leisure and work" (0.81), (2) "Feeling accepted as a gay person"

(0.66), and (3) "Work that you love to do" (0.57). Factor variance was 1.983. The eigenvalue for the factor was 1.5. The factor alpha was 0.61. The factor accounted for 7.9% of the total variance.

Factor 4. **Finer Things** consisted of three items: (1) "How much debt that you have" (0.81), (2) "A clean, neat house" (0.77), and (3) "Access to alternative health care" (0.36). Factor variance was 1.86. The eigenvalue was 1.46. The alpha coefficient was 0.50. The factor accounted for 7.7% of the total variance.

Factor 5. **World Issues** consisted of two items: (1) "Who is President of the U.S." (0.89) and (2) "Peace in the world" (0.70). Factor variance was 1.689. The eigenvalue was 1.72. Cronbach's alpha was 0.67. The factor accounted for 6.2% of the overall variance.

Factor 6. **Mobility** consisted of three items: (1) "Access to driving an automobile" (0.83), (2) "Whether other people are happy" (0.47), and (3) "Shopping located close to home" (0. 263). Factor variance was 1.508. The eigenvalue for the factor was 1.37. The alpha coefficient was 0.37. The factor accounted for 6% of overall variance.

In summary, there were six factors to emerge from the principal components analysis of the environmental effects on health as perceived by the sample. The six factors accounted for 62.9% of the total variance for the scale. Factors were named as follows: (a) Physician and Leisure, (b) Home and Neighborhood, (c) Balance of Work and Leisure, (d) Finer Things, (e) World Issues, and (f) Mobility.

Question 1 What is the congruence between theoretical components of self-care agency and factors isolated from the Self-as-Carer Inventory?

Pearson Product Moment Correlations were applied to the items that measured overall self-care agency score, health state, and self-care operations. In

turn, these items were: (1) the total score from the Self-as-Carer Inventory, (2) the two items that measured health state from the end of the Self-as-Carer Inventory (but not included in the total score for the instrument), and (3) the total score from the HIV-Related Self-Care Behaviors Inventory.

It was important first to demonstrate that there was a correlation between the total score from the Self-as-Carer Inventory and the HIV-Related Self-Care Behaviors Checklist because self-care operations are one of the concepts that make up the construct known as self-care agency. It is the position of this research that self-care operations have been measured by the total score from the HIV-Related Self-Care Behaviors Checklist. The correlation between the total scores from the Self-as-Carer Inventory and the HIV-Related Self-Care Behaviors Checklist was $\underline{r} = 0.13$ ($p < 0.03$).

Because it was proposed in the theory that self-care agency would vary according to the basic conditioning factors, a correlation matrix was devised to demonstrate the correlations between each of the basic conditioning factors and the total score from the Self-as-Carer Inventory.

There were six correlations between the basic conditioning factors and self-care agency. Income was correlated with self-care agency ($\underline{r} = -0.27$; $p < 0.005$). The inverse relationship necessitated secondary analysis to determine which factor of income was the significant contributor. It was determined that significance came from the answer to the sub-item "Was enough to live in the Bay Area" based on one-way Analysis of Variance (ANOVA), with each of the items from the variable analyzed separately ($\underline{F} = 7.830$; $\underline{p} < 0.006$). A four year college degree was also significant ($\underline{r} = 0.21$, $\underline{p} < 0.005$). Health in general was significantly correlated ($\underline{r} = 0.17$, $\underline{p} < 0.004$), as was health at this moment ($\underline{r} = 0.17$, $\underline{p} < 0.004$) and the number of friends reported ($\underline{r} = 0.18$, $\underline{p} < 0.008$). Finally, length

of time living in the Bay Area was correlated with self-care agency scores (r = 0.28, $p < 0.00$).

Subsequent to the initial run of correlations, a forward stepwise multiple regression was performed. All basic conditioning factors were entered as a group into the model as predictors, including income. Four of the five (income did not achieve significance) significant correlations between the basic conditioning factors and self-care agency also proved significant predictors of self-care agency in the multiple regression. Because age was a continuous variable on the demographics instrument, and because there was not a normal distribution of age, it was entered into the equation by way of "dummy coding" based on the distribution of the ages of the sample. Table 13 shows the results of the multiple regression of basic conditioning factors with self-care agency as the dependent variable and the basic conditioning factors as independent variables.

Table 16

Multiple Regression of Basic Conditioning Factors as Predictors of Self-Care Agency Scores from the Self-as-Carer Inventory

Variable Name	B	Beta at entry	Squared semi-partial	Multiple R	R-square
Length of time living in the Bay Area*	6.34	0.25	0.06	0.31	0.09 (1)
Health in general**	2.35	0.17	0.03	0.37	0.14 (2)
How many friends does one have*	2.67	0.18	0.03	0.40	0.16 (2)

Four year college degree as highest level of education*	4.87	0.15	0.03	0.43	0.18 (2)

* basic conditioning factor (B.C.F.) from the list of basic conditioning factors identified in chapter three

**one of the two measures of health state from the Self-as-Carer Inventory; the other measure of health state is "health at this moment;" health state is also a basic conditioning factor

(1) $p < 0.00$

(2) $p < 0.01$

. Once all predictors had been added into the regression equation, the equation accounted for only 18% of the variance in the self-care agency score. Thus, 18% of the variance of the summed score from the Self-as-Carer Inventory was attributed to the measurement of the basic conditioning factors, leaving 82% of the variance in self-care agency unaccounted. Length of time living in the Bay Area emerged as the first predictor variable in the regression. Six percent of the variance in self-care agency was attributed to the predictor of length of time living in the area. Length of time living in the Bay Area was part of the measure of the basic conditioning factor known as the sociocultural orientation.

The second variable to emerge in the regression equation was health in general. It contributed 3% of variance to the overall score. The measure of health in general was one of two component variables of the basic conditioning factor known as health state. Both health in general and health at this moment were items tacked on to the Self-as-Carer Inventory, but were not part of the summated score of self-care agency. Finally, a four year college degree, which was another sociocultural basic conditioning factor, accounted for 3% in the overall prediction of self-care agency. No other variables from the basic conditioning factors achieved significance as predictors of self-care agency.

It was then necessary to determine whether the measure of self-care operations was a significant predictor of self-care agency when it was entered along with the basic conditioning factors in a forward stepwise regression. This time, the predictor of self-care operations was added to the correlation matrix from which this second regression was performed. No significance was attributed to the addition of the score from the measure of self-care operations when this analysis was performed.

Question 2 What are the relationships among T helper cell counts, self-care practices, and the total score from the HIV-Related Self-Care Behaviors Checklist?

The answer to the second question required the division of the sample according to the last reported value of the absolute number of T helper cells. Subjects with less than 50 T helper cells were categorized as "Group 1" and those with more than 50 T helper cells were classified as "Group 2." Pearson product moment correlations were calculated with each item from the HIV-Related Self-Care Behavior Checklist correlated with the total score from the same instrument.

Table 17

Pearson Product Moment Correlations between Items on the HIV-Related Self-Care Behaviors Checklist

Item Number from the Inventory	Less than 50 T Helper Cells (p value, two-tailed T test)	More than 50 T helpers (p value, two-tailed T test)
1: Make changes in medications	0.1622 (0.03)	- 0.0053 (0.95)*
2: Take medications	0.2795 (0.0001)	0.2452 (0.01)
3: Take vitamins	0.5768 (0.000)	0.5892 (0.000)
4: Eat a nutritious diet	0.3876 (0.000)	0.4605 (0.000)
5: Snack between meals	0.0094 (0.899)*	0.0627 (0.5134)*
6: Participate in physical activities	0.4865 (0.000)	0.5357 (0.000)
7: Plan activities to fit self-care	0.2413 (0.001)	0.2558 (0.007)
8: Do leisure activities	0.2503 (0.0006)	0.4051 (0.000)
9: Use aerosol pentamidine	0.1922 (0.009)	0.1556 (0.10)*
10: Take meds to prevent PCP	0.3709 (0.000)	0.3338 (0.0003)
11: Take AZT/ddI/ddC	0.4496 (0.000)	0.4422 (0.000)
12: Get enough sleep at night	0.4030 (0.000)	0.4422 (0.000)
13: Talk with friends	0.2332 (0.0015)	0.3518 (0.000)
14: Meditate or pray	0.1658 (0.02)	0.1705 (0.07)*
15: Seek out entertaining things	0.500 (0.000)	0.5163 (0.000)

n Group 1 = 187
n Group 2 = 114
n Total = 301
*N.S. at .05 level

Both group 1 and group 2 showed insignificant correlations between item number 5, "Snack between meals," and the total score from the HIV-Related Self-Care Behaviors Checklist. It was also the one item that was not grouped into one of the 3 factors from the principal components analysis of the instrument. There were three correlations in group 2 that were insignificant, but were significant for

the same items in group 1: (1) item 1 = "Make changes in medications," (2) item 9 = "Use aerosol pentamidine," and (3) item 14 = "Meditate or pray."

Question 3 What are the self-care practices of an HIV seropositive gay man with less than 200 T helper cells, and how do these self-care operations change across time in serial measurements?

A discussion of question #3 begins with a summary of the biographical and clinical indices of the one subject selected to complete the ninety days of recordings. The subject was selected from a group of subjects available to the researcher on the grounds that (a) he met the entry criteria for the other 300 subjects admitted to the study, (b) his health history was known by the researcher, and that (c) his medical records were obtainable for reference purposes during the phase of data analysis. He recorded his responses to questions from the instrument entitled HIV Self-Care Operations Questions for Subject Response (Appendix E). The questions on this instrument guided his responses, and prompted him to recall information about self-care operations that the theory treated as essential for understanding the concept.

The subject was a white male, 40 years of age, who lived in San Francisco with his life partner of 8 years. He and his partner owned their home in one of the city's neighborhoods that was a mixture of gay and heterosexual households. He was employed by one of the city's private AIDS clinical drug trial facilities, so he was in daily contact with information pertaining to new and experimental treatment of HIV and its related infections. He was born in Los Angeles, was educated at a California university in public affairs/public relations, and was in regular contact with his family of origin. Both mother and father still resided in Los Angeles. The subject was from Italian-American heritage, and was from the third generation

born outside Sicily. He was baptized and confirmed Roman Catholic, but had not practiced in this faith for more than ten years.

The subject had resided in the city for more than ten years, where he had been variously employed in public relations throughout this period of time. He was employed in public relations at the time of diagnosis with HIV infection. He had been part of the Gay Men's Cohort Study, from which serum samples had been frozen since the year of 1978. One serum sample from 1978 was tested in 1985, after Enzyme-Linked Immunoassay for HTLV-III antibody was released for confirmatory evidence of infection to the retrovirus that is today called the Human Immunodeficiency Virus (HIV). It was in 1985 that the subject was confirmed as infected by HIV.

At the time of confirmation of HIV serostatus in 1985 the subject already had experienced a decline in circulating T helper cells to 500 cells. He suffered his first round with oral candidiasis in 1986, which is a fungal infection that is routinely associated with immune compromise. In 1988, his T helper cell count dropped below 250 cells, and he was started on aerosol pentamidine as primary prophylaxis against Pneumocystis carinii pneumonia, which is a pulmonary protozoan infection that is associated with T helper cell counts of less than 200 cells. He remained on aerosol pentamidine until May of 1991, when he was switched to the oral agent, trimethoprim/sulfamethoxazole.

He was yet to develop an infection by Pneumocystis carinii at the time that the data were collected for this study. He remained on trimethoprim/sulfamethoxazole throughout the time of the data collection without evidence of side effects from the sulfonamide drug, including evidence of early signs of hypersensitivity. At the time of entry into this study, he had a recent report of eight (8) T helper cells. This report was from September of 1991. All of his immune marker tests, such as T helper cell counts and T helper cell ratios, were

evaluated at the same medical center laboratory, thus providing consistency in reagents, instrumentation, and interpretation.

The subject's initial AIDS-defining diagnosis was cytomegalovirus infection of both retinae. This diagnosis was made by an ophthalmologist in the area in which the subject lived and who was well known by the investigator for his diagnostic acumen and treatment management of such infections in HIV infected patients. The diagnosis was made in November of 1990. The subject was reticent at the start to undergo conventional treatment of the infection, which was 10 mg/kg intravenous ganciclovir for 14 days followed by 5 mg/kg intravenous ganciclovir daily thereafter. The treatment was known by the subject to be for the remainder of his life.

His reticence to undergo conventional treatment was later to be related to this investigator in the course of a screening interview by the investigator for a study of the oral admixture of ganciclovir, which was in phase I/II testing at the end of 1990. The subject had already received 2 rounds of laser sclerosing therapy of both retinae's CMV lesions with subsequent stabilization of CMV growth, which is the sign used to establish that the laser therapy was effective.

In the course of the interview with this investigator in 1990, the subject learned that his options for oral ganciclovir management were positive for him to remain free of daily intravenous therapy, as long as the CMV lesions in the retinae did not recur. Over the winter holidays of Christmas and New Year's of 1990 he was initiated into the protocol that would later provide him with oral ganciclovir.

Subsequent clinical management of the subject by this investigator was enacted in the relationship of adult nurse practitioner to patient. The investigator for this study was an adult nurse practitioner who was charged with the clinical evaluation of subjects enrolled in clinical drug trials for the treatment of HIV-related infections at an institution other that the one in which the subject for this

study worked as a coordinator of clinical trials. Significant clinical sequellae included: (a) a precipitous drop in neutrophils, such as associated with intravenous ganciclovir therapy in one third of patients who received the drug, (b) eventual need for the concomitant use of granulocyte colony stimulating factor (GCSF) to raise the number of circulating white blood cells, and (c) various Staphylococcal and eczema-like integumentary infections. The subject had not reactivated old CMV lesions nor had he developed new lesions from the date of initial diagnosis in November, 1990 to the time of data collection for this study. This was remarkable in that the average length of time to reactivation of lesions or the development of new CMV lesions was 90 days on oral ganciclovir therapy.

There were few intercurrent infections suffered by the subject since the initial CMV retinitis diagnosis. He reported four "head colds" in the period of time from November, 1990 to September, 1991. In February and March, 1991, he experienced a three week period of bronchitis associated with a five pound weight loss. After antibiotic recovery, the subject regained the weight.

The subject's daily health practices were consistently practiced, as reported in the bi-weekly examinations performed by the investigator in the evaluation of the subject on the oral ganciclovir protocol. He exercised at the gym early mornings on workdays, attended an aerobics class at noon, and often ran 4 to 6 miles on the weekend days. He frequently reported riding his bicycle across the Golden Gate Bridge, through the Marin Headlands (mostly an uphill gradient of 45 degrees or more), and back to his home, which was a trek of 25 miles or more.

He reported that he seldom if ever took vitamins, mineral supplements, or herbs. He ate three meals each day, and occasionally snacked in the mid-afternoon and late evening. He and his life partner took vacations at least twice each year, and traveled to destinations that were remote from their residence, such as Hawaii on one occasion during this study. Business travel for the subject was limited to

three or four trips each year. One business trip was made to Florence, Italy for the VII International Conference on AIDS in the Summer of 1991. There were no trips to developing countries of the world during the two year period prior to entrance into this study or introduction to the investigator for the oral ganciclovir protocol.

The subject had known that he was gay from the time of his years in high school. But he had made conscious effort to self-identify as gay only since college. He reported that this "coming-out" experience was not tumultuous, that he had early on disclosed his sexual orientation to his parents, and that, at least to some extent, his drifting from his Catholic heritage was due to the religious institution's antipathy toward him as a gay man. He reported no spiritual practices such as mediation, centering, praying, or the like. Spiritual practices were not part of his life at home as a child, with the exception of attendance at Mass. He was not educated in Catholic schools.

The subject was one of four siblings, all of whom were male. The other three brothers are ostensibly heterosexual in orientation. The father is ill with chronic obstructive pulmonary disease, and continues to smoke cigarettes. The mother is alive and in "reasonable" health for her age. Both parents are in their mid-sixties. This concludes the discussion of the biographical and clinical indices of the subject. The remainder of the discussion of study question three is directed to the three core categories that emerged from the analysis of the transcribed recordings of one subject.

The answer to the third research question is a description of each of the three core categories by providing examples of the category from the text. Self-care operations that changed across the ninety days were emphasized. Three core categories emerged from the analysis of transcribed recordings of one subject. The

three core categories were: (a) Learning at Work, (b) Flexible Self-Care, and (c) Everyday a Well Day.

Learning at Work

The subject who made the daily recordings of self-care operations was employed in the arena of new and experimental clinical pharmaceutical trials for the management of AIDS-related diseases. Therefore, it was reasonable that he should acquire at least some of his information about the management of his own disease process from his place of employment. Information was gathered from nurses, printed literature, and other health care workers. Information accrual is first presented according to the properties of the information, and then the conditions of the information are discussed.

One example of the properties of information acquired from a source at work was:

> Yes, I have acquired information today from other health care workers and printed material. The information from the health care worker was about a new study about taking blood out of people and running it through a machine and doing something to it, to the T8's, taking the T8's out and putting them back in the body...its sounds interesting but I don't have many details yet...I would be very interested in doing it because it is for people with very low T cells.

The quote from the subject depicts his interest in acquiring new information at work. However, it also begins to reveal two differences in the information that the subject acquired. In this instance, the subject does not have an immediate need to incorporate the treatment regimen into his self-care. There were other instances in which he did need to incorporate the treatment into his self-care.

An example of his need to incorporate newly acquired information from learning at work into his self-care follows:

> I went to see my ophthalmologist to have my eyes examined, and I got some information from him about cotton wool spots, because I thought I had a cotton wool spot. He thought I was having reactivation of my

> retinitis. It turns out that I was right, that it was a cotton wool spot. He says it goes to show that patients know their own bodies better than their doctors do sometimes, so that it was a good learning experience for him, as well as for me.

The immediate need for the information was the way that this entry was distinguishable from the former entry. A second way that the entry was different was in the concept of the "knowing body," which was a preliminary category identified first in chapter three. Knowing his body as well as he did was considered a requisite for self-care, since knowledge of the body is reflected among the foundational capabilities of self-care agency. The subject knew his body better than did the physician, even though the subject needed words from the physician to describe the change in vision that was associated with cotton wool spots versus the change in vision associated with reactivation of cytomegalovirus infection in his retinae.

It was the subject's ongoing concern with his eyes (cytomegalovirus has a propensity to infect the retinae, and the subject's retinae had been infected for 14 months at the time that these recordings were made) that also qualified the difference between information that was not needed immediately and information that was required. He noted on many occasions, in reference to the question about information accrual on the HIV Self-Care Operations Questions for Subject Response (e.g., Appendix E, question #1), that he acquired most of his information about his disease while on the job. For example, the subject was the passive recipient of information that was judged by him to be non-immediate:

> I did acquire some information (at work) today about steroids--the different types of steroids and their side effects, their effect on the immune system, and I will incorporate this into a knowledge base about steroids. If I ever come up against a situation where I need to take them, I might think twice about taking them.

There is no indication that the subject initiated the inquiry into the subject of steroids. Rather, the transcribed text left the impression that he had received the information by virtue of being in a work place where the information was available.

In reference to his eyes, the subject makes another entry. There is a clear initiation to gain information on the part of the subject:

> I acquired some new information today about foscarnet and the induction period from another doctor. *I was asking* (emphasis added) about what the induction period is compared to DHPG, and he explained it all to me. I figure although I don't have to incorporate this into my regime now, there might be a time when I will need to use foscarnet, because the ganciclovir won't be working anymore, so it is useful information.

The emphasis added to the text reveals the initiation of the subject to gather information about the only other drug for management of infection with cytomegalovirus. There was no evidence that he was experiencing reactivation of the disease in his eyes, since it had only been three days before that the ophthalmologist had confirmed that indeed the temporary changes in vision had been due to cotton wool spots and not the new or reactivated cytomegalovirus disease. Thus, the subject's eyes were more important to him in distinguishing information that was needed immediately from lesser important information. Moreover, information about his eyes was important enough for him to seek out, while other information (non-eye related) was received passively while at work.

The category of information at work was named after examining the text to see what were the conditions of information accrual. It was noted throughout the transcribed text that the subject received information on work days while at work, for the most part. Therefore, the condition of being at work was the predisposing factor in when and where the information was received.

On weekends, the subject rarely received information about his disease management. The first series of questions that were used as cues for the subject in

formulating his responses had to do with the information that he acquired each day that the recordings were made. See Appendix E for the complete list of these questions, as well as for all other questions that were part of the HIV Self-Care Operations Questions for Subject Response. For example, in reference to the questions that pertained to information acquired, the following entry into the text depicted an average weekend day:

> "Today is Saturday...I have not acquired any information today, it's Saturday."

The entry suggests the possible explanation that weekends are meant for purposes other than information accrual about disease management. More likely, however, is the explanation that the weekends do not present the necessary condition for information accrual, which for this subject is presence at work. He worked on week days, and never on weekends.

Flexible Self-Care

Self-care practices for the subject were clearly divided according to routine self-care practices and circumstance-related change to self-care practices. The text revealed a clear routine of self-care practices that the subject practiced on a week day basis and a weekend basis. It also revealed the kinds of circumstances that might make the subject change his routine. The routine self-care will be presented first, followed by modified self-care practices with a presentation of the range of properties that prompted the modification.

An example of the routine self-care practice of exercise on a week day follows:

> I worked out for an hour at the gym, and then at lunch went to an aerobics class...in general I feel great...

Such was the routine of self-care for exercise on any given work day. However, on the weekends, the routine was modified slightly:

> Today is Saturday...Yes, I worked out, I exercised. I worked out at the gym this morning for an hour, and then went for a bike ride for an hour and a half this afternoon. Then I worked around the house for the rest of the day.

Thus, routine self-care usually did not change the activity engaged in, but did change the duration of time spent in the activity depending on the day of the week.

There were three conditions of modifying the self-care routine. They were: (1) intercurrent illness, (2) fatigue, and (3) vacation or other out-of-town trip. Representative entries for each of the three conditions are presented in the following discussion.

There were numerous minor intercurrent illnesses for the subject in the course of 90 days of recordings. One way to judge whether the intercurrent illness was major or minor was according to the energy level report of the subject. Energy level was reported on a scale of 1 to 10, with the anchors representing 1 = no energy and 10 = full of energy (the scale appeared on the HIV Self-Care Operations Questions for Subject Response, a copy of which is in Appendix E). The answer to the question of level of energy came after the report of new symptoms. On one day the subject reported:

> There are no new symptoms of HIV disease. I do have a cold with some sort of sinus problem. And I've been taking some sort of antihistamines for it. It seems to be a problem that's going around. My energy level, because of that---my energy level is maybe about a 7 today.

The subject's energy level was almost always reported as 10 for the period of time for the recordings. In the report of self-care for the same day as the preceding entry, the subject went on to say that the intercurrent illness affected his pace of movement through the day ("It was a fairly slow movement day"),

and reported that he didn't exercise. The fact that he didn't exercise because of the intercurrent illness produced the following report:

> "I get a little angst about that (not exercising), seeing as how I'm on such a regular schedule."

Intercurrent illness did not only affect the routine of exercise, it also changed his usual waking pattern, which was reported to be a routine without the need for rest or naps during the day. On the same day as the above entry, the subject napped at noon, even though it was a work day. He stated that the nap and not exercising were both examples of taking care of himself, and that these were not his usual pattern.

Fatigue was the second condition reported that required the subject to change his routine of self-care. There was no consistent reason for fatigue. There were occasions in the course of 90 days when the subject had not gotten an adequate amount of sleep the night before, or he had participated in late night parties, such as parties associated with the Christmas holidays. Words other than fatigue that he used to describe the phenomenon included: (1) "felt a little tired," (2) "couldn't do everything I wanted to," and (3) "wasn't feeling up to it." The report in fatigue was consistently coupled with changes in one of the following: (1) need for more sleep at night, (2) refraining from or limiting the amount of exercise, (3) altering social plans, and (4) taking midday naps or short rest periods of 30 minutes duration.

Like the report of lowered level of energy associated with intercurrent illnesses, fatigue was also coupled with reports of lowered energy. For example:

> My energy level today was about a 7. I felt fine today, felt a little tired from a little too much partying the last few days. I did exercise today. I worked out at the gym for about an hour this morning. What I did to take care of myself today was take a nap...for half an hour. I knew my energy level was down.

The above entry was isolated from any report of intercurrent illness, and serves as an example of the modification of self-care due to fatigue. Self-care was modified in the areas of rest and exercise. The subject included a nap in the day's schedule, and did not attend the aerobics class at noon this day. One notes again the presence of the exercise routine even when fatigue is present, however.

Trouble sleeping was associated with fatigue on another occasion. He added Benadryl to his daily regimen of drugs when he was experiencing insomnia at one point over the Christmas holidays.

> I'm adding this (Benadryl) starting tonight because I'm having a little problem sleeping, so I thought Benadryl might help. I saw my doctor today and he suggested that I do that.

The condition of the fatigue was significant for the subject, because it forced him to adapt his routine for self care. He mentioned as follow-up the next day that the Benadryl "worked," and that he would probably continue taking it as long as he needed it.

There were three out-of-town trips made during the course of 90 days. The self-care routine that was associated with his daily life in San Francisco was interrupted when he was in another place. For example:

> Today was a slow movement day. I didn't exercise. It was raining here in Hawaii, and we just laid around the house all day and read and napped...I won't be doing the same things tomorrow, but I will still be on vacation.

It was clear that during each of the out-of-town trips that he adapted his patterns of self-care for exercise, rest, and nutrition to the place in which he was located.

Every Day a Well Day

The routine nature of his self-care was a strong theme throughout the transcribed recordings. In the prior section the condition of routine self-care, namely the day of the week, was presented. It was noted that the subject's routine was different for weekends and week days. It was presented in order to

distinguish routine from modified self-care. In this section, two properties of the major category of routine self-care will be presented to distinguish the properties of self-care for this subject. The two properties are: (1) knowing self and (2) self as sick vs. self as well. Elements of daily self-care practices will be presented in the discussion of routine self-care beneath each of the properties.

The property of the knowing self was a meaningful way to answer why did the subject maintain a routine to his daily self-care. The example of the subject's ability to distinguish minor changes in visual acuity associated with cotton wool spots and major changes associated with cytomegalovirus has been presented under the category of learning at work. But it was in reference to the report of anxiety and depression in each day's report that the reason for the self-care routine became most obvious.

The subject was asked on a daily basis what his levels of anxiety and depression were on a scale of 1 to 10, with 1 = no anxiety or depression and 10 = extremes in either dimension. Again, the anxiety scale appeared on the HIV Self-Care Operations Questions for Subject Response (Appendix E). On days when he was free of both anxiety and depression, he was also following the routine that he had established for exercise, rest, sleep, nutrition, drugs, and the recognition and treatment of symptoms. However, when anxious or depressed, there was an unplanned interruption in the routine.

The knowing self, as a property of routine self-care, was the name given to his own internal regulator, which maintained routine self-care to avoid the sensations associated with anxiety and depression. It was already noted that the subject experienced "angst" when he changed his exercise routine.

Weekends were the times that the subject dedicated to living his life without the specter of AIDS. Hence, he made numerous references to "taking time off" from thinking about the disease, and instead focusing on "living my life."

There were so many entries to this phenomenon that it was difficult not to isolate it as a core category. In fact, in chapter three, it was noted that it was one of the early concepts that emerged from the first thirty days of transcribed recordings. There it was named "Let me just be and not be sick today."

"Shifting gears" was a term used by the subject to keep himself in a wellness pattern of health. This meant that he was willfully changing his mindset when it came to weekends away from his job as a client coordinator in a clinical trails unit. He went on to explain on several occasions that the reason for the change from weekday to weekend was to keep himself well. Therefore, the concept of self-as-well versus self-as-sick was incorporated into the third core category, because it was clearly a component of Every Day a Well Day.

Question 4 Are changes in the activation of self-care operations correlated with changes in Self-as-Carer Inventory scores?

There were five points in the ninety days of recordings that the one subject completed the Self-as-Carer Inventory. The total score was 40 each time he completed it. Therefore, there was no variance in score of self-care agency across the ninety days in which he was making recordings of his self-care operations.

There were twelve points in time in the ninety days of recordings that the one subject completed the HIV-Related Self-Care Behavior Checklist. The total score was 53 or 54 each time the subject completed it. Therefore, there was little variance in the score of self-care operations across the ninety days in which he was making recordings of his self-care operations.

The increase in total score on the HIV-Related Self-Care Behavior Checklist was attributed to one item, number 13, which asked "Talk with your friends/loved ones about your health?" Until the fortieth day of the recordings of daily self-care operations the subject circled the number five on the Likert scale for item 13. After the fortieth day he circled the number four.

The transcribed recordings of self-care operations were examined for evidence of fewer talks with family and friends or other evidence of diminishment in emphasis on talking with family and friends about health. The pattern of reporting of talks with family on weekends was no different after the fortieth day. It was clear that, after the fortieth day of recordings, the subject provided shorter and more precise answers to the questions from the HIV-Self-Care Operations Questions. But these shorter and more precise answers did not omit references to the spouse and friends, with whom he mentioned conversations on weekends. In brief, there was no change in the amount or frequency in reported conversations with the subject's spouse or with friends after the fortieth day.

Finally, the three factors from the HIV-Related Self-Care Behavior Checklist were compared with the three core categories to emerge from the transcriptions of responses by the one subject to the HIV Self-Care Operations Questions. The three factors from the former were reported in the analysis of research question number two, and the three core categories from the latter were reported under the analysis of research question three. The one subject's first data collection point to the HIV-Related Self-Care Behavior Checklist was entered into the analysis of question number two. The first intent of the comparison was to

Figure 3

Comparison between Factors from the HIV-Related Self-Care Behavior Checklist and Core Categories (CC) from the Transcribed Data of Self-Care Operations

Factor 1: Maintaining Wellness	**CC 3: Every Day a Well Day**
Factor 2: Taking Medications and Vitamins	**CC 3: Every Day a Well Day**
Factor 3: Modifying Self-Care Practices	**CC 2: Flexible Self-Care**

determine to what extent the two were congruent. The second intent was to ascertain differences between the two. Diagram 1 depicts the three factors from

the HIV-Related Self-Care Behavior Checklist on the left and the three core categories from the transcribed data on the right.

Initial inspection of figure 3 reveals striking similarities in the names attributed to factors one and two and the third core category. Factor three also was similar to core category two. The real test of congruence, however, was in whether the items from the factors and transcribed data were congruent.

Factor one contained six items from the HIV-Related Self-Care Behavior Checklist, which were items 8, 15, 4, 7, 6, and 14. The items included regularity of leisure activities, frequency of engaging in entertaining things to do, eating nutritious meals, and working activities into an overall plan of self-care. Hence, the factor was named according to the summary of the common denominator of all of the items for the factor. The common denominator was health maintenance.

The core category of "Every day a well day" was congruent with these items for factor 1. For example, on a workday, that was like most other workdays, the subject stated:

> "I took care of myself by exercising and by keeping to my Monday through Friday routine."

Another example of his routine self-care practices was the statement:

> "I took care of myself by just doing the usual routine for Thursday."

Factor 2 from the HIV-Related Self-Care Behavior Checklist was also congruent with core category 3, which was Every Day a Well Day. Items 11, 3, 10, and 2 comprised factor 2 from the HIV-Related Self-Care Behavior Checklist. All four items addressed the regularity by which the respondent (a) took medications (antiretrovirals), (b) took vitamins and herbs, and (c) took medications to prevent a common pneumonia in persons infected by HIV.

The third core category contained within it numerous examples of the regularity by which the subject used antiretrovirals, did not use vitamins or herbs,

and used medications to prevent Pneumocystis carinii pneumonia. For example, in response to the question, "Today have you started, stopped, or changed the dosages and kinds of medications that you take?" the subject answered the same for most every day of the 90 days of data collected. The following quote is but one example of this pattern of responses about medications:

"I haven't changed any doses or any of the medications that I take today."
In reference to vitamins he stated, " I never take vitamins or herbs." He did not take any vitamins or herbs throughout the period of data collection.

Knowledge of his prophylaxis for Pneumocystis carinii pneumonia came not from his recordings but from another study in which the subject was enrolled, and through which he was well known to the investigator. The subject continued to be treated with Bactrim as prophylaxis for the pneumonia throughout the period of data collection for this study.

The third factor, which was Modifying Self-Care, corresponded with the second core category, which was named Flexible Self-Care. The subject developed two colds during the ninety days of data collection. During the course of one cold he stated:

> I'm going to take care of myself by resting as much as possible to get rid of this cold...I plan on napping...I plan on taking a nap when I get home...Depending on how I feel, I will see how I react tomorrow.

There were other related reports of introducing flexibility to self-care that corresponded with item descriptors for factor 3 from the HIV-Related Self-Care Behavior Checklist. The items for factor 3 were numbers 1, 9, 13, and 12.

Factor 3 items could be summarized by the relationship between the shifts in feelings of well-being and self-care behaviors. Item 1, for example, with the largest component score for the items in this factor stated: "Make changes in your medications based on how you feel." The factor was distinguished from routine

self-care according to the emphasis placed on temporary alterations introduced into self-care based on feeling states. One example of the feeling state as it altered routine self-care patterns was the quote in the previous paragraph about napping. Indeed, another item from factor 3, number 12, stated "Get enough sleep at night." It was the cold that necessitated more sleep during the day than that was acquired at night.

Question 5 Is the calculated value of the therapeutic self-care demand correlated with Self-as-Carer Inventory scores?

The calculated value of the therapeutic self-care demand has been operationalized as the combination of the three items used to measure the health deviation self-care requisite and the three items used to measure the methods applied to treat the self-care requisites. Therefore, the total score is the combined raw score of the following items used to measure the health deviation self-care requisite of the sample: (1) Year diagnosed with HIV, (2) Last T Helper cell count, (3) total score from the list of opportunistic infections (OI's). In addition, there were the items used to measure the methods to treat the health deviation self-care requisites: (4) total score from medications used to prevent Pneumocystis carinii pneumonia, (5) total score from medications used, and (6) number of hospitalizations. There were 291 sets of responses to these six items from the HIV-Specific Self-Care Demand Inventory that were used to establish measures of

Table 18

Measures of Central Tendency for the Calculated Value of the Therapeutic Self-Care Demand

Mean	Median	Mode	Range	SD
12.73	13.00	14.00	6 - 20	2.96

n = 291

central tendency as represented in table 18.

The mean calculated value of the therapeutic self-care demand was 12.73. The median score (13) was closely associated in proximity to the average score. The distribution of scores fell into a bell-shaped curve, with the mode of 14.00 and the median of 13 falling at the center of the curve.

The total score from the therapeutic self-care demand was designated the dependent variable in a multiple regression analysis to determine the ranked contributions of each of the component parts of the total score. Therefore, the three health deviation self-care requisites and the three methods for treatment were placed into a forward stepwise regression. The strongest predictor of the total therapeutic self-care demand score was the item called medications, which was one of the three measures of methods. The squared partial was 0.4889 ($F = 271.680$; $p < 0.00$). It was followed closely in the percentage of prediction of therapeutic self-care demand by the year that HIV was diagnosed, which was one of the measures of health deviation self-care requisites (squared partial = 0.4831; $F = 264.447$; $p < 0.00$).

The other four predictors appeared in the following order: (1) last T helper cell count ($F = 3.835$), (2) total of the opportunistic infections ($F = 98.0$), (3) total of the medications used to prevent Pneumocystis carinii pneumonia ($F = 4.43$), and (4) number of times hospitalized ($F = 48.79$). All F scores were significant at the .05 level.

The therapeutic self-care demand scores were correlated overall with the total score from the Self-as-Carer Inventory ($r = - 0.3778$; two-tailed T of 0.000). The explanation for the inverse relationship between therapeutic self-care demand and self-care agency was partially resolved through multiple regression as depicted in table 19.

Table 19

Therapeutic Self-Care Demand as Predictor of Self-Care Agency: TSCD Less than Median Value and TSCD Greater than Median Value

Group	B	Beta at entry	Squared semi-partial	Multiple R	R-square
Total group				0.30	0.09
Less than median score of 14	10.0	0.30	0.92	0.28	0.08 (1)
More than or equal to median score of 14	6.95	0.17	0.07	0.02	0.01 (2)

n = 297; df = 295
(1) $p < 0.00$
(2) $p < 0.14$

The median score from the therapeutic self-care demand was 14. It was used as the point at which to divide the sample into half. "Less than" in table 15 represents total scores on the therapeutic self-care demand that were less than a total score of 14. "More than" represents total scores on the therapeutic self-care demand that were equal to or greater than 14. The regression analysis demonstrated that the lower total score on the therapeutic self-care demand was a predictor of higher self-care agency (which was a lower total score on the Self-as-Carer Inventory), while the higher therapeutic self-care demand score was not.

Only 9% of the total score from the Self-as-Carer Inventory was predicted by the therapeutic self-care demand score. It was interesting to note that the significant contribution to the predictive value of the therapeutic self-care demand came from only one of the two groups, namely the group with the lower therapeutic self-care demand score. The lower than median score group accounted for 92% of the total variance in therapeutic self-care demand.

The problem of explaining the inverted relationship between self-care agency and the therapeutic self-care demand was resolved by examining the composites of the two total scores. The total score of self-care agency was the summated score from the Self-as-Carer Inventory. **A lower total score on the Self-as-Carer Inventory signified a higher level of self-care agency.** The total score of the therapeutic self-care demand was the summated score of three items used to measure health deviation self-care requisites and three items used to measure methods by which to treat the health deviation self-care requisites. Both summated scores were non-standardized. **A lower score on the therapeutic self-care demand signified a lesser therapeutic self-care demand**. The lower therapeutic self-care demand predicted self-care agency because the subjects with lower therapeutic self-care demand scores had higher levels of self-care agency. The meaningfulness of this relationship in light of self-care deficit theory is discussed in chapter five.

Summary

Results have been reported concerning sample characteristics, instrument reliability and validity, and study questions. The sample was characterized as mostly Caucasian, college-educated, professional or managerial in categories of occupation, having spent 5 or more years in their chosen occupations, and whose income was enough to live in the Bay Area comfortably. In addition, the sample was characterized as having originated from urban American centers, having lived in the Bay Area for more than five years, and residing in neighborhoods that were a combination of heterosexual and gay/lesbian. Further characteristics of the subjects' families and sexual identities were presented.

Reliability and validity were reported for three instruments: (a) the Self-as-Carer Inventory, (b) the HIV-Related Self-Care Behavior Checklist, and (c) the HIV-Specific Self-Care Demand Inventory. Reliability was determined by

Cronbach's alpha. Validity was determined by expert panel review for the new instruments and by principal components analysis for all three instruments.

The results from the five study questions were presented. Study questions 1, 2, and 5 were analyzed with parametric statistics. Questions 3 and 4 were analyzed with analysis of text, and with comparison between factors from principal components analysis of one instrument and core categories from the analysis of text.

Chapter 5

Discussion and Conclusions

Introduction

This chapter presents the findings from the study in relation to study questions and instrument testing. The chapter also presents the limitations of the study, and entertains explanations for the findings associated with the study questions. Each study question is addressed in numerical sequence. Theoretical implications of the findings not addressed under the discussion of each study question are presented under its own sub-heading. The chapter concludes with discussions of clinical implications and suggestions for future research.

Research Questions

Question 1 What is the congruence among theoretical components of self-care agency, the basic conditioning factors, and factors isolated from the Self-as-Carer Inventory?

Self-care agency has been difficult to measure because it is a construct that is composed of four concepts. Two of the four concepts, viz. foundational capabilities and power components, have been identified as consistent with factors to have emerged from principal components analyses of instruments that have measured self-care agency. However, most of the research to have used self-care agency instruments has only focused on the power components (Gast, et al., 1989). Therefore, the factors that emerged from the principal components analysis of the Self-as-Carer Inventory, as presented in chapter four in table 9, were compared with the power components only.

It was not surprising that seven out of ten power components shared at least some congruence with factors isolated from the Self-as-Carer Inventory. It would have been inconsistent with other studies if there had been an exact one-to-one congruence between power components and factors. Geden and Taylor

(1991) hypothesized that the lack of a one-to-one congruence in their studies between the power components and factors from the Self-as-Carer Inventory was due to the measurement of the foundational capabilities by way of the power components. Thus, the Self-as-Carer Inventory measured both the foundational capabilities and the power components.

The component of self-care agency known as self-care operations was measured by way of the total score from the HIV-Related Self-Care Behaviors Checklist. It was expected that there would be a strong correlation between the scores of both instruments. However, the meager value of the Pearson product moment correlation (0.13) did not meet the expectation about a strong correlation. There were at least two explanations for this value. First, there may have been few immediate threats to health, such as impending health crises, that challenged the sample of HIV-infected gay men at the time that they completed the instruments for this study. Impending health crises are one example of changes in health state, and the theory maintains that self-care agency will vary as health state changes. Second, the self-care operations instrument used by the study may not be sensitive enough to measure the many self-care practices that change on a day-by-day basis.

The theory predicted that self-care agency would vary according to the basic conditioning factors. But not all of the basic conditioning factors were predictors of self-care agency. The multiple regression analysis of basic conditioning factors as predictors of self-care agency provided two unexpected results. First, only three of the ten basic conditioning factors actually predicted self-care agency scores. Second, these three predictors accounted for only 18% of the total variance in self-care agency scores. Each of these findings will be addressed in turn.

There were four items that comprised the three basic conditioning factors of self-care agency. The three basic conditioning factors to emerge as predictors of self-care agency were sociocultural orientation, health state, and family systems factors. Two items that measured sociocultural orientation were significant predictors: length of time living in the Bay Area and a four year college degree. One explanation for the significance of length of time living in the Bay Area was the fact that the sample lived in the area on the average for more than five years, and that self-care agency was influenced by the familiarity of the sample withth its environment. Familiarity with the environment would assist the subject in achieving each of the following factors that emerged from the analysis of the Self-as-Carer Inventory: (a) setting priorities for self-care (factor 1), (b) information seeking (factor 2), (c) adapting the self-care routine (factor 6), and (d) the environment as the exigency in self-care (factor 7).

A four year college degree was the average response for the sample. It comes as no surprise that a higher level of education should predict self-care agency, since the theory maintains that self-care agency will vary according to "educability" (Orem, 1991, p. 145). The importance of this predictor is that the lesser educated persons who are infected by HIV may be in need of more assistance in meeting self-care needs than those with a four year degree. But it is not clear whether the ability to be educated ("educability") is best measured by years of formal education, as represented by the item used here to measure education. It could be that there is a measure of educability that will be a stronger predictor than this one. A four year degree accounted for only 3% of the total variance in self-care agency scores in this sample.

Health state, the second of the three basic conditioning factors, was measured by two items from the Self-as-Carer Inventory--one which measured health in general and the other that measured health at this moment. Health at this

moment did not produce significant prediction of self-care agency. However, health in general was a significant predictor. The disparity in predictive value between the two items used to measure health state is consistent with the explanation for the meager correlation between self-care agency and self-care operations reported above. The explanation for the meager correlation was that there may have been few immediate threats to health in the sample. Indeed, had there been more immediate threats to health, the item of health at this moment might have been a significant predictor of self-care agency.

Family systems factors emerged as the third basic conditioning factor to predict self-care agency. One item that measured family systems factors, which was the number of friends that the subject had, was the significant predictor in the multiple regression equation. The item was worded in such a way to clearly distinguish the definition of friend as one who could be called at any time of the day or night to ask for help. Many subjects commented on this definition when they returned their instruments to the researcher. Some of the comments were: "I never thought about my friends like that...I mean I guess that I have fewer friends than I thought I had," and "I realized that I had more friends than ever when I came down with AIDS." The specificity of the definition probably contributed to the predictive value of the item. In addition, the reliability of friends to persons who are gay and who are separated often from biological relatives becomes all the more integral to self-care agency when the gay man is diagnosed with a life-threatening disease. Hence, there were two explanations for the predictive value of friends in the regression equation.

It was a problem that only 18% of the variance in self-care agency scores could be predicted by the three basic conditioning factors. The theory predicted that self-care agency should vary according to all of the basic conditioning factors. But if the basic conditioning factors do not vary much in the sample, then it should

follow that there will be little variance in their predictive impact on self-care agency. In fact, there was pronounced homogeneity in the sample. The sample members shared the same self-acknowledged sexual orientation, same gender, as well as similar T helper cell counts, education, age, ethnicity, and length of time living in the Bay Area.

The homogeneity of the sample was explained by the location and characteristics of the research site from which subjects were recruited. The research site was a medical center located in the heart of one of San Francisco's so-called gay districts. Large numbers of gay men infected by HIV are served by the same six to twelve medical providers who have been in practice at the site for the duration of the HIV epidemic. It was estimated in the 1989-90 fiscal year by the San Francisco Public Health Department that one fifth of all HIV-related health care services were provided by the medical center in which these six to twelve medical providers maintained their practices.

The remainder of the discussion of the first study question pertains to the differences in factors to have emerged from principal components analysis of the Self-as-Carer Inventory in this sample and the analysis performed by Geden and Taylor (1991) in other samples. Geden and Taylor reported a four-factor outcome for their analysis, whereas a ten-factor outcome has been reported by this study.

Geden and Taylor proposed that the Self-as-Carer Inventory was congruent with the theoretical components of self-care agency because each of their four factors could be related to either phase one or phase two self-care operations. Phase one and phase two self-care operations are the theoretical division of the component concept of self-care agency known as self-care operations. Factors one and two of their Self-as-Carer Inventory data corresponded with phase one operations, which were operations pertaining to

intellectual and integrative functions. Factors three and four corresponded with phase two operations, which were operations related to the initiation of self-care (Geden & Taylor, 1991, p. 50).

This investigator discussed his ten-factor analysis of the Self-as-Carer Inventory with Geden and Taylor (1992). They suggested that factors one through four corresponded with phase one self-care operations, and that factors five through nine corresponded with phase two self-care operations. If this is so, then the first four factors, which are (a) Physical Strength and Setting Priorities for Self-Care, (b) Information Seeking, (c) Taking Responsibility for Self, (d) Knowledge of Self, corresponded with intellectual and investigative self-care operations--phase one self-care operations.

Phase two self-care operations, which are composed of operations involving the initiation of self-care, were represented by factors five through nine: (a) Transitional Period of Decision-Making, (b) Adapting the Self-Care Routine, (c) Environment as the Exigency in Self-Care, (d) Flexibility in Self-Care, and (e) Help-Seeking. The tenth factor, Hearing and Vision, was an anomaly to Geden and Taylor as well as this investigator. Thus, the division of the ten factors according to phase one and two self-care operations from the Self-as-Carer Inventory was consistent with the grouping of factors proposed by Geden and Taylor.

Question 2: What are the relationships among T helper cell counts, self-care practices, and the total score from the HIV-Related Self-Care Behaviors Checklist?

The kinds of self-care practices addressed under study question two that distinguished the group with fewer T helper cells from the group with more than 50 cells were meaningful. First, there was an inverted relationship between membership in the larger T helper cell group and response to the first item on the

HIV-Related Self-Care Behavior Checklist, which was "Make changes in medications." The item under examination here was correlated with similar items under the factor named Modifying Self-Care Practices (factor 3: HIV-Related Self-Care Behavior Checklist).

It was noted in the presentation of factor 3 that items were similar on two accounts: (a) self-care practices were modified, and (b) self-care practices were modified according to feeling states. It is reasonable that feeling states would be in greater flux as illness symptoms develop. Illness symptoms are more prevalent in the lower T helper cell group than in the larger cell group. For example, there are several opportunistic infections associated with less than 50 T helper cells, such as cytomegalovirus retinitis and Mycobacterium avium intracellulare infection (Abrams, 1991). Therefore, it is reasonable to conclude that illness symptoms that are more prevalent in the lower T helper cell group will produce changes in feeling states, and that, in turn, these feeling states will be correlated with making changes in medications. The positive correlation between lower T helper cell group membership and item 1 can be attributed to morbidity and associated mood states.

Lovejoy and Paul (1990) reported higher symptom distress among a sample drawn from the same aerosol pentamidine unit as the one used for recruitment of this study's sample. Using the McCorkle-Young Symptom Distress Scale, the Profile of Mood States, and the HIV-Symptom Distress Scale (derived by Lovejoy), the authors concluded that symptom distress increased as opportunistic infections were present.

It is reasonable to create the hypothesis from their findings that mood influenced the frequency in changes in medications reported by the lower T helper cell group in this sample, since mood corresponded with the presence of opportunistic infections and opportunistic infections were likely to be more common in the lower T helper cell group. Returning to the investigation reported

here, Chi-square was used to answer the question whether there was any difference in the incidence of opportunistic infections between groups of T helper cells. Significant difference was determined in the incidence of M.avium intracellulare between groups of T helper cells, with the less than 50 T helper cell group reporting more of it than the greater than 50 cell group ($df = 1$, chi-square = 3.01, $p < 0.04$).

The theoretical framework of trusting derived by Getty and Stern (1990) from their grounded theory investigation of self-care by gay men with HIV infection is relevant to the discussion of the second research question as well. The authors determined that trusting was necessary for their sample to complete developmental tasks relative to self-care management of HIV infection. These tasks included (a) unlearning myths about homosexuality, (b) searching for lovers and friends, (c) reconciling their heterosexual network with their homosexual identity, and (d) managing health risks.

It is only the fourth task, managing health risks, that has relevance to the findings of this study. The phenomenon of trusting probably characterizes this sample in general, since the sample was drawn from the same 6 to 12 primary care medical providers of a small gay physician-dominated collection of physicians, which had been treating HIV disease for 10 years. It was concluded that the sample was homogeneous in their trust of the prescriptive authority of its physicians, and were therefore compliant with what their physicians told them in how to manage personal health risks. Hence, subjects were compliant with the regimen of prophylaxis that brought them to the aerosol pentamidine unit on the days that data were collected for this study.

But trusting goes far deeper in the community of gay male, HIV infected individuals in San Francisco. This investigator has observed that gay men teach each other about disease management, and that they trust what they hear from

another HIV infected gay man. For example, in small groups in symptom management that have been convened by this investigator, it has been routine that no more than 15 minutes of formal presentation can be planned for an hour-long session because there will be at least 45 minutes of member-generated discussion that will consume the hour. The discussion often will be centered around what one or others have learned about the topic of the day.

It was curious that item 9 ("Take aerosol pentamidine") from the HIV-Related Self-Care Behavior Checklist also was correlated significantly with the lower T helper cell group and not with the higher cell group. There are two explanations for this correlational difference. First, item 9 was correlated with factor 3, as was "Make changes in medications," based on the changes in feeling states. The higher T cell group use aerosol pentamidine when they "feel like it." This is consistent with the investigator's observations about the relationship among perceived relative risk of developing Pneumocystis carinii pneumonia (PCP), number of T helper cells, and compliance with the therapeutic regimen. In brief, the investigator has observed that the lower T helper cell group members perceive the risk of developing the pneumonia greater than members from the higher cell group, because most of them have experienced PCP at least once. However, chi-square analysis of the incidence of prior PCP according to the group identifier of less than 50 T helper cells or more than 50 cells did not reveal a significant difference ($df = 1$, Pearson chi-square = 1.184, $p < 0.277$).

The second explanation for the difference in significance to the correlations is the conventional trajectory of prophylaxis for the opportunistic infection based on the number of T helper cells. In the conventional trajectory of prophylaxis it is recommended that PCP prophylaxis should start when the T helper cells reach 200. However, in practice, PCP prophylaxis often begins whenever the patient's T

helper cell count drops below 200 cells. Thus, the higher cell group members might have only recently learned that they needed aerosol pentamidine.

But many patients do not discover that their T helper cell counts have dropped below 200 for 90 days or more, depending on many factors (reference). Since it was not assessed in this study whether the higher T helper cell group members had only recently required PCP prophylaxis, the second explanation could not be substantiated. Further doubt was cast over the second explanation by virtue of the significant correlation between item 10, "Take medications to prevent PCP (other than aerosol pentamidine)," and the higher T helper cell group. There was a significant correlation between item 10 and the higher T helper cell group. But it is still possible that oral prophylaxis, such as in the form of a sulfonamide or dapsone, could have begun as much as 30 days before the first aerosol pentamidine treatment. If this was so, then oral prophylaxis was correlated with higher T helper cell counts while aerosol pentamidine was not.

There is a third explanation of the difference that will require future research to determine. The explanation is this: Greater significance might have been attributed to the ability of aerosol pentamidine to be effective against PCP in the lower T helper cell group than in the higher cell group. This explanation is consistent with the definition of the therapeutic self-care demand from the Nursing Development Conference Group (NDCG, 1979):

> The (therapeutic self-care) demand when formulated is essentially a design for actions to be taken: The design makes explicit the reasons for the actions, the nature of the actions, the relationships among the sets of actions, and the expected results of action that are stipulated as required by, or desirable by, a person (p. 119).

Thus, the expected result of PCP prophylaxis is greater in significance for the lower T helper cell group because the lower group might have attributed greater

importance to the result of prophylaxis from the aerosol pentamidine than the higher T helper cell group.

The third difference in correlations between grouping of T helper cells and items from the HIV-Related Self-Care Behavior Checklist was in item 14, "Meditate or pray." Item 14 was correlated with factor 1, Maintaining Wellness, in the factor analysis of the instrument. It was correlated with items associated with diet, exercise, and rest. There it was considered meaningful in so far as it contributed to the subject's overall state of health. The question to be considered now is whether there is a difference in maintaining wellness between the groups or whether there is only a difference in meditation and prayer. It is addressed under recommendations for future research.

But all of these differences must be weighed in the balance of magnitude of the Pearson product moment correlations. With the exception of item 1 from the HIV-Related Self-Care Behaviors Checklist, which was "Make changes in medications," both groups had relatively small correlational values for items that showed significant differences. It was clear that the two groups were different in reference to making changes in medications based on the actual Pearson r correlations. So it was difficult to interpret whether there was any real meaning to the differences between items 9 and 14. That there was a difference in significance to use of aerosol pentamidine between the groups could have been mediated by many factors, such as (a) duration of treatment with aerosol pentamidine, (b) concomitant use of oral anti-PCP agents, and (c) recurrence of PCP.

Question 3 What are the self-care operations of an HIV-seropositive gay man with less than 200 T helper cells, and how do these self-care operations change across time in serial measurements?

Question 4 Are changes in the activation of self-care operations correlated with changes in Self-as-Carer Inventory scores?

Both research question three and question four involved the analysis of transcribed recordings of one subject. The analysis of the text of transcribed recordings was presented in chapter four in the manner of a discussion of each of the core categories. Therefore, the discussion here is limited to the significance of the first core category, which was Learning at Work. The first core category was not congruent with any of the three factors to emerge from the factor analysis of the HIV-Related Self-Care Behaviors Checklist, the instrument used to measure self-care operations.

It was considered peculiar to this one subject that he acquired all of his health-related information on the job. Very few HIV-infected persons are in similar positions to gain access on a daily basis to nursing and medical researchers who study experimental treatment modalities for HIV infection. Therefore, the core category of Learning at Work had more to do with Factor 2 from the Self-as-Carer Inventory, which was labeled Information Seeking, than it had to do with any of the three factors from the HIV-Related Self-Care Behaviors Checklist. It was probably a trait of this one subject to link himself to a job in which he could obtain daily information about his own disease management.

The question should be raised whether items need to be added to the HIV-Related Self-Care Behaviors Checklist that pertain to specific information seeking behaviors practiced by persons with HIV disease. This question must be considered because the subject responded to queries about information accrual. These queries or prompts about information accrual came directly from the fourth edition of Orem's text (1991) on self-care, as presented in the instrument entitled HIV Self-Care Operations Questions for Subject Response. In brief, the prompts that were provided to the subject were derived from the theory, and so must be considered when measuring self-care operations of HIV-infected persons in future studies that use self-care deficit theory as a conceptual framework. An alternative

to the addition of items about information accrual to the HIV-Related Self-Care Behaviors Checklist would be the use of Lovejoy's instrument on information seeking for HIV-infected persons (Lovejoy, et al., 1991).

Question 5 Is the calculated value of the therapeutic self-care demand correlated with Self-as-Carer Inventory scores?

The measurement of the therapeutic self-care demand was limited by the study to six items. These six items were distributed between items that measured the purpose for seeking health care (health deviation self-care requisites) and items that measured the ways that subjects actually medicated themselves, which were the methods that subjects used to treat themselves when they were ill. Thus, health deviation self-care requisites were the purposes for which medications were taken.

It remains a problem that the operational definition of the therapeutic self-care demand, which is the summative score of all six items, might not be a valid measure of the construct. The problem of the validity of the operational definition primarily centers on the items used to measure health deviation self-care requisites. All three items might actually be measuring the health state of persons infected by HIV, and not the purposes for which the medications were used. For example, the history of opportunistic infections--one of the items--provided a total score for all opportunistic infections that were part of the subject's history of HIV infection. Individual subjects with more than two opportunistic infections were clearly in a worse state of health in general than those with less than two opportunistic infections. But it was not clear that their worse state of health was the purpose for which they medicated themselves with prophylaxis drugs for Pneumocystis carinii pneumonia and drugs for HIV infection, two of the three items used to measure drugs that were used to self-manage the illness.

Further work will need to be done with refining an operational definition for the construct of the therapeutic self-care demand. One direction for future work would be the development of items for the HIV-Specific Self-Care Demand Inventory that link drugs and other therapies to purposes for which they are taken, similar to the manner in which a medication history is taken. Usually at the end to every line of a medication history there is a column dedicated to the purposes for which a drug is taken. The provider who completes the drug history often records the purpose for which the drug is taken in the patient's own words. This idea could be expanded to include a list of standard drugs and therapies for HIV infection along with lists of routine purposes for which drugs and therapies are recommended.

However, it was important that the scores from the therapeutic self-care demand fell into a bell-shaped curve as presented in graph 1 in chapter four. The normal distribution of scores allowed the investigator to draw conclusions with greater certainty when the therapeutic self-care demand was discovered to be a predictor of self-care agency.

The forward stepwise regression of the six items against the total score from the items (the total score = the therapeutic self-care demand) revealed that the most significant predictor of score was the medications taken. What this means is that pharmaceutical treatment of HIV infection and related opportunistic infections is the best predictor of the therapeutic self-care demand. One explanation for this finding is the importance of this factor to the population of research subjects from among the three methods measured for the treatment of the self-care requisite. The research literature about the need to keep taking antiretrovirals has been widely disseminated as information to the population from which this sample was taken.

The sample was drawn from a private medical center's population of HIV infected patients. It is meaningful to repeat this exigency because there was a routine of monthly or bimonthly visits to the primary care physician for patients of the medical center. It is also important because the research subjects had known of personal HIV serostatus on the average of four years. Therefore, there was a combination of medical supervision and longevity with knowledge of diagnosis that also explained the importance of the predictive value of medications. In short, there had been a long period of time in which patients had the chance to receive education about the importance of medications in managing their disease.

The second predictor of the therapeutic self-care demand was years since HIV antibody status was diagnosed. This was the first predictor to load that came from the list of three self-care requisites. The meaning of this predictor, loading before the others, probably was associated with the reasons presented above in the discussion of the first predictor. There were four years on the average since diagnosis of HIV serostatus. Plenty of time had elapsed for subjects to acquire information about treatment, develop a plan for care, and to enact the plan for self-care.

Therapeutic Self-Care Demand Scores and Self-Care Agency Scores Correlated

The inverted relationship between the therapeutic self-care demand and self-care agency was explained in chapter four in brief. It was said there that, in this sample, the higher the score on the therapeutic self-care demand, the higher was the score on the Self-as-Carer Inventory. A higher score from the Self-as-Carer Inventory represented lower self-care agency. This means that: (a) self-care agency is not measurably activated by an increase in self-care demand, or (b) the items used to measure the therapeutic self-care demand are actually measuring the health-deviation self-care requisite, or (c) the self-care demand is greater than available self-care agency, and, therefore, nursing agency is required to relieve the

therapeutic self-care demand of the sample members with above average scores on the therapeutic self-care demand. Both (a) and (c) might be true, with (a) explaining the need for (c), while (b) suggests a problem with construct validity.

The discussion has already addressed the unresolved issue of construct validity for the therapeutic self-care demand. The discussion will not explore the topic further. It is necessary to consider the theoretical relationships among identification of the therapeutic self-care demand, adequacy of self-care agency, and the activation of nursing agency. Nursing agency has been defined by the theory as:

> ...a complex property or attribute of persons educated and trained as nurses that is enabling when exercised for knowing and helping others know their therapeutic self-care demands, for helping others meet their therapeutic self-care demands, and in helping others regulate the exercise or development of their self-care agency or their dependent care agency (Orem, 1991, p. 54-65).

It is necessary to define nursing agency, because it has not figured into the variables of the study until this point. The theory maintains that nursing agency is activated when self-care agency is not adequate to handle the therapeutic self-care demand.

It is reasonable to conclude that, as the therapeutic self-care demand increases, there should be a corresponding rise in self-care agency, unless self-care agency is inadequate to treat the therapeutic self-care demand. Therefore, it follows that the sample from this study required nursing agency, because there was an inverted relationship between therapeutic self-care demand scores and self-care agency.

Implications for Self-Care Deficit Theory

The relationship between self-care agency and the therapeutic self-care demand, as presented in self-care deficit theory, was supported in this study.

Because the theory holds that the relationship between the two must be established prior to the delivery of nursing care, the study provides evidence that it is possible to measure the relationship between them and that nurses can determine when to intervene based on any similar measurement strategy.

Prior to this study no other investigator of the theory had measured self-care agency with a sample that was homogeneous in demographics. Therefore, it was important that the homogeneous demographics (basic conditioning factors) created very little variance in self-care agency scores as predicted by the theory. A heterogeneous sample of subjects might have shown greater variance in self-care agency scores. More studies will need to be done along similar lines using the basic conditioning factors as predictor variables.

Returning to the 15 criteria for evaluating theory-testing research presented in chapter two (Acton, et al., 1991), this study has been limited by the operational definition of the therapeutic self-care demand, and, therefore, fails to meet the requirements of criterion 9, "The instruments must be theoretically valid and reliable" and criterion 7, "The operational definitions are clearly derived from the theoretic frame of reference." However, the process of substruction, also presented in chapter two, will continue to prove useful to future research in creating an operational definition for the construct.

Limitations

Numerous limitations have been addressed in the discussion of findings throughout chapter five. In addition, limitations identified in this study are those that are specific to explanatory and descriptive research designs, as well as to the use of self-report to obtain data (Kaplan, 1964; Katz, 1953, Kerlinger, 1973; Nunnally, 1978). These limitations include, but are not limited to: (a) selection bias, (b) additional sampling errors that may not support the assumption that the sample is engaged in a developmental trajectory when it is measured at one point

in time, and (c) errors associated with individual understanding of items on the paper and pencil tools. Other limitations involve the use of Likert-type scales (Brown, 1976; Edwards, 1957; Kerlinger, 1973; Nunnally, 1978). Additional limitations were identified as follows:

1. The setting to obtain data were not randomly selected, nor were study subjects randomly selected. Therefore, findings from this study may not be representative of persons with HIV infection who seek out their health care from public agencies, such as federal, state, and county facilities. Subjects in public-owned facilities would more likely be more heterogeneous than the sample under study based on numerous reports about the demographics of persons with AIDS treated in these facilities.

2. The study is limited by the phenomenon of response bias, which is related to information that subjects were willing to relay by way of the study instruments, including the bias associated with the social desirability of information requested.

3. The responses of subjects are not necessarily their feelings, attitudes, or priorities.

4. Because the subjects were seated behind a transparent screen throughout their completion of these instruments (separated from the investigators by this screen of glass) another limitation is the possible effect of the screen exerted on subjects' responses. Other factors, such as noise level, the use of a television set continuously inside the treatment area, and the time of day that all instruments were completed were also not controlled by the investigator.

5. Reliability testing for two instruments developed by the investigator for this study was not performed prior to the data collection reported herein.

6. It was not ruled out that there was a regression to the mean that occurred when multiple predictors were used in a multiple regression analysis. Such was the problem of applying parametric statistics to a cross-sectional design.

Implications for Nursing

Empirical validation of relationships proposed by self-care deficit theory has direct impact on nursing. The empirical validation of the relationship between self-care agency and the therapeutic self-care demand, as presented in this study, was important for nurse researchers who work from the persuasion of self-care deficit theory. This study's validation of the relationship provides researchers with more grist for future inquiry into new instrument development, for critique of the operational definitions of the related constructs, and for possible refinement of theoretical relationships.

There were several implications for nursing practice and research from this study. First, nurses will eventually need to accurately measure the self-care agency and therapeutic self-care demand of persons infected by HIV. This study advances the argument that measurement of both constructs can aid a nurse in determining whether there is a legitimate need for nursing care for the person infected. It is possible to use the instruments from this study in the assessment of patients in both inpatient and outpatient settings, due to the limited amount of time required for instrument completion.

Second, the measurement of self-care behaviors of HIV infected persons were grouped according to T helper cell count. Nurses may eventually use the instrument developed to measure self-care behaviors for identifying their HIV-infected patients according to self-care practices. Further identification of patients for nursing treatment purposes might also include dividing them according to T helper cell count.

Third, nurses can use this study to anticipate the self-care practices and self-care agency of other samples with similar demographic characteristics. So little information is known about the self-care practices of the population with these demographic characteristics that these findings bring to light knowledge about self-care practices that was not known prior.

Suggestions for Future Research

It is suggested that the factors from the Self-as-Carer Inventory be analyzed along with the factors from the HIV-Related Self-Care Behaviors Checklist by way of canonical correlation to establish factor patterns of convergence between the two instruments.

It is also suggested that the Self-as-Carer Inventory be used in a future study, along with the measurement of the basic conditioning factors, with a sample that is more heterogeneous than the sample from this study. One suggestion might be that instruments be used with a sample of HIV infected persons who do not share similar age, gender, education, and ethnicity. The purpose of this study would be to determine empirical validation for the theoretical proposition that self-care agency varies with the basic conditioning factors.

Other suggestions for future research are:

1. Refine the measurement of the therapeutic self-care demand by further work on instrument development.

2. Refine the measurement of self-care behaviors. For example, the transcribed data showed patterns of workday and non-workday self-care behaviors. Perhaps categorize responses according to the day of the week in which the self-care practice is enacted or add an information-seeking instrument to the tool that measures self-care operations.

3. Further refine the measurement of self-care behaviors by interviewing subjects with demographic characteristics other than this sample, to determine additional items for the interval scale that measures self-care behaviors.

4. Measure the impact of nursing interventions when they are performed after the therapeutic self-care demand has been established as present.

Summary

The basic conditioning factors may indeed create variance in overall self-care agency and therapeutic self-care demand scores, as theorized in self-care deficit theory, but only so in a more heterogeneous sample. This study's sample was far too similar in age, ethnicity, developmental state, use of sociocultural resources, and environment to produce any measurable variance in overall scores of self-care agency and therapeutic self-care demand. However, there was reason to believe that the prediction of variance might be true in another sample because the sample's educational level differences, income, and chronic health state created variance in overall self-care agency and therapeutic self-care demand scores.

There was no prior operationalized definition of the therapeutic self-care demand in the literature. So this study provided an operational definition for the construct that will be useful for dialogue among self-care deficit theorists and for future work at delineating the construct for research.

The study calls for additional research to determine the self-care practices of HIV seropositive individuals as they relate to relieving health deviation self-care requisites. It is suggested that instrument development will be necessary in order to define both the health deviation self-care requisites and treatment modalities for HIV infected persons.

Canonical correlation was suggested as a statistical strategy to correlate the factors from instruments used to measure concepts from self-care deficit theory.

This had been a promising strategy for other self-care deficit theory researchers such as Denyes (1980).

The study supported the theoretical relationship between self-care agency and the therapeutic self-care demand. It was concluded that more work will need to be done to establish the impact of nursing interventions once the therapeutic self-care demand has been measured. It may be, as the theory maintains, that nursing interventions make a greater impact when they are provided to patients only with active therapeutic self-care demands that cannot be treated by self-care agency alone.

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Appendix A

Table 11

Direct Oblimin (Oblique) Rotated Factor Pattern of the Self-as-Carer Inventory (N 301)**

*	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9
9	0.84								
13	0.83								
36	0.74								
25	0.58								
28	0.51								
29	0.45								
32		0.75							
23		0.70							
33		0.70							
10		0.64							
2		0.63							
18		0.55							
31			0.95						
16			0.95						
14			0.63						
17			0.58						
38				0.83					
34				0.73					
21				0.64					
39				0.60					
15				0.56					

22				0.49					
40				0.48					
20					0.82				
11					0.73				
4					0.65				
24					0.53				
3						0.78			
1						0.58			
5						0.57			
8							0.80		
19							0.77		
12							0.51		
26								0.76	
30								0.73	
37								0.66	
7									0.78
35									0.69
Eigenvalue	10.9	3.26	2.96	2.48	2.16	1.85	1.73	1.56	1.4
Proportion	0.25	.074	.067	.056	.049	.042	.039	.036	.032
Cum.	0.25	.324	.391	.447	.496	.538	.577	.613	.645

* The first column represents the corresponding question number from the Self-as-Carer Inventory

** The tenth factor consisted of one item, question 27, with a component score of 0.78; cum. .675

Appendix B

Table 14

Varimax Rotated Factor Pattern of the Sub-Scale, Patterns of Daily Living, from the HIV-Specific Therapeutic Self-Care Demand Inventory

Item #	Fac. 1	Fac. 2	Fac. 3	Fac. 4	Fac. 5	Fac. 6	Fac. 7	Fac. 8
22	0.78							
23	0.76							
21	0.68							
15		0.72						
8		0.65						
17		0.53						
18		0.53						
6			0.79					
7			0.70					
10				0.77				
9				0.67				
11				0.60				
4					0.86			
14					0.56			
13					0.53			
19						0.76		
12						0.48		
2							0.83	
20							0.56	
3							0.41	
5								0.83
1								0.64
Eigen value	4.09	2.54	1.88	1.54	1.42	1.22	1.08	1.05
Prop.	0.19	0.12	0.09	0.07	0.06	0.06	0.05	0.05
Cum.	0.19	0.31	0.40	0.47	0.53	0.59	0.64	0.69

*Item # is the sequential number assigned to the item as it is printed on the scale, from 1 to 23.

Appendix C

Table 15

Varimax Rotated Factor Pattern of the Sub-Scale, Environmental Effects on Health, from the HIV-Specific Therapeutic Self-Care Demand Inventory

Item* Identifier	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
17	0.82					
18	0.811					
13	0.503					
12	0.502					
19	0.488					
6		0.749				
7		0.739				
5		0.649				
11			0.813			
10			0.675			
14			0.573			
4				0.806		
3				0.774		
20				0.357		
8					0.889	
9					0.703	
16						0.826
2						0.473
15						0.263
Eigenvalue	4.76	1.90	1.50	1.46	1.17	1.13

Proportion	0.25	0.10	0.08	0.08	0.06	0.06
Cumulative	0.25	0.35	0.43	0.51	0.57	0.63

*Item identifier is the sequential number assigned to the item as it is printed on the scale (1-20)

Appendix D

Table 13

Varimax Rotated Factor Pattern of the HIV-Related Self-Care Behaviors Checklist

Question Number	Factor 1	Factor 2	Factor3
8	0.72		
15	0.70		
4	0.63		
7	0.58		
6	0.44		
14	0.29		
11		0.67	
3		0.62	
10		0.45	
2		0.44	
1			0.69
9			0.68
13			0.39
12			0.34
Eigenvalue	2.58	1.96	1.65
Proportion	0.26	0.20	0.17
Cumulative	0.26	0.46	0.63

Appendix E

Questionnaire Packet

1. Self-as-Carer Inventory
2. HIV-Related Self-Care Behaviors Checklist
3. Demographics Inventory
4. HIV-Specific Self-Care Demand Inventory
5. HIV Self-Care Operations Questions for Subject Response

Day of your birth (1-31)/Last 4 digits of your social security number

Form A

__ / ____

day soc. sec. no.

Self-As-Carer Inventory

Instructions. Below are a number of statements about caring for yourself. (The word "self-care" is used a lot. It means those things you do for yourself to maintain life, health, and well-being.)

Use a #2 pencil to mark the number that best describes how you take care of yourself. Marking the number "6" means the statement is a very accurate statement about how you care for yourself; marking number "1" means that the statement is not at all accurate.

	Very Accurate					Very Inaccurate
My joints are flexible enough for me to take care of myself.	6	5	4	3	2	1
I consider health information in choosing solutions to problems in caring for myself.	6	5	4	3	2	1
How I take care of myself fits in satisfactorily with my family life.	6	5	4	3	2	1
I try out new ways to take care of myself based on information from experts.	6	5	4	3	2	1
My self-care routine fits in with other parts of my life.	6	5	4	3	2	1
I watch for signs that tell me if I am taking good care of myself.	6	5	4	3	2	1
I think about my self-care problems differently depending on the type of problem I have.	6	5	4	3	2	1
I watch for things around me that will influence me in taking care of myself.	6	5	4	3	2	1
My strength is adequate for the physical work in caring for myself.	6	5	4	3	2	1
I pay attention to signals telling me to change the way I care for myself.	6	5	4	3	2	1
I plan my self-care according to the energy I have.	6	5	4	3	2	1
I am aware of things around me that affect my ability to take care of myself.	6	5	4	3	2	1
I have the necessary skills to care for myself.	6	5	4	3	2	1
I stick to my decisions about caring for myself even when I run into setbacks.	6	5	4	3	2	1
I know the resources I need to take care of myself.	6	5	4	3	2	1
I follow through on health care prescribed for me.	6	5	4	3	2	1
I take care of myself because my health is important to me.	6	5	4	3	2	1
I remember health care information about what I should do for myself.	6	5	4	3	2	1
I judge how much energy I need to take care of myself.	6	5	4	3	2	1
To make a decision about my care, I look at the pros and cons of the option.	6	5	4	3	2	1
It matters to me that I care for myself.	6	5	4	3	2	1
I know when I have enough energy to take care of myself.	6	5	4	3	2	1

Day of your birth (1-31)/Last 4 digits of your social security number

Form A

__ / ____

day soc. sec. no.

	Very Accurate					Very Inaccurate
I know where to find good information I need to help me take care of myself. . . .	6	5	4	3	2	1
I relate my self-care actions to one another to reach my health goals.	6	5	4	3	2	1
I have the physical balance I need in order to take care of myself.	6	5	4	3	2	1
I fit new self-care actions into my existing routine.	6	5	4	3	2	1
I hearing and vision are adequate to allow me to care for myself.	6	5	4	3	2	1
The way I take care of myself is consistent with what I consider important in my life.	6	5	4	3	2	1
I do what I know is best in taking care of myself even though I may not like it. . .	6	5	4	3	2	1
I do my self-care in a variety of ways.	6	5	4	3	2	1
I follow through with decisions I make about caring for myself.	6	5	4	3	2	1
I have an established routine for caring for myself.	6	5	4	3	2	1
I consider the effects of decisions on my health and self-care.	6	5	4	3	2	1
I knowingly spend my energies on the most important self-care tasks.	6	5	4	3	2	1
I use information from authorities to help me take better care of myself.	6	5	4	3	2	1
I have enough muscle strength to perform my self-care.	6	5	4	3	2	1
I explore several alternatives before I make a decision about my self-care.	6	5	4	3	2	1
I know why I make the choices I do in order to care for myself.	6	5	4	3	2	1
I know which actions to do first to best to accomplish my self-care.	6	5	4	3	2	1
Once I begin to care for myself in a certain way, I check to see if it is working. . .	6	5	4	3	2	1
	Healthy					Unhealthy
Using a scale of 1 to 1, how would you rate your health at this moment?	6	5	4	3	2	1
	Healthy					Unhealthy
Using a scale of 1 to 1, how would you rate your own health in general?	6	5	4	3	2	1
	All					None
Using a scale of 1 to 1, how much of your own care are you providing?	6	5	4	3	2	1

S#_____

HIV-RELATED SELF-CARE BEHAVIOR CHECKLIST

We want to know how often you do each of the following things. **There are no right or wrong answers.** Circle one number for each item that best shows how often you perform this activity. If the statement doesn't apply to you, circle not applicable (N/A).

How often do you:	Never	Once A Month	Once A Week	Several Times A Week	At Least Once A Day	N/A
1. Make changes in your medications based on how you feel (such as feeling up or feeling down)?	1	2	3	4	5	6
2. Take medications (other than vitamins or herbs) that you obtain from a source other than a doctor or other legal prescriber?	1	2	3	4	5	6
3. Take vitamins or herbs for your health?	1	2	3	4	5	6
4. Eat what you consider to be a nutritious diet?	1	2	3	4	5	6
5. Snack between meals to maintain/regain your weight?	1	2	3	4	5	6
6. Participate in physical activities?	1	2	3	4	5	6
7. Plan activities to fit with your plans for self-care, such as rest?	1	2	3	4	5	6
8. Do leisure activities?	1	2	3	4	5	6

PAGE 2 SELF CARE BEHAVIORS

How often do you:	Never	Once A Month	Once A Week	Several Times A Week	At Least Once A Day	N/A
9. Use aerosol pentamidine?	1	2	3	4	5	6
10. Take medications (other than aerosol pentamidine) to prevent PCP?	1	2	3	4	5	6
11. Take AZT/ddI/ddC, alone or in combination?	1	2	3	4	5	6
12. Get enough sleep at night?	1	2	3	4	5	6
13. Talk with your friends/ loved ones about your health?	1	2	3	4	5	6
14. Meditate or pray?	1	2	3	4	5	6
15. Seek out entertaining things to do?	1	2	3	4	5	6

_____S#

Demographics Inventory

1. Age____(fill in your age in years)

2. Highest level of education completed: (use a check mark to identify one)
   (1) grammar school___
   (2) high school___
   (3) some college___
   (4) associate degree___
   (5) four year degree___
   (6) graduate degree___
   (7) technical school___

3. Your occupation:_____(use your job title)

4. For how many years have you practiced your current occupation?
   (1) less than one year___
   (2) 1-2 years
   (3) 2-5 years
   (4) more than 5 years___

5. Your ethnic identity: (use a check mark for the one that best applies)
   (1) American Indian___
   (2) African American (Black)___
   (3) Hispanic, Latino___
   (4) South Pacific Islander___
   (5) Southeast Asian___
   (6) Caucasian (not listed above)___
   (7) Taiwanese or Mainland Chinese___
   (8) Other: (specify)_____

6. Living arrangements: (check as many as apply)
   (1) Live alone___
   (2) Live with roommate(s)___
   (3) Live with lover or spouse___
   (4) Live with parents or siblings___
   (5) Live with your children___

7. Your income last year: (just your personal income; check one)
   (1) Was enough to live comfortably in the Bay Area____
   (2) Was enough to live in the Bay Area, but you were not comfortable____
   (3) Was not enough to live in the Bay Area; you needed public or private assistances____
   (4) No response____

____S#

HIV-Specific Therapeutic Self-Care Demand Inventory

Please answer the following questions as quickly as possible. There are no right or wrong answers. If you do not know the answer to a question, leave the item blank.

1. What was your city or town of origin? _____(please add the state or country as necessary to identify the location)

2. How long have you lived in the Bay Area?
   (1) less than 6 months___
   (2) 6 months - 2 years___
   (3) 2 - 5 years___
   (4) greater than 5 years___

3. How would you characterize the make-up of your neighborhood?
   (1) predominantly gay and lesbian___
   (2) predominantly heterosexual___
   (3) a mixture of the two___

4. How many friends do you have that you can call at any hour of the day or night to ask for help?
   (1) none___
   (2) one___
   (3) two___
   (3) three___
   (4) four or more___

5. Have you experienced (been part of) one of the following?
   (1) heterosexual marriage___
   (2) gay or lesbian lovers (spousal)___

6. In which of the following arenas have you been out of the closet about your sexual identity? (check all that apply):
   (1) with parents___
   (2) with some friends but not with others___
   (3) with all friends but not with all acquaintances___
   (4) with all friends and acquaintances___
   (5) on the job with some co-workers but not with the boss___
   (6) on the job with all co-workers and with the boss___
   (7) not out of the closet with any of the above___

7. When were you first identified as HIV positive after testing?
   (1) year prior to 1985: _____(record the year only if your blood was drawn and frozen)
   FROM THE FOLLOWING, CHECK THE YEAR THAT APPLIES:
   (2) 1985___
   (3) 1986___
   (4) 1987___
   (5) 1988___
   (6) 1989___
   (7) 1990___
   (8) 1991___

8. Last T helper cell count:_____

9. Date of the last T helper cell count:_____

10. Which of the following do you use to **PREVENT** getting PCP? (Check all that apply)
    (1) Bactrim___
    (2) dapsone___
    (3) aerosol pentamidine___
    (4) trimethoprim___
    (5) IV pentamidine___
    (6) other (identify):_____

11. Do you have an AIDS diagnosis?
    (1) Yes___
    (2) No___
    If not, skip questions #13 and #14. If yes, answer the next two questions.

12. Have you had one of the following? (Check all that apply)
    (1) PCP___
    (2) CMV in your eyes___
    (3) CMV in your stomach, esophagus, or intestines___
    (4) K.S.___
    (5) HIV wasting syndrome___
    (6) HIV dementia___
    (7) Thrush in your esophagus___
    (8) MAI (non-typical tuberculosis)
    (9) Other (please identify): _____
    _____
    _____

13. How many times have you been hospitalized to treat a condition associated with AIDS?
    (1) only once___
    (2) twice___
    (3) more than twice___

14. What are the medications that you use? (Check all that apply; disregard medications used to prevent PCP; also disregard vitamins, herbs, and minerals as these are addressed later)
    (1) Lamprene___
    (2) Myambutol (ethambutol)___
    (3) I.N.H.___
    (4) Rifampin or Rifabutin___
    (5) clorithromycin or azithromycin___
    (6) fluconazole (Diflucan)___
    (7) ketoconazole (Nizoral)___
    (8) Mycelex troche___
    (9) ciprofloxacin (Cipro)___
    (10) Amphotericin B___
    (11) AZT (Retrovir, zidovudine)___
    (12) ddI___
    (13) ddC___
    (14) d4T___
    (15) Other (please specify):_____
    _____

15. How many times in the past **THIRTY** days have you seen your physician or other health care provider who provides you with primary health care?

(1) 1 - 2___
(2) 3 - 5___
(3) 6 - 9___
(4) more than 9___
(5) have not seen at all___

16. Do you routinely use the services of any of the following health care professionals? (Check all that you use)

(1) psychotherapist___
(2) registered nurse___
(3) chiropractor___
(4) massage therapist___
(5) acupuncturist/herbal specialist___
(6) physical therapist___
(7) occupational therapist___
(8) spiritual healer/spiritual guide___
(9) Other (please specify):_____

17. Which of the following community services have you used at any time in the past to deal with HIV infection? (Check all that apply to you)

(1) Project Open Hand___
(2) San Francisco AIDS Foundation___
(3) Project Inform___
(4) Ethnic oriented AIDS support/information group___
(5) Living Room___
(6) AA/NA/other 12-step program___
(7) Church or synagogue group___
(8) 18th Street Services___
(9) Buyer's Club___
(9) Other (please specify):_____

18. Of the services that you checked under question #18 above, which service have you used most often? (You may use either a number or may print the name of the service here):_____

19. Just considering the service that you have used most often, rate the adequacy of this service according to the following:

(1) excellent___
(2) above average___
(3) average___
(4) below average___
(5) poor

20. Does your income each month combined with your health insurance benefits cover your health care needs in a given month (30 days)?

(1) Yes___
(2) No___

If you answered no, please answer question #21. If you answered yes, skip question #21.

21. On the average, how much **more** money in a given month (30 days) do you need to cover your health care costs?

(1) $1.00-150.00___
(2) 151.00-249.00___
(3) 250.00-399.00___
(4) 400.00-749.00___
(5) more than 750.00___

22. Of the following activities of daily living, identify which activities are patterned in your daily life. A pattern is defined as 1) a regular amount of time that you perform the activity, 2) minimal change from day to day, and 3) something about which you rarely if ever give any thought.

KEY: 1 = very strong pattern; 6 = no pattern at all

Circle the number that applies to each item according to the pattern of the activity in your daily life.

	EXAMPLE:	1	2	3	4	5	6
eating meals		1	2	3	4	5	6
drinking alcohol		1	2	3	4	5	6
exercising		1	2	3	4	5	6
snacking (eating between meals)		1	2	3	4	5	6
taking prescribed medications		1	2	3	4	5	6
watching television		1	2	3	4	5	6
reading leisurely		1	2	3	4	5	6
talking with friends		1	2	3	4	5	6
shopping for food		1	2	3	4	5	6
cooking meals		1	2	3	4	5	6
working at place of employment		1	2	3	4	5	6
paying bills		1	2	3	4	5	6
cleaning house		1	2	3	4	5	6
doing yard work		1	2	3	4	5	6
socializing with friends/family		1	2	3	4	5	6
reading materials about health		1	2	3	4	5	6
praying/meditating		1	2	3	4	5	6
talking with relatives far away		1	2	3	4	5	6
doing your laundry		1	2	3	4	5	6
attending religious services		1	2	3	4	5	6
taking vitamins/herbs/supplements		1	2	3	4	5	6
eating foods to promote health		1	2	3	4	5	6
practicing a hobby		1	2	3	4	5	6

23. What is the effect of the following factors on your health?

1 = great effect; 6 = no effect at all

Circle the number that best describes the effect that the factor has on your health.

	EXAMPLE:	1	2	3	4	5	6
how much money you have		1	2	3	4	5	6
whether other people are happy		1	2	3	4	5	6
a clean, neat house		1	2	3	4	5	6
how much debt you have		1	2	3	4	5	6

orderly home life	1	2	3	4	5	6
a gay-friendly community	1	2	3	4	5	6
supportive friends/family	1	2	3	4	5	6
who is President of the U.S.	1	2	3	4	5	6
peace in the world	1	2	3	4	5	6
feeling accepted as a gay person	1	2	3	4	5	6
balance of leisure and work	1	2	3	4	5	6
regular vacations	1	2	3	4	5	6
money/time to take vacations	1	2	3	4	5	6
work that you love to do	1	2	3	4	5	6
shopping located close to home	1	2	3	4	5	6
access to driving an automobile	1	2	3	4	5	6
physician whom you like	1	2	3	4	5	6
physician whom you respect	1	2	3	4	5	6
free time to do what you want	1	2	3	4	5	6
access to alternative health care	1	2	3	4	5	6

HIV Self-Care Operations Questions for Subject Response

DIRECTIONS: 1) Turn on the tape recorder, 2) Speak directly into the microphone, 3) Occasionally look at the tape to make sure that the recorder is working, 4) Go through your answers to the questions in the order in which they appear on this form, 5) Take as much or as little time as you like, 6) You may turn the recorder on pause as you like while thinking through your response, and 7) PLEASE NOTE TODAY'S DATE PRIOR TO GIVING YOUR RESPONSES.

1. Today have you attended information sessions, meetings, or forums of Project Inform, the Immune Enhancement Program, or other groups that transmit knowledge regarding HIV infection or AIDS?

Today have you acquired information from any of the following sources?

physician___ nurse___ other health care worker___ printed literature____ kind of literature _____TV____ Radio____ newspaper_____ other media_____ word of mouth_____

Identify the information about HIV disease or some aspect of your health care that you have acquired today. (For example, today you learned that your health care benefits will soon change to Medi-Cal.)

_____

Is any of the information obtained today new to you? Yes___ No___ If YES, identify the information:

_____

If this information is NEW to you, will you incorporate it into your daily life? YES___ NO____ If YES, how will you incorporate

it?_____

For example, let's suppose that you learned something new about the prevention of PCP, and now you plan to incorporate Bactrim into your prevention regimen.

And, was this decision considered one that you made alone or along with your significant other or health care provider?

Has any newly obtained information obtained made you reconsider a decision that you had made previously or were just about to make about a health-related problem? Please elaborate...

2. <u>Answer only once</u>: With regard to your body, what do you know happens to you when you are ill even before a health care worker confirms your illness? AFTER ANSWERING THIS QUESTION, DRAW A LINE THROUGH THE QUESTION TO HELP YOU REMEMBER NOT TO ANSWER IT AGAIN.

Today have you developed any symptoms of HIV disease? YES___ NO____ If YES, answer the next question, please.

What were the symptoms that you experienced today (if any)?

Did you feel ill or not well today, even if you did not experience symptoms of the disease?

How do you feel in general when you develop symptoms of HIV disease?

How was you energy level today on a scale of 1 to 10, with 10 being "FULL OF ENERGY" and 1 being "DEVOID OF ENERGY."

3. Today have you started, stopped, or changed the dosages and kinds of medications that you take? If yes, identify the drugs and their amounts. For example, perhaps you noticed that you had thrush in your mouth this morning, so you started Mycelex troches three times a day.

Was today a "fast" movement day or a "slow" movement day? Please elaborate...

Did you exercise today? YES___ NO____ If YES, state the kind of exercise and for how long you did it.

What foods did you eat? Is this a usual day's diet for you?

What vitamins/minerals/herbs did you consume other than in your food? Please be specific to include names of vitamins/supplements and their amounts.

Did you nap or rest today? YES____ NO_____ If YES, how long and how many rest periods did you take.

How much time did you spend alone today?

How much time did you spend with others?

How much time did you spend:

paying bills?

making phone calls?

carrying out your personal business?

working?

playing?

relaxing (doing recreational type of things)?

On a scale of 1 to 10, with 10 being most severe and 1 being none, how much anxiety did you experience today?

Using the same scale, how much depression did you experience today?

4. Have you decided today to change anything concerning the way that you take care of yourself? Or have you decided to continue taking care of yourself in the ways that you have in the recent past? Please elaborate.

Today have you made a conscious decision not to change anything, even through you know a change might help? Please elaborate...

5. What have you done today to get ready to take care of yourself? For example, lately your appetite has been on the low side, but today you decided to call a group of friends to have dinner with you with the intent that eating with others might perk up your appetite.

6.a. Were you able to start and complete activities of taking care of yourself today--something that you identified as having a beginning and an end? For example, today you relaxed for an entire thirty minutes by starting and completing a meditation session.

6.b. Was your ability to care for yourself today in any way affected by persons, events, or finances in your life? Please elaborate.

7. a. Have you achieved the results that you wanted by doing something to take care of yourself today? What was it that you did and what were the results?

7.b. If you didn't achieve the results that you wanted, such as you tried a new skin creme to alleviate dry skin but it only made your skin feel greasy, what was the action that you performed and what was the outcome?

8. Looking back at your answers for question #8, what has been your thinking about the things that you've done to take care of yourself? Do you want to go on doing the same things tomorrow? If not tomorrow, do you want to do these things at a later time, such as the next time that the same problem comes up?

9. Continuing along the same lines as questions #8 and #9, will you change or continue the same ways of taking care of yourself as you have already done?
9 b. Do you need more information about the things that you have done to take care of yourself, such as whether you need to learn about a new health-care product or another self-help group?

IF YOU HAVE NOT ALREADY NOTED TODAY'S DATE ON THE TAPE, PLEASE DO SO NOW. ALSO STATE HOW MANY MINUTES IT HAS TAKEN YOU TO COMPLETE TODAY'S SESSION.

TURN OFF THE TAPE RECORDER.

IF IT IS TIME FOR YOU TO REST, HAVE A GOOD REST.

IF YOU NEED TO SPEAK TO ED FREEMAN, PLEASE CALL 863-1241.

Appendix F

Consent to be a Research Subject

University of California, San Francisco
CONSENT TO BE A RESEARCH SUBJECT

Self-Care Agency in Gay Men Infected with the Human Immunodeficiency Virus (HIV)

A. Purpose and Background

Dr. Susan Gortner, Ph.D. and Edward M. Freeman, M.S., R.N., C., in the UCSF School of Nursing, are conducting a study on the abilities of gay men infected with the Human Immunodeficiency Virus (HIV) to practice self-care.

This study is designed to gather information about the self-care abilities of gay men infected with HIV who have 200 or less T helper cells. I have been asked to participate in this study because I am a gay man with 200 T helper cells or less.

B. Procedures

If I agree to be in the study, the following will occur:

Either option #1 or option #2 will be followed. I agree to the option next to which I have affixed my initials.

1. I will be interviewed one time to complete several questionnaires pertaining to my self-care abilities and self-care practices_____(initials).
2. I will be asked to record daily observations regarding my self-care behaviors into a microcassette recorder. I understand that these tapes will be transcribed to be used in the development of a self-care questionnaire. Completing the self-care questionnaire will take about 10 minutes each day. I will record my observations every day for 90 days (3 months). In addition, I will complete several other questionnaires pertaining to my self-care abilities and self-care practices _____(initials).

C. Risks/Discomforts

Risks and discomforts in participating in this study may be the potential loss of privacy. However, my name and/or other source of identification is not noted on any of the study questionnaires or on audiotape. Also, there may be some discomfort from being asked to think about my current problems related to my diagnosis of HIV infection.

I am under no pressure from my doctor, nurse, or respiratory therapist to participate. My care will not change as a result of my responses to the study. The survey will be coded and when completed will then be kept at all times in a locked, confidential file not accessible to any other than the investigator.

9/19/91
H555-07208-01

D. Benefits

There are no direct benefits to me from participating in this study. However, I may be stimulated to think through my own ideas about my self-care. It is hoped that the information gained from the study will contribute to the development of knowledge of self-care practices needed for nurses to plan their nursing care.

E. Alternatives

I am free to refuse to participate or to withdraw from this research at any time without jeopardizing my health care.

F. Costs

There will be NO costs to me as a result of taking part in this study.

G. Reimbursement

I will not be reimbursed for participating in this study.

H. Questions

This study has been explained to me by Edward M. ("Ed") Freeman. If I have further questions about this study, I may call Ed Freeman at 863-1241.

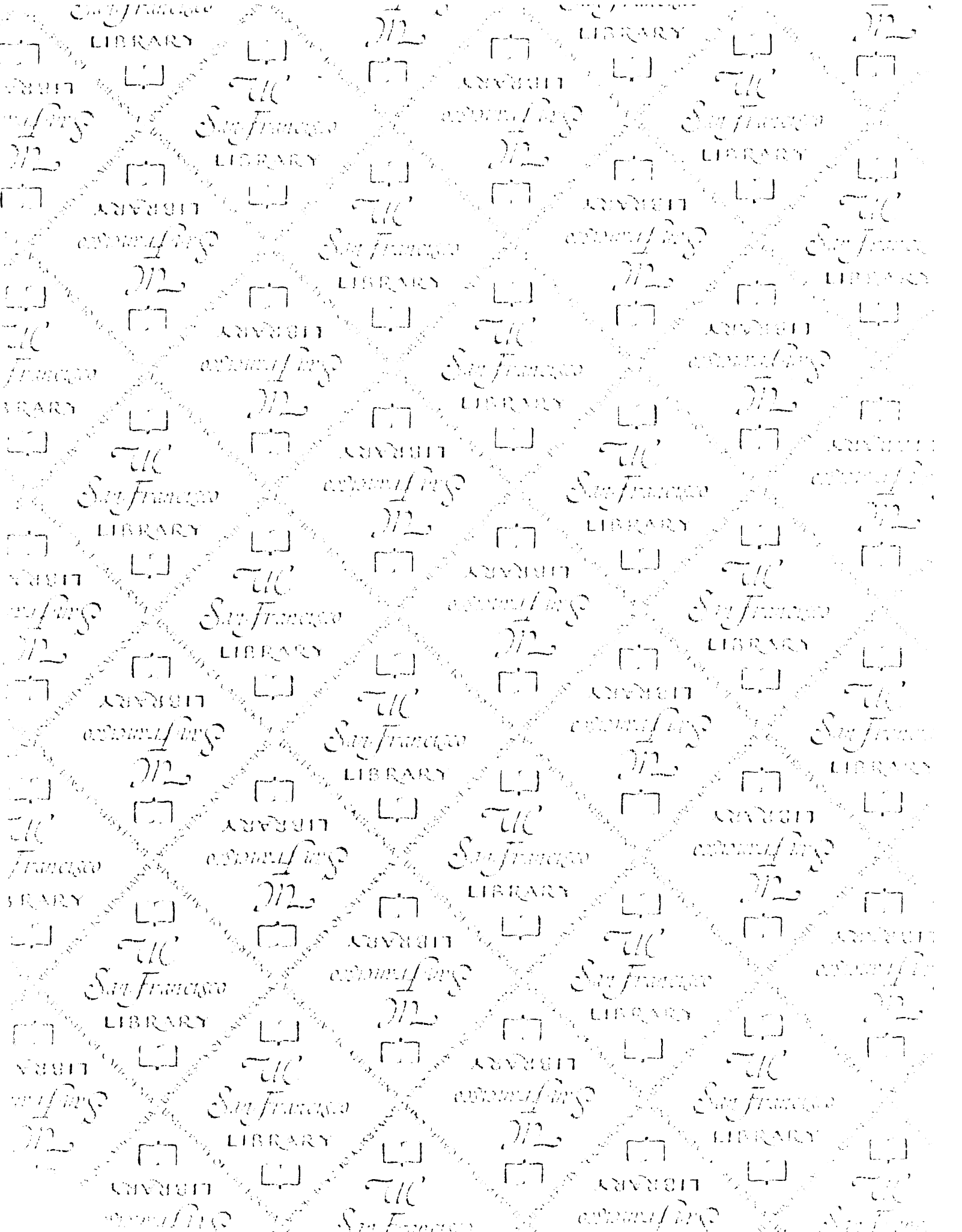
If I have any questions or comments about participation in this study, I should first talk to the investigator. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the Committee office between 8:00 am and 5:00 pm, Monday through Friday, by calling (415) 476-1814, or by writing to the Committee on Human Research, Suite 11, Laurel Heights Campus, Box 0616, University of California, San Francisco, San Francisco, CA. 94143.

I have been given a copy of this consent to keep .

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient, student, or employee at UCSF or Davies Medical Center.

DATE	SUBJECT'S SIGNATURE
	Person Obtaining Consent

9/19/91
H555-07208-01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