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An Analysis Of The Social Support Network Of Gay Men Living With Hiv

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NOTE TO USERS

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AN ANALYSIS OF THE SOCIAL SUPPORT NETWORK OF GAY MEN LIVING WITH HIV

A Dissertation

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In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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by

Bridget Roberts-Pittman

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CERTIFICATE OF APPROVAL

DOCTORAL DISSERTATION

This is to certify that the Doctoral Dissertation of

Bridget Roberts-Pittman

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has been approved by the Examining Committee for the dissertation requirement for the

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ABSTRACT

This study examined the social support networks of gay men living with HIV. This study represents a unique detailing of the specific members of their social support networks. Eighty-five participants completed the Social Support Questionnaire (Wright, 1995) initially and at 6-month intervals for a 2-year period. The participants were divided into 3 groups defined by HIV status: (a) asymptomatic; (b) symptomatic; and (c) AIDS. Seven participants were randomly selected from each group, resulting in the sample of 21 participants with 238 different individuals within the networks. Networks were examined in terms of stability of the members within the specific networks. Family members were more stable over time than friends within the support networks. This finding challenges the barrier theory and offers critical information for professionals working to improve the quality of life for individuals living with HIV.

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Introduction

Despite a dramatic improvement in treatment in the last decade, human immunodeficiency virus (HIV) remains an enormous health concern in the United States and around the world (Masur, Kaplan, & Holmes, 2002). By 2002, an estimated 886,575 individuals had been diagnosed with HIV in the United States, with men representing an overwhelming proportion of those diagnosed, approximately 718,000 cases compared to 159,000 cases in women. Homosexual male contact remains the primary way in which HIV is transmitted in the United States. According to the HIV/AIDS Surveillance Report generated by the Centers for Disease Control and Prevention (CDC, 2004), an estimated 420,000 individuals diagnosed with HIV were reportedly infected through homosexual contact, while an additional 59,000 individuals identified both homosexual contact and injection drug use as their exposure category. These staggering numbers demonstrate that gay men remain the largest group of individuals infected with HIV. Because gay men continue to make a greater percentage of individuals with HIV, medical and mental health professionals need more information regarding the variables that improve quality of life. One such variable is social support. Information on social support will assist individuals infected, as well as their family and friends, as they deal with this illness and help improve their quality of life.

Gay men living with HIV are faced with a multitude of stressors, including the physiological consequences of the illness, loss of employment and financial resources, changing self-image, and loss of control over their lives. Many of these stressors are common among sufferers of other chronic illnesses; however, unique and even stronger

stressors such as social isolation, stigmatization and alienation from peer and support groups impact an individual living with HIV (Hays, Chauncey, & Tobey, 1990; Herek, Capitanio, & Widaman, 2002). Social support has been shown to be a critical element in adjusting to and coping with chronic illness (DiMateo & Hays, 1981), and has been a main factor in decreasing depressive symptoms among gay men living with HIV (Leserman et al., 2000). Like people with other chronic illnesses, individuals with HIV turn to medical and mental health professionals for assistance. However, Gottlieb (1981) noted that although patients turn to professionals, the most critical support is provided by family and friends. Living with a chronic illness, such as HIV, means dependence on medications and a busy schedule of appointments with professionals. Moreover, memory difficulties are strongly linked to HIV (Jennings & Jennings, 1991), making consistent adherence to medications difficult for many of the individuals infected. Family members and friends may assist the individual with a chronic illness to remember life-sustaining events, such as adherence to medication regimens and appointments with professionals (Corless, Bakken, Nicholas, & Holzemer, 2000). With these factors in mind, as well as the staggering number of HIV cases in the United States and around the world, research on the support systems of persons living with HIV is crucial for patients, their families and friends, and the professional community.

Importance of Family Members

Smith and Rapkin (1996) offer a "barrier theory" to explain why family members are perceived as less helpful than friends for gay men living with HIV. The barrier theory postulates that several barriers exist that keep individuals from seeking out the support of

their families. These barriers include limited access to family members, lack of acceptance from their families, little intimacy in family relationships, negative interactions, feelings of being smothered, and wanting to protect family members. In addition, barrier theorists suggest that gay men are not accustomed to asking for help and would find doing so very difficult. Other reasons include the idea that gay men living with HIV may already feel isolated and stigmatized and not want to be a burden on their families (Herek & Glunt, 1988). Similarly, such individuals may have elderly parents with personal difficulties of their own and individuals with HIV do not want to add to their personal problems. Lastly, seeking support from family members would mean disclosure of their HIV status and sexual orientation and some may not be willing to share such information (Serovich, 2001).

However, a growing body of research demonstrates the importance of family members, as family support has been shown to be more critical than friend support in decreasing the risk behaviors of gay men living with HIV (Kimberly & Serovich, 1999). Such research can assist professionals in assessment and treatment, as well as alleviate some of the demands placed on them. For the families and friends, such research can provide a framework to guide them in being supportive and helpful as their loved ones face HIV (Hoffman, 1991). Further, Noring, Dubler, Birkhead, and Agins (2001) stress the importance of professionals' engaging family and friends to provide support and education to the persons infected. Such support will likely increase the persons' readiness for treatment, sustain treatment maintenance, and offer encouragement and assistance.

Research on the social support networks of gay men living with HIV will also shed light on these relationships, which have not been examined (Palmer & Bor, 2001).

Social Support

In general, studies have shown that individuals adjust better to stressful life situations when social support is available, as compared to when it is not (Cohen & Wills, 1985). Further, numerous studies have shown that social support is inversely related to psychological distress among individuals living with HIV (Koopman, Gore-Felton, Marouf, & Butler, 2000; Schmitz & Crystal, 2000) and specifically gay men living with HIV (Hall, 1999; Hays, Turner, & Coates, 1992).

Serovich, Brucker, and Kimberly (2000) stated that researchers have not yet studied lack of access to family members. However, many have concluded that having HIV causes strain in the social network, thus limiting the availability of family members (Burgoyne & Saunders, 2000). Serovich et al. further argue that family support may represent a small but important proportion of the total number of individuals within the social support network. Several reasons may help explain why they represent a small proportion. Those reasons may include that the family is quite small in number, family members may live at a distance, or the family members could be unavailable due to illness or age. Given this, Serovich et al. argue that studies which only examine frequencies of social support networks may not represent the true amount of support men living with HIV may receive from their families. Friends may be more plentiful in numbers in regard to the social support network, and thus only appear to be offering more support.

Serovich et al. (2000) tested the barrier theory by comparing the support gay men with HIV received from both family and friends. Social support was defined as availability of the supportive individual, the level of intimacy in the relationship, and disclosure (meaning whether or not the supportive individual knew of the HIV diagnosis). They hypothesized that as support increased, individuals with HIV would report better health outcomes, less depression, and fewer symptoms and less disease progression. They concluded that barriers do exist that hinder individuals' willingness to seek out support. However, they found that the same barriers existed for both family and friends. Further, they found that it was the number of supportive individuals that led to more positive outcomes. They concluded that other factors may explain why families do not appear as supportive as friends. One factor may be the level of satisfaction with the relationships between individuals with HIV and their family members. Gay men living with HIV who feel a sense of satisfaction from their relationships with family members may be more willing to gain support from them. Serovich et al. encouraged more research to focus on the family relationships of gay men living with HIV, such as investigating the impact of families and the support they provide to these men.

Other findings further suggest that family members provide critical support to gay men living with HIV. Vandehey and Shuff (2001) examined social support networks of gay men living with HIV over the course of a 2-year period. Participants identified supportive individuals as family, friend, or professional. Over the course of the study, they found that the amount of social support from family and friends remained consistent. They recommended that further research examine the impact of negative social support

providers on the health outcomes of gay men living with HIV. Similarly, Siegel, Ravels, and Karus (1997) suggested further research to explore the impact of negative social support providers and networks on gay men living with HIV. They offered two suggestions. One is to look at the stability of a support system over time by examining the exact number of supportive individuals within one's network. The second is to assess specifically which groups provide the most support when comparing friends, families, and professionals.

Kadushin (1999) also tested the barrier theory by examining the perceived support of men with HIV. Results suggest that men with HIV perceived friends as more supportive and they were more likely to turn to friends for support. Other results suggest that as their illness progresses, especially to AIDS, men with HIV sought more support from their families and their families in turn were highly supportive. Mothers and sisters were identified as the most supportive with fathers and brothers seen as less supportive. The researcher postulated that the same reasons that keep individuals living with HIV from seeking family support in general likely also hinder men living with HIV to turn to their fathers or brothers for support and that more information on the importance of family members is needed.

This study examined the social support network of men living with HIV in more detail than previous research. Specifically, this study looked at: (a) the relationships identified within the social support networks of gay men living with HIV; (b) how these relationships compared over time; and (c) how factors such as age, propinquity, and perceived support impact the social support networks. Previous research has failed to

look at the characteristics and relatedness of the specific individuals who make up the social support networks of gay men living with HIV. Further, no studies have attempted to offer a detailed description of these individuals. Instead, researchers have defined the individuals in broad terms such as "family members" or "friends" and studied groups or categories. This research is important given the alarming and still increasing number of individuals diagnosed with HIV or AIDS. Research to better understand social support networks will lead to an awareness of the health issues, as well as the social issues, that affect individuals living with HIV (Faber & Wasserman, 2002).

Method

Participants

The sample included male participants who completed the Social Supports Questionnaire (SSQ) at each six-month interval for the two years of the study as part of the Indiana Integration of Care Project (IICP). The participants were divided into three groups based on their self-identified HIV status: (a) asymptomatic; (b) symptomatic; and (c) AIDS. Twenty-seven men identified their HIV status as symptomatic while 34 men identified their health status as AIDS. Thirteen identified their HIV status as asymptomatic. Eleven men were removed as their HIV status changed during the course of the two years. Of the 11 men removed, 5 reported a change in health status from asymptomatic to symptomatic, while 6 reported a change from symptomatic to AIDS. Seven men were randomly chosen from each of the three groups, resulting in the sample of 21 participants. Due to the small percentage of women (9%) participating in the IICP, the sample for this study is limited to male participants.

Of the 21 men included this study, 19 (90%) were Caucasian, 1 (5%) was African-American and 1 (5%) was Hispanic. The mean age was 36.8 (SD = 8.83). In terms of relationship status, 7 (33%) reported being in a noncommitted relationship while 4 (19%) reported being in a committed relationship. Seven (33%) reported being single, 2 (10%) reported being divorced, and 1 (5%) reported being widowed. An almost even split existed between those who reported being employed (n = 10; 48%) and unemployed (n = 11; 52%). The majority (n = 14; 66%) reported at least some education beyond a high school diploma. Twelve (57%) men reported a monthly income of less than $1000, while nine (43%) reported a monthly income above $1000 per month. Sixteen of the men were diagnosed with HIV in Indiana, while five were living in other states at the time of their diagnosis. At the time of diagnosis, two participants were living in Florida, another in California, and one participant each living in Pennsylvania and Michigan respectively.

Instrumentation

Client Information Form. The demographics of race, age, relationship status, employment status, level of education, income status, and residence at time of HIV diagnosis were taken from the Client Information Form.

Social Supports Questionnaire (SSQ). The Social Supports Questionnaire, designed by Wright (1995) examines multiple variables related to social support. Participants completing the form are allowed to identify up to nine individuals by whom they feel supported. Along with the individuals' first name or initials, participants are asked to give the gender, age, race, sexual orientation, HIV status, and the geographic distance for the people they identified as supportive. In addition, participants are asked

about frequency of contact, perceived closeness, support regarding the participant's HIV diagnosis, and whether or not the supportive individuals are also diagnosed with AIDS. Participants who had more than nine supportive individuals were asked to write the number of additional supporters at the bottom of the page.

Procedures

Participants (N = 275) were enrolled as part of a state-wide HIV service demonstration, the IICP. Prior to their participation in the study, the participants had to be diagnosed with HIV and all were currently receiving HIV care coordination services or mental health services through the state's mental health centers. The participant identified his health status from three choices: (a) asymptomatic; (b) symptomatic; and (c) AIDS.

Each participant completed the Client Information From, the Health Status Questionnaire (Wu et al., 1991; Synder et al., 1991) and the Social Supports Questionnaire (Wright, 1995) upon enrollment in the study and at each six-month follow-up for the next two years. The participants received the questionnaires in the mail and were given self-addressed envelopes in which to return the completed questionnaires. As an incentive, the participants received $25.00 once they had properly completed and returned the questionnaires. Eighty-five men completed the questionnaires at all of the follow-up time intervals. Twenty-one participants, seven from each of the three health status categories, were randomly chosen from these 85 men. This study compares their questionnaires at the different time intervals.

Results

Participants (N = 21) identified 238 different individuals within their social support networks. Relationships were identified as: (a) friend; (b) partner;

(c) mother/step-mother/mother-in-law; (d) father/step-father/father-in-law; (e) professional; (f) sibling; (g) other family member (i.e., grandmother, cousin); and (h) other. Participants identified 164 supportive individuals as friends (69%). Combining the groups that represented family relationships (i.e., mother/step-mother/mother-in-law, father/step-father/father-in-law, sibling, other family relative), participants identified 46 family members as supportive (19%). Frequencies of each relationship were calculated. Results are displayed in Table 1.

Next, the individuals within the different relationship groups were compared in terms of their stability over time. First, the number of men who listed a particular relationship category was determined for each group. In other words, the number is displayed in column n of Table 2 representing the number of men who listed the relationship category. In each HIV status group, all participants listed at least one friend. Family members were also listed often, but not one family relationship category was listed every time for all participants. Next, the average stability was calculated to determine the consistency of each relationship category over the five time intervals. The numbers displayed in the stability columns of Table 2 represent the average number of intervals in which that relationship category was identified by those who listed the particular relationship.

Of the 13 participants who listed their mothers, mothers were present on average 4.00 times for the asymptomatic group, 5.00 times for the symptomatic group, and 4.33 times for the AIDS group. Eleven participants listed their fathers, and on average fathers were present 3.00 times for the asymptomatic group, 4.33 times for the symptomatic group, and 3.25 times for the AIDS group. Siblings were present on average 2.83 times

for the asymptomatic group, 2.53 times for the symptomatic group, and 3.93 times for the AIDS group. In terms of other family members (i.e., grandmother, cousin), they were present on average 2.33 times for the asymptomatic group, 4.00 times for the symptomatic group, and 2.00 times for the AIDS group. All participants listed at least one friend, yet, they were only present at average of 1.69 times for the asymptomatic group, 1.48 times for the symptomatic group, and 1.48 times for the AIDS group. Fourteen participants listed a partner and on average this person was present 3.00 times for the asymptomatic group, 2.33 times for the symptomatic group, and 3.67 times for the AIDS group. Of the four participants who listed a professional (e.g., therapist, care coordinator), the individual was present an average of 4.00 times for the asymptomatic group, 2.00 times for the symptomatic group, and 1.00 times for the AIDS group. Ten participants listed another relationship defined as "other," such as a co-worker or pastor. On average these individuals were present 1.50 times for the asymptomatic group, 1.83 times for the symptomatic group, and 1.00 times for the AIDS group.

Next, the factors of age, propinquity, and perceived support were explored by calculating the frequencies for each variable. The majority of individuals listed as supportive fell within the age range of 30-39 (34%) followed closely by the age ranges of 20-29 (18%) and 40-49 (20%). The majority of supportive individuals lived a distance of 6-20 miles away (29%) from the individual living with HIV while 25% lived only 0-5 miles away. A large majority (69%) of supportive individuals were identified as very supportive. The frequencies are displayed in Tables 3, 4, and 5.

The three factors, age, propinquity, and level of support, did not appear to distinguish the three groups from each other. Results of these factors were quite similar

among the groups. One difference showed that participants in the asymptomatic category identified supportive individuals who were on average ten years younger than the supportive individuals listed in the other two HIV status groups. Participants in the three HIV status groups found support from individuals who lived in close proximity to them. Further, individuals listed as supportive were perceived as quite supportive with the support identified as either very or somewhat supportive. The results are shown in Table 6.

Discussion

An estimated 886,000 individuals in the United States are living with HIV and approximately 40,000 new cases of infection are reported each year. In Indiana, approximately 3,600 individuals are living with HIV with 507 new cases of infection reported in 2003 (CDC, 2004). These staggering numbers illustrate the value of determining variables that can positively contribute to improving the quality of life for individuals living with HIV.

Previous studies have been conducted in larger metropolitan areas, while this study examined the networks of gay men living with HIV residing in rural areas. The results of this study challenge the barrier theory and present support for the importance of family in the lives of gay men living with HIV. While family members have previously been viewed as less supportive, the current study suggests that family members provide critical support to individuals living with HIV. Supporters of the barrier theory state that individuals with HIV are not likely to seek support from family because certain barriers exist (Smith & Rapkin, 1996). The postulated barriers of aged parents, geographical distance between family members and individuals infected, and lack of closeness in the

family relationships did not exist for the individuals in this study, which challenges the barrier theory. In this study, family members were present more often than friends across the five time intervals. Further, the participants identified the degree of support from family members and friends as either very supportive or somewhat supportive. Lastly, supportive individuals on average lived within 20 miles of the individual living with HIV. These findings dispute the key barriers comprising the barrier theory.

The findings also are consistent with a study conducted by Vandehey and Shuff (2001) which demonstrates that support from both family and friends remains consistent over time. This disputes previous beliefs that the support from family members will increase as the individual progresses to a more serious stage of HIV.

One limitation of this study is that the participants were asked about individuals they identified as supportive as opposed to those individuals they perceived as not supportive. Despite this limitation, it is apparent that further research is needed in this area. Until recently, researchers have not viewed family members as a critical part of the social support network of individuals living with HIV and this support has gone unrecognized. To date, there is no cure for HIV, making information to improve the quality of life of those individuals infected invaluable.

Recommendations

Longitudinal studies examining the stability of social support networks over time are needed for individuals living with HIV living in large metropolitan areas. This research would be valuable as a large percentage of gay men living with HIV live in such urban areas. According to the HIV/AIDS Surveillance Report (CDC, 2004), more than 155,000 individuals with HIV were living in the state of New York and more than

128,000 were living in the state of California. These numbers suggest that nearly one-third of the individuals with HIV live in one of these two states.

This study used a descriptive approach to closely examine the members of the social support networks because previous quantitative methods have overlooked important details of the social support networks. It is recommended that qualitative approaches, such as interviews, be conducted to better assess the details of the social support networks and possibly shed light on the importance of family members. Such studies could also identify protective factors within these support networks. Additionally, dramatic improvements in medications have led to improvement in immune functioning and a decrease in mortality rates. But despite these improvements, adherence to medication regimens remains the most critical factor in determining the benefits of the medication and social support is a major contributor to adherence (Catz, Kelly, & Bogart, 2000).

Qualitative analysis is also recommended to examine many areas of inquiry. First, qualitative analysis could explore reasons why friends change over time and what characteristics signify friends who are stable, as opposed to those who are less consistent. In contrast, such analysis could reveal reasons why family members are more consistent over time and yet individuals with HIV are not alerting medical and mental health professionals to the critical support they receive from family members. Further, qualitative analysis could explore negative interactions within relationships on the progression of HIV. Researchers have identified the hindrance of negative interactions on individuals with HIV, but this relationship is not well understood (Fleishman, et al., 2000; Ingram, Jones, Fass, Neidig, & Song, 1999). By examining these interactions in

detail, researchers may determine ways to prevent such influences from having detrimental effects on individuals living with HIV. Additionally, further research may determine what consequences arise for those gay men living with HIV who choose to stay in close proximity to their family members.

Research is also needed on the social support networks of women living with HIV. Because women make up a small percentage of individuals living with HIV, their specific needs are often unacknowledged. Women living with HIV are often the primary caregiver for children, they have limited access to health care, and they have fewer financial resources.

Practical applications

Members of the medical and mental health community need to consider these findings. Practitioners providing direct medical and mental health services to gay men living with HIV must be aware of the valuable support provided by family members. The widespread acceptance of the barrier theory may have created biased or mistaken preconceptions about family members. Based on the findings of this study, such preconceptions lead to inaccurate beliefs and miss critical support for individuals living with HIV.

The results suggest that family members are more supportive than postulated by the barrier theory. Further studies need to examine the important contribution that family members are making to individuals living with HIV. HIV remains an enormous health concern in the United States and around the world. Further, rates of infection are still rising dramatically and particularly for younger persons and persons of ethnic minority groups (CDC, 2004). The continued spread of the disease means vital support must be

identified and utilized. In addition, researchers and practitioners can employ influential individuals to assist infected persons in getting the care they need (Faber & Wasserman, 2002).

TABLES

Table 1

Specific Relationships Identified Within Support Networks

Relationship	n	%
Friend	164	69
Partner	14	06
Mother/Step-mother/Mother-in-law	13	05
Father/Step-father/Father-in-law	11	05
Professional	4	02
Sibling	13	05
Other family relative	9	04
Other	10	04

Table 2

Frequencies of Relationship Category and Average Stability by HIV Status

	Asymptomatic (n =7)		Symptomatic (n = 7)		AIDS (n = 7)	
	n	Stability	n	Stability	n	Stability
Mom	5	4.00	2	5.00	6	4.33
Dad	5	3.00	3	4.33	3	3.25
Sibling	4	2.83	4	2.53	5	3.93
Other family	3	2.33	3	4.0	3	2.00
Friends	7	1.69	7	1.48	7	1.48
Partner	5	3.00	3	2.33	6	3.67
Therapist/ professional	1	4.00	1	2.00	2	1.00
Other	2	1.50	5	1.83	3	1.00

Table 3

Frequencies of Age by HIV Status

Age	Asymptomatic		Symptomatic		AIDS		Total	
	n	%	n	%	n	%	n	%
0-19	1	.4	0	0.0	0	0.0	1	0.0
20-29	1	.4	1	.4	0	0.0	2	.8
30-39	17	7.1	9	3.8	29	12.2	55	23.1
40-49	33	13.9	35	14.7	36	15.1	104	43.7
50-59	14	5.9	27	11.3	14	5.9	55	23.1
60-69	4	1.7	9	3.8	4	1.7	17	7.1
70+	3	1.3	1	.4	0	0.0	4	1.7

Table 4

Frequencies of Propinquity by HIV Status

Closeness	Asymptomatic		Symptomatic		AIDS		Total	
	n	%	n	%	n	%	n	%
Same house	3	1.3	12	5.0	11	4.6	26	10.9
0-5 miles	14	5.9	27	11.3	30	12.6	71	29.8
6-20 miles	23	9.7	13	5.5	18	33.6	54	22.7
21-75 miles	7	2.9	8	3.7	10	4.2	25	10.5
75 miles or more	11	4.6	26	10.9	25	10.5	62	26.1

Table 5

Frequencies of Degree of Support by HIV Status

Support	Asymptomatic		Symptomatic		AIDS		Total	
	n	%	n	%	n	%	n	%
Very	48	20.0	57	24.2	77	32.8	182	76.4
Somewhat	3	1.4	27	10.0	16	6.6	46	19.3
Not very	1	.2	2	1.0	0	0.0	3	1.3
Don't know	5	3.2	1	.4	1	.2	7	2.9

Table 6

Differences Among Groups Based on Age, Propinquity and Perceived Support

Group	Asymptomatic	Symptomatic	AIDS
Median age of supportive individuals	30-39	40-49	40-49
Median distance of supportive individuals	6-20 miles	6-20 miles	6-20 miles
Median of perceived support	Very	Very	Very

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APPENDIX A: THE RESEARCH PROBLEM

Purpose of Study

The purpose of this study was to investigate the social support network of men living with HIV. This study is unique in that no study has looked at characteristics and relatedness of specific individuals comprising the social support network. Further, no studies have attempted to offer a detailed description of the individuals making up the social support networks of gay men living with HIV. Instead, researchers have defined the individuals in broader terms such "family members" or "friend." This study examined the individuals in more detail. This research is critical given the alarming and still increasing number of individuals diagnosed with HIV or AIDS. Research to better understand the social support networks will lead to an awareness of the health issues, as well as the social issues, that affect individuals living with HIV (Faber & Wasserman, 2002).

The data for this study were collected as a part of the Indiana Integration of Care Project (IICP). This study examined the social support networks of individuals infected with HIV at five different time periods: the onset of the study, the 6-month follow-up, the 12-month follow-up, the 18-month follow-up, and the 24-month follow-up. More specifically, this study investigated how do relationships within the support network change over time.

Researchers have examined the impact of social support on individuals living with HIV; yet, more research is needed. In one study, Ingram, Jones, Fass, Neidig, and Song (1999) examined the positive and negative social interactions and found that

negative social interactions were highly correlated with reported symptoms of depression among individuals living with HIV. Given the results, the researchers recommended further research, particularly longitudinal studies, to assess the stability of social support networks over time.

Statement of the Problem

Barrier theory postulates that family members are not perceived as supportive for various reasons; thus, the impact of family members has not yet been adequately explored. Researchers and health care providers have overlooked a potentially vital network, despite the number of studies that suggest perceived social support is linked to better health, fewer depressive symptoms, and overall positive perception of life for gay men living with HIV. Studying the supportive relationships identified by gay men living with HIV may lead to more comprehensive and valuable assessments and interventions for this population. Weeks, Clair, Borgatti, Radda, and Schensul (2002) argued that further research needs to explore more closely the interpersonal relationships, social ties, and interconnections among individuals at risk of spreading the deadly disease. Previous researchers have examined the spread of HIV through networks, yet, little is known about how better understanding the social networks can assist providers in assessing social support and linking individuals to needed support. The goal of this study was to add critical information that may lead to effective strategies in providing support and assistance to individuals living with HIV. Further, research to better understand the social support networks will lead to an awareness of the health issues, as well as the social issues, that affect individuals living with HIV (Faber & Wasserman, 2002). Further, this

study looked closely at many factors such as age, geographical distance, and perceived closeness that affect the support systems of gay men living with HIV. Previous researchers have broadly examined the support networks, but have failed to closely examine the wealth of detailed information available. Research from a broad perspective misses critical information that sheds light on changes over time, as well as the importance of certain individuals and their stability within the network.

This study focused specifically on the importance of the individuals within the social support networks of gay men living with HIV for several reasons. First, it is critical to focus on the most important members as they will become key players in deterring the spread of HIV (Friedman, Curtis, Neaigus, Jose, & Des Jarlais, 1999). In addition, by identifying the important individuals of the network, researchers and practitioners can utilize influential individuals to assist infected persons in getting the care they need (Faber & Wasserman, 2002).

Research Questions

1. What relationships within the social support network are identified by gay men living with HIV and are these similar across the HIV status groups?
2. When comparing the social support networks of individuals across the spectrum of HIV, how do the networks of individuals compare over time in terms of stability?
3. Descriptively, how do gay men living with HIV rate the factors such as age, propinquity, and perceived support on their social support networks?

Definitions

HIV-infected/HIV-positive: A positive blood anti-body test indicating the infection of human immunodeficiency virus (HIV). This also includes individuals diagnosed with Acquired Immune Deficiency Syndrome (AIDS).

AIDS: The infected person has a T-cell count below 200/mm^3 or has experienced an opportunistic infection.

Symptomatic: The individual infected with HIV experiences somatic problems commonly associated with HIV.

Asymptomatic: The individual infected with HIV experiences no somatic problems.

Social support network: The number of individuals and their relationship type that are identified as providing support.

Delimitations

The following were the delimitations of the present study:

1. Participants were delimited to those who had a positive blood anti-body test for the HIV infection and, therefore, were aware of their HIV-positive status.
2. Participants were delimited to those receiving care coordination through the state care coordination system.
3. Participants were delimited to males.
4. Participants filled out the questionnaires at six-month time intervals, therefore there may be effects due to testing.
5. The sample was obtained from 1992 through 1994 before new drugs, such as protease inhibitors, were available.

Assumptions

The following were the assumptions of the present study:

1. Historical effects of the participants were distributed across all participants, with the exception of those variables explored in this study.
2. Participants accurately and candidly responded to the questions contained in the instruments.
3. The instruments used accurately assessed those characteristics which they were designed to measure.

Limitations

Following were the limitations inherent in this study:

1. This project relied on self-report data and therefore includes inherent limitations, such as subjectivity.
2. This project relied on the follow-up of participants for two years. It did not follow them for a longer period of time which might give a more complex picture of the social support networks.
3. Brothers and sisters were combined to create the family member category of siblings.
4. All partners were combined to create the category of partner.

APPENDIX B: LITERATURE REVIEW

Health Status

Acquired immunodeficiency syndrome (AIDS) is caused by the human immunodeficiency virus (HIV), type-1. The course of the infection is often characterized by a long time interval between initial infection and the onset of serious symptoms. During the time interval phase, CD4+ cells become disabled and die as they are the portal receptors for the virus. Healthy CD4+ cells are responsible for activating other cells, such as cytotoxic T and B cells, to launch an immune response. When the CD4 count falls below 500/mm^3, approximately half on the individual's immune system response has been destroyed. At this point, the individual may be susceptible to minor infections, such as cold sores and fungal infections. Once the cell count falls below 200/mm^3, life-threatening opportunistic infections and cancers are likely to occur. At a cell count below 200/mm^3 or at the onset of opportunistic infections, the individual is identified as having AIDS, the end stage of HIV. The presence of life-threatening infections, such as pneumocystic carinii pneumonia, or cancers including Kaposi's sarcoma, are likely in the individual with HIV (Schneiderman, Antoni, Saab, & Ironson, 2001). The results of a study by Hogg, Yip, Chan, and Wood (2001) confirmed the results of previous studies that reported CD4 count as the most important marker of disease progression, especially death for individuals with AIDS. Researchers have examined the impact social support has on the progression of HIV (Hall, 1999; Evans, Leserman, Perkins, & Stern, 1997). Further, numerous studies have shown that social support for individuals living with HIV is linked to better health outcomes such as fewer physical and emotional symptoms

(Serovich, Brucker, & Kimberly, 2000) and such positive outcomes are particularly true for gay men living with HIV (Hall, 1999; Hays, Turner, & Coates, 1992).

Theoretical Framework

Many studies comparing family support to support offered by friends have shown that friends are perceived as more supportive to persons living with HIV (Friedland, Renwick, & McColl, 1996; Hays, Catania, McKusick, & Coates, 1990). This appears especially true for gay men living with HIV (Namir, Alumbaugh, Fawzy, & Wolcott, 1989). Smith and Rapkin (1996) offer a "barrier theory" to explain why family members are perceived as less helpful than friends for gay men living with HIV. The barrier theory postulates that several reasons or barriers exist to keep individuals from seeking out the support of their families. These barriers include lack of access to family members, lack of acceptance from their families, lack of intimacy in the relationships, negative interactions, feelings of being smothered, and wanting to protect family members. In addition, barrier theorists suggest that gay men are not accustomed to asking for help and would find doing so very difficult. Other reasons include that gay men living with HIV may already feel isolated and stigmatized and not want to be a burden for their families (Herek & Glunt, 1988). Similarly, such individuals may have elderly parents with many personal difficulties of their own and the individuals with HIV do not want to add to their parents' personal problems. Lastly, seeking support from family would mean disclosure regarding their HIV status and sexual orientation and some may not be willing to share such information with family members (Serovich, 2001).

Serovich, Brucker, and Kimberly (2000) stated that researchers have not yet studied lack of access to family members. However, many have concluded that having HIV causes strain in the social network, limiting the availability of family members (Burgoyne & Saunders, 2000). Serovich et al. further argue that family support may represent a small, but important, proportion of the total number of individuals within the social support network. Several reasons may help explain why they represent a small proportion. Those reasons may include that the family is quite small in number, family members may live at a distance, or the family members may be unavailable due to illness or age. Given this, Serovich et al. argue that studies only looking at frequencies of social support networks may not represent the true amount of support men living with HIV may receive from their families. Friends may be more plentiful in numbers in regard to the social support network, and thus only appear to be offering more support.

Serovich et al. (2000) tested the barrier theory by comparing the support gay men with HIV received from both family and friends. Social support was defined as availability of the supportive individual, the level of intimacy in the relationship, and disclosure, meaning whether or not the supportive individual knew of the HIV diagnosis. They hypothesized that as support increased, the individual with HIV would report better health outcomes, less depression, fewer symptoms, and less disease progression. They concluded that barriers do exist and hinder individuals' willingness to seek out support. However, they found that the same barriers existed for both family and friends. Further, they found that it was the number of supportive individuals that led to more positive outcomes. It was concluded that support may not exist for the barrier theory and that

other factors may explain why families do not appear as supportive. One factor may be the level of satisfaction with the relationships between individuals with HIV and their family members. Gay men living with HIV who feel a sense of satisfaction from their relationships with their family members may be more willing to gain support from them. Serovich et al. encouraged more research to focus on family relationships of gay men living with HIV, such as investigating the impact of families and the support they provide to these individuals.

The findings of Vandehey and Shuff (2001) mirror the above study. Vandehey and Shuff examined social support networks over the course of a 2-year period. Participants identified supportive individuals as family, friend, or professional. Over the course of the study, they found that the amount of social support from family and friends remained consistent. They recommended that further research examine the impact of negative social support providers on the health outcomes of gay men living with HIV. Siegel, Ravels, and Karus (1997) suggested further research explore the impact of negative social support providers and networks on gay men living with HIV. They offered two suggestions. One suggested way of doing so is to look at the stability of a support system over time by examining the exact number of supportive individuals within one's network. Another recommendation is to assess specifically which groups provide the most support when comparing friends, families, and professionals.

Kadushin (1999) also tested the barrier theory by examining the perceived support of men with HIV. Results suggest that men with HIV perceived friends as more supportive and they were more likely to turn to friends for support. Other results suggest

that as their illness progressed, especially to AIDS, men with HIV sought more support from their families and their families in turn were highly supportive. Mothers and sisters were identified as the most supportive with fathers and brothers seen as less supportive. The researcher postulated that the same reasons that keep individuals living with HIV from seeking family support in general likely also hinders men living with HIV from turning to their fathers or brothers for support.

Social Support

Social support remains a difficult construct to identify and measure in research studies (Barrera, 1986). One reason for this is that varying definitions are available for social support (Tolsdorf, 1976). Similarly, terms such as "social network," "psychosocial assets," and "perceived social support" have been used interchangeably in the literature, but researchers do not agree on common definitions or uses for these terms. Schaefer, Coyne, and Lazarus (1981) argue for a distinction between the number of individuals within a person's network and the perceived support gained from social interactions. Social network, they assert, specifically defines the composition and structure of the network, such as the number of persons involved or the content of the relationship. They further argue that two assumptions are often made about social networks that may or may not be true. The first assumption is that benefits of a social network are directly proportional to the number of individuals within the network. The second assumption is that a relationship is equivalent to getting support from that individual. They point out that a positive correlation may often exist between the social network size and the amount

of social support; however, this ignores the demands, constraints and conflicts that also are associated with social relationships.

In an attempt to clarify the term "social support," three types of support have been described in the literature: emotional, tangible, and informational. Emotional support refers to the intimacy, attachment, and reassurance one gets from another. Tangible support is defined as the direct aid or services provided to an individual. Informational support means the advice or feedback given to help one solve a problem or assess how he or she is doing. Schaefer et al. (1981) further argue for this distinction, suggesting that the different types of support could be independent of each other. As shown in their study of middle-aged individuals with HIV, tangible support was identified as the most significant of the types of support and was correlated inversely to depression and negative morale.

In general, studies have shown that individuals adjust better to stressful life situations when social support is available, as compared to when it is not (Cohen & Wills, 1985). Further, numerous studies have shown that social support is negatively related to psychological distress among individuals living with HIV (Koopman, Gore-Felton, Marouf, & Butler, 2000; Schmitz & Crystal, 2000) and specifically gay men living with HIV (Hall, 1999; Hays et al., 1992). Hays, Chauncey, and Tobey (1990) examined the structural and functional characteristics of the social support network of gay men with HIV to ascertain which characteristics were most related to psychological well-being. The characteristics most highly correlated with psychological well-being were the degree to which the men felt others reciprocated support to other men within their network, the amount of emotional and informational support they received, the number of close

relationships and the percentage of friends in their network as compared to family members. In addition, having another HIV-infected person in the social network positively correlated with psychological well-being.

Wolcott, Namir, Fawzy, Gottlieb, and Mitsuyasu (1986) explored the social support networks, attitudes toward homosexuality, and illness concerns of gay men infected with HIV. In general, individuals had a small support network of at least four persons by whom they felt supported and to whom they felt they could turn if needed. A strong support network was positively correlated to several factors relating to psychological well-being. Those with a strong social network reported more "optimistic" views of their health, psychological well-being, and social status. In addition, the men tended to report better perceived global health, higher self-esteem, lower levels of mood disturbance, lower levels of illness concerns, and an overall higher quality of life. Similarly, Nicholson and Long (1990) found that gay men living with HIV who reported greater self-esteem were more likely to also report a better mood state and more proactive coping, which was defined as seeking out social support and planful problem-solving.

Pakenham, Dadds, and Terry (1994) looked at coping strategies and social support for individuals infected with HIV at different stages of HIV progression, symptomatic and asymptomatic. They looked at two ways of coping. The first is problem-focused, which refers to strategies implemented by the individual to alter the source of the stress. The second is emotion-focused, which means ways to reduce the emotional distress caused by the problematic circumstance. The researchers hypothesized that the preferred type of coping strategy would be directly related to the level of

perceived control over the stressor. For example, in low-control situations, it was hypothesized that emotion-focused coping will be used; however, problem-focused coping was likely used when the individual perceives some control over the stressor. In relation to HIV, individuals in the asymptomatic stage were expected to prefer problem-focused strategies, while individuals in the symptomatic stage were expected to engage in emotion-focused coping strategies as they may have felt less control over situations during this stage. The results indicated that coping strategies and social support did not differ across the stages of HIV.

Another study examined men with AIDS or AIDS-related complex (ARC) as part of a longitudinal examination of social support and distress (Zich & Temoshok, 1987). Social support was defined as either emotionally-sustaining or problem-solving. An example of emotionally-sustaining help was having someone to talk to about problems. An example of problem-solving help was having someone to offer suggestions. The participants who reported more perceived social support also reported less distress, hopelessness, and depression. In addition, emotionally-sustaining help was preferred over problem-solving help. The authors noted that emotionally-sustaining help may likely come from family or friends, whereas problem-solving help is more likely offered from a professional. They called for research that examines the specific members of a support system for persons with AIDS to improve their quality of life (Zich & Temoshok).

Pakenham et al. (1994) described two existing hypotheses that explain the relationship between coping strategies and social support with psychological adjustment. One hypothesis is the stress-buffering model, which postulates that social support and

coping strategies work to buffer the individual from the stress and thus, only high levels of stress are critical. The second hypothesis is the model of main effects, which suggests that regardless of the level of stress, social support and coping strategies have main or direct effects on adjustment. Moreover, coping strategies and adjustment did not differ in relation to HIV stage. In contrast, adjustment was associated with coping strategies and social support.

Review of Related Literature

The following review focuses on the impact of HIV on emotional functioning. Social support has been linked to a dramatic decrease in depressive symptoms (Moneyham, 1999) and has been a critical variable in treatment adherence for individuals with HIV (Jacobsen, Hanggi, & Ott, 1996).

Common physical complaints of young individuals infected with HIV are fatigue, insomnia, and weight loss. Given that these are often common symptoms for otherwise healthy persons with HIV, these individuals are often not being properly assessed for depression, although these same physical complaints could be indicators of depression. Perkins, Leserman, Stern and Baum (1995) explored somatic complaints of gay men in early stages of their infection to gain a better understanding of the etiology of the complaints. They indeed found that the somatic complaints were indicators of mood disturbance. At the six-month follow up, the same somatic complaints had increased along with other symptoms of depression.

In a 6-year study of men living with HIV, Burack (1992) found that men suffering from moderate to severe depression lost greater numbers of disease fighting cells and

were more likely to develop AIDS more quickly and subsequently die sooner than non-depressed men infected with HIV. Burack urged that treating depression may be critical to slow the progression of the disease. Further, it is critical to study depression among individuals infected with HIV as depression is related to other important medical and mental health factors. Depressed individuals with HIV are more likely to suffer unsatisfactory physical, social, and role functioning as well as more chronic pain and perceive their current health status as worse than it may be. Depression is also linked to the higher rates of suicidal ideation for individuals infected with HIV and the increase in suicide among individuals with AIDS (Lyketsos et al., 1996). Unfortunately, in some cases, depression is misdiagnosed as fatigue and the individual does not receive proper treatment, which impacts the progression of the disease (Moneyham, 1999). Lyketsos et al. conducted a longitudinal study examining depressive outcomes of individuals with HIV prior to the onset of AIDS. The researchers followed 911 individuals infected with HIV 5 years before their diagnosis of AIDS and 2 years following the diagnosis. Results indicated that all measures of depression, such as overall depressive symptoms, nonsomatic depressive symptoms, syndromal depression, and severe depression, were elevated significantly beginning within 12 to 18 months of the AIDS diagnosis.

Depression and anxiety have been studied in regards to their relationship to disease progression. Evans et al. (1995) looked at the impact of stress on natural killer cells in the immune system. The two killer cells that are believed to be most responsible for fighting HIV are KN cells and cytotoxic/suppressor T lymphocytes. Anxiety and stress were directly related to the progression of the disease. Gay men living with HIV

categorized as asymptomatic that reported more severe stress in their lives also had significantly lower counts of natural killer cells. In addition, Leserman et al. (1999) found that faster disease progression was related to more cumulative stressful events, more cumulative depressive symptoms, and less cumulative social support when examining these factors in a study of gay men living with HIV who were asymptomatic at baseline. Similarly, Burack, Barrett, Stall, and Chesney (1993) found that gay men living with HIV and also suffering from depression had much faster rates of decline in CD4 count than men who were identified as nondepressed.

To expand on their prior study, Leserman et al. (2000) examined stress, coping strategies, depressive symptoms, and cortisol levels on the progression to HIV. The study revealed duplicate findings of their previous work. In addition, when followed up to 7.5 years, they noted that men with higher levels of cortisol and those using coping strategies, such as denial, were more likely to progress to AIDS faster. Similar results suggest that severe life stress is related to increases in depression and in the progression of HIV to AIDS (Evans, Leserman, Perkins, & Stern, 1997). Furthermore, Patterson, Semple, Temoshok, and Atkinson (1995) found that men infected with HIV who reported less depressive symptoms also reported higher CD4+ lymphocyte counts and an increase in concentration of serum beta sub 2-microglobulin, two important variables in the progression of HIV.

Rabkin, Goetz, Remien, and Williams (1997) found results contrary to the above findings and social support appeared to be a protective factor in their study. When comparing the rates of depression for gay men who were HIV-positive and HIV-negative

over the course of 4 years, the researchers found no significant differences among the groups. In other words, the rates of depression for each group remained the same as the disease progressed for the HIV-infected individuals. One important finding is that the participants also reported that their social support increased as the study continued.

APPENDIX C: METHOD

Participants

See pages 7-8 for a complete description of the participants.

Instrumentation

Client Information Form. Participants completed the client information form to obtain demographic data. The demographic information used for this study was the participants, age, race, relationship status, employment status, level of education, income status, and residence at time of HIV diagnosis.

Social Supports Questionnaire (SSQ). The Social Supports Questionnaire designed by Wright (1995) examines multiple variables related to social support. Participants completing the form are allowed to identify up to nine individuals by whom they feel supported. Along with their first name or initials, participants are asked to give the gender, age, race, sexual orientation, HIV status, and the geographic distance for the person they identified as supportive. In addition, participants are asked about frequency of contact, perceived closeness, support regarding the participant's AIDS diagnosis, and whether or not the supportive individual is also diagnosed with AIDS. Participants identified the supportive individual's age from one of the eight choices: (a) 0-9; (b) 10-19; (c) 20-29; (d) 30-39; (e) 40-49; (f) 50-59; (g) 60-69; and (h) 70 and up. Participants identified the supportive individual's propinquity from one of five choices: (a) lives in the same house; (b) 0-5 miles; (c) 6-20 miles; (d) 21-75 miles; and (e) 75 miles or more. Participants identified the supportive individual's degree of supportiveness regarding their HIV status from one of four choices: (a) very; (b) somewhat; (c) not very; and (d)

they don't know about it. If the participant had more than nine supportive individuals, they were asked to write the number of additional supporters at the bottom of the page. Reliability and validity measures are not relevant for this study as social support networks change with a person's needs and lifestyle changes. This rationale is supported by Scott (1992).

Data Analysis

A descriptive approach was utilized to explore the details of the social support networks. The small sample size of 21 allowed for an intimate look at the specific individuals identified as supportive to gay men living with HIV.

The first research question asks, "What relationships within the social support network are identified by gay men living with HIV and are these similar across the HIV status groups?" The first question examined the specific members of the identified social support network at each time interval by calculating the frequencies for each relationship category. The second research question asks, "When comparing the social support networks of individuals across the HIV spectrum status groups, how do the networks compare over time in terms of stability?" Multiple steps were used to calculate the stability of the relationships over time.

First, the presence or absence of each individual within the network was listed at each time interval. If the person was present, he or she received a score of 1 and if the individual was not listed at time intervals, he or she received a score of 0. Next, the number of participants who listed this relationship was added together representing the frequency of unique individuals within the network. This number is displayed in the

column labeled n of Table 2 (research article section). For example, five of the seven participants within the asymptomatic group listed their mother.

The next step involved calculating the stability of the relationship over the time intervals. Within each group, the average number was calculated that represented how often the particular relationship was present. After the relationships were identified for each participant, the sum was calculated representing the number of times the relationship was listed by the participant across the time intervals. For example, the table below details the stability of mothers for this group. In other words, mothers were present an average of 4.0 intervals out of five intervals. The same calculation was used for each relationship category across the three groups.

Participant	Relationship	Initial	6	12	18	24	Total
A	Mom	1	1	1	1	1	5
B	Mom	1	1	1	1	0	4
C	Mom	1	1	1	1	1	5
E	Mom	1	0	1	0	0	2
G	Mom	1	1	1	0	1	4
Total							20
						Stability = 20/5 = 4.00	

If the participant listed two different individuals within the same relationship category, the average score was used to compute the stability. For example, participant G listed both his mother and his step-mother. The score of 3.5 was used when calculating the stability for this relationship group. The same calculation was used to compute the stability for friends as many participants listed more than one friend.

Participant	Relationship	Initial	6	12	18	24	Total
G	Step-father	1	1	1	0	1	4
	Father	1	1	0	0	1	3
Total							7
						Stability = 7/2 = 3.5	

To compute the average stability, the scores for each relationship category were totaled and then divided by the total number of persons present. For example, one participant in the asymptomatic group listed 12 different friends. However, the 12 different friends only appeared 19 times across the five time intervals. Nineteen was divided by 12 giving a stability score of 1.58. The stability score represents the average number of intervals the person was present in the network. The stability was calculated this way for each friend and then the average of these seven scores represents the stability score given in the average stability column of Table 2 (research article section).

Friend	Initial	6-month	12-month	18-month	24-month	TOTAL
TA	1	0	0	0	0	1
MI	1	0	0	0	0	1
RI	1	1	1	0	0	3
VI	1	1	0	0	0	2
AZ	1	0	0	1	1	3
AL	0	1	0	0	1	2
MA	1	0	0	0	1	2
VJ	0	0	0	1	0	1
RJ	0	0	0	1	0	1
RH	0	0	0	0	1	1
MS	0	0	0	0	1	1
ME	0	0	0	0	1	1
						19/12 = 1.58

This table demonstrates how the average stability was calculated. In other words, the score of 1.80 means that friends were present an average of 1.80 times across the 5 time intervals.

Participant	Average for friends
A	1.80
B	1.60
C	1.23
D	2.27
E	3.10
F	1.26
G	1.34
Average stability	12.6/7 = 1.80

Once the changes within the network were examined, the third research question was answered. The third research question asks, "Descriptively, how do gay men living with HIV rate the factors such as age, propinquity, and perceived support on their social support networks?" As part of completing the Social Support Questionnaire, participants answered questions regarding this information for each individual within the support system. The researcher examined each of these factors in terms of their impact on the changes within the system. This was accomplished by examining the descriptive statistics of each of the categories making up the Social Support Questionnaire.

APPENDIX D: COPIES OF INSTRUMENTATION

Date Entered - _____
Initials - _____
Date Verified - _____
Initials - _____

Research Numbers
PN - _____
CCN - _____
MHCN - _____
TN - _____

CLIENT INFORMATION

Survey of the

Indiana Integration of Care Project

Indiana State University

Third Edition

Instructions: Please read the following questions and respond by choosing the best answer. Instructions for different sections are located throughout the survey. In some instances, you will be asked to elaborate in the space provided. When you have completed the questionnaires, please return them in the enclosed postage-paid envelope. All information is strictly confidential. If you have any questions or would like to discuss this survey, please call the Indiana Integration of Care Project (IICP) at:

1 (800) 381-3688

1. DATE OF INTAKE (first visit or contact), readmission, or transfer to HIV/AIDS care coordination

MONTH:
( ) JAN. ( ) FEB. ( ) MAR. ( ) APR. ( ) MAY ( ) JUN.
( ) JUL. ( ) AUG. ( ) SEPT. ( ) OCT. ( ) NOV. ( ) DEC.

YEAR:
( ) 1987 ( ) 1988 ( ) 1989 ( ) 1990 ( ) 1991
( ) 1992 ( ) 1993 ( ) 1994 ( ) 1995 ( ) 1996

( ) Check here if you have never enrolled or received care coordination services.

2. DATE OF BIRTH

____/____/___

3. SEX

( ) Male
( ) Female

4. RACE

( ) American Indian or Alaskan Native
( ) Asian/Pacific Islander
( ) Black/African American
( ) Hispanic/Latino
( ) White/Caucasian
( ) Biracial/Multiracial

5. RELATIONSHIP STATUS

( ) Married/Committed Relationship (spouse, partner, lover, etc.)
( ) Living with someone (not married/committed relationship)
( ) Single (never married/committed relationship)
( ) Widowed
( ) Divorced
( ) Separated

6. TYPE OF RESIDENCE

( ) Private house/apartment
( ) Boarding house/rented room/rooming house
( ) Community residential home (group or halfway home)
( ) Nursing home
( ) Jail/prison
( ) No regular residence or in shelter, on street
( ) Other (Name place of residence if not listed above): ____

7. LIVING ARRANGEMENT

Which living situation applies to you? (Indicate ***all that apply***):

( ) Alone
( ) With spouse/partner
( ) With children
( ) With relatives other than spouse/children
( ) With non-relatives
( ) With parents

8. STATE/COUNTY OF RESIDENCE

_____/_____
state/county

9. ZIP CODE OF RESIDENCE

_____

10. EDUCATION

Indicate the highest level of education (or equivalent) you have completed. (Select ***only one***):

( ) Grade School
( ) Junior High School
( ) High School
( ) GED
( ) Trade School Vocational Technical Program
( ) Some college courses but no Bachelor's degree
( ) Graduated College - Associate's degree (2 yr.)
( ) Graduated College - Bachelor's degree (4 yr.)
( ) Some graduate courses but no graduate degree
( ) Master's degree (MS, MA, MBA, etc.)
( ) Doctorate (MD, DVM, PhD, DDS, etc.)
( ) Other (Specify) :

11. EMPLOYMENT STATUS

As of today, which ONE of the following items best describes your current occupation/job status? *(Select only one item on this page)*

MANAGERIAL/PROFESSIONAL/EXECUTIVE:

EXECUTIVE/ADMINISTRATIVE/MANAGERIAL:

( ) Accountant/Auditor/Financial Manager
( ) Administrator
( ) Sales Manager
( ) All other Managers
( ) Supervisors
( ) Another Executive/Administrative /Managerial Occupation (Specifiy): _____

PROFESSIONAL SPECIALTY:

( ) Architect
( ) Artist
( ) Banker/Broker
( ) Clergy
( ) Dentist
( ) Dietitian
( ) Engineer
( ) Lawyer
( ) Mathematics/Computer Scientist
( ) Performer/Entertainer
( ) Pharmacist
( ) Physician
( ) Professor/Instructor
( ) Psychologist/Counselor
( ) Registered Nurse
( ) Teacher - Primary
( ) Teacher - Secondary
( ) Veterinarian
( ) Writer/Journalist
( ) Other Health Professional
( ) Another Professional Specialty Occupation (Specifiy): _____

TECHNICAL/SALES/ADMINISTRATIVE SUPPORT:

( ) Administrative Support/Clerical/Office Help
( ) Computer Operations
( ) Computer Programmer
( ) Health Technician
( ) Insurance Adjuster/Bill Collections
( ) Retail Sales/Cashier
( ) Sales-Financial/Business
( ) Travel Agent
( ) Another Technical/Sales Administrative Support Occupation (Specifiy): _____

SERVICE:

( ) Cleaning/Building/Household Service
( ) Food Service
( ) Health Service/Assistant/Aide
( ) Protective Services
( ) Barber/Beautician/Cosmetologist
( ) Another Service Occupation (Specifiy): _____

FARMING/FORESTRY/FISHING:

( ) Farm Operations/Manager
( ) Another Farming/Forestry/Fishing Occupation (Specifiy): _____

CRAFTSMAN/REPAIRMAN:

( ) Construction Trade
( ) Paint Contractor
( ) New Home Contractor
( ) Remodeling/Room Addition Contractor
( ) Mechanics/Repairs
( ) Precision Occupations
( ) Another Craftsman/Repairman Occupation (Specifiy): _____

OPERATOR/LABORER:

( ) General Laborer
( ) Machine Operator
( ) Transportation/Material Moving
( ) Another Operator/Laborer Occupation (Specifiy): _____

OTHERS:

( ) Armed Forces
( ) Homemaker
( ) Student
( ) Another than any of the above (Specifiy): _____

NOT EMPLOYED:

( ) Retiree
( ) Laid off from job
( ) Volunteer
( ) Seeking employment
( ) Incapacitated or disabled
( ) Other (Specify) :

ONLY ONE ITEM SHOULD BE SELECTED ON THIS PAGE

12. CURRENT OR MOST RECENT TYPE OF EMPLOYMENT (Select *only one*):

( ) Full-time
( ) Part-time, because of health status
( ) Part-time, but not because of health status
( ) Unemployed
( ) Other

13. JOB DISCRIMINATION

Have you ever been turned down for a job, laid off, or fired because of your HIV-positive status?

( ) no
( ) yes

14. HEALTH CARE DISCRIMINATION

Have you ever been turned down for health care services because of your HIV-positive status?

( ) no
( ) yes

15. INCOME RANGE

Please indicate your household's **gross MONTHLY income** in dollars. Be sure to combine the total income for all household members living at home **before** taxes (wages or salaries, income from self-employment, rents, dividends, etc.). (Select *only one*).

( ) Below 200
( ) 200-399
( ) 400-599
( ) 600-799
( ) 800-999
( ) 1,000-1,199
( ) 1,200-1,399
( ) 1,400-1,599
( ) 1,600-1,799
( ) 1,800-1,999
( ) 2,000-2,199
( ) 2,200-2,399
( ) 2,400-2,599
( ) 2,600-2,799
( ) 2,800-2,999
( ) 3,000-3,999
( ) 4,000-4,999
( ) Over 5,000

16. HIV RISK CATEGORY

Which risk factors apply to you? (Indicate ***all that apply***):

( ) Sexual partners are only men
( ) Sexual partners are only women
( ) Sexual partners are both men and women
( ) Intravenous drug user
( ) Hemophilia
( ) Transfusion/transplant recipient
( ) Mother is/was HIV-positive or has/had AIDS
( ) Unknown at this time

17. HIV STATUS

Please indicate the **month and year** you first tested HIV-positive:

MONTH:

( ) JAN.	( ) FEB.	( ) MAR.	( ) APR.	( ) MAY	( ) JUN.
( ) JUL.	( ) AUG.	( ) SEPT.	( ) OCT.	( ) NOV.	( ) DEC.

YEAR:

( ) 1981	( ) 1982	( ) 1983	( ) 1984	( ) 1985
( ) 1986	( ) 1987	( ) 1988	( ) 1989	( ) 1990
( ) 1991	( ) 1992	( ) 1993	( ) 1994	( ) 1995

State in which you first tested HIV-positive: (Select ***only one***)

( ) Alabama
( ) Alaska
( ) Arizona
( ) Arkansas
( ) California
( ) Colorado
( ) Connecticut
( ) Delaware
( ) Florida
( ) Georgia
( ) Hawaii
( ) Idaho
( ) Illinois
( ) Indiana
( ) Iowa
( ) Kansas
( ) Kentucky
( ) Louisiana
( ) Maine
( ) Maryland
( ) Massachusetts
( ) Michigan
( ) Minnesota
( ) Mississippi
( ) Missouri
( ) Montana
( ) Nebraska
( ) Nevada
( ) New Hampshire
( ) New Jersey
( ) New Mexico
( ) New York
( ) North Carolina
( ) North Dakota
( ) Ohio
( ) Oklahoma
( ) Oregon
( ) Pennsylvania
( ) Rhode Island
( ) South Carolina
( ) South Dakota
( ) Tennessee
( ) Texas
( ) Utah
( ) Vermont
( ) Virginia
( ) Washington (State)
( ) Washington, D.C.
( ) West Virginia
( ) Wisconsin
( ) Wyoming
( ) U.S. Territories
( ) Not in the United States/Outside the United States

18. T4 CELL COUNT STATUS

In addition to testing HIV-positive, do you have a T4 count of 200 or below?

( ) no
( ) yes
( ) unkown

If yes, please indicate the **month and year** you first learned your T4 count was 200 or below:

MONTH:

( ) JAN.	( ) FEB.	( ) MAR.	( ) APR.	( ) MAY	( ) JUN.
( ) JUL.	( ) AUG.	( ) SEPT.	( ) OCT.	( ) NOV.	( ) DEC.

YEAR:

( ) 1981	( ) 1982	( ) 1983	( ) 1984	( ) 1985
( ) 1986	( ) 1987	( ) 1988	( ) 1989	( ) 1990
( ) 1991	( ) 1992	( ) 1993	( ) 1994	( ) 1995

State in which you first learned your T4 count was 200 or below: (Select ***only one***)

( ) Alabama	( ) Maryland	( ) Rhode Island
( ) Alaska	( ) Massachusetts	( ) South Carolina
( ) Arizona	( ) Michigan	( ) South Dakota
( ) Arkansas	( ) Minnesota	( ) Tennessee
( ) California	( ) Mississippi	( ) Texas
( ) Colorado	( ) Missouri	( ) Utah
( ) Connecticut	( ) Montana	( ) Vermont
( ) Delaware	( ) Nebraska	( ) Virginia
( ) Florida	( ) Nevada	( ) Washington (State)
( ) Georgia	( ) New Hampshire	( ) Washington, D.C.
( ) Hawaii	( ) New Jersey	( ) West Virginia
( ) Idaho	( ) New Mexico	( ) Wisconsin
( ) Illinois	( ) New York	( ) Wyoming
( ) Indiana	( ) North Carolina	( ) U.S. Territories
( ) Iowa	( ) North Dakota	( ) Not in the United States/Outside the United States
( ) Kansas	( ) Ohio	
( ) Kentucky	( ) Oklahoma	
( ) Louisiana	( ) Oregon	
( ) Maine	( ) Pennsylvania	

INFORMED CONSENT FORM

Indiana Integration of Care Project (IICP)

PROJECT DESCRIPTION

You are asked to join several hundred other people from across the state to be in a study looking at the effects of support, mental health care, and medical care on the health of persons living with HIV/AIDS. What we find will help us to better plan and integrate health services that meet the needs of persons living with HIV/AIDS.
This study is a part of the Indiana Integration of Care Project (IICP) which is funded by the U.S. Public Health Service. IICP is a Special Project of National Significance and will be a model for the nation on how mental health care can become a part of medical care. It is a joint project of the Indiana State Department of Health and Indiana State University (ISU). Dr. I. Michael Shuff, Research Assistant Professor of Counseling Psychology at ISU, is the project director.

PROCEDURES

If you decide to be a part of this study, you will get a set of questionnaires to fill out every six months. These questionnaires will ask you about your current living circumstances, your health, the kinds of health and human services you are getting, and your support from others. You will get $25.00 for each set of questionnaires you fill out and return. It will take about one hour to fill out each set of questionnaires.
If you are receiving mental health services, your counselor will also receive a questionnaire shortly after you become part of the study. These questionnaires will ask for his/her assessment of your functioning. Your counselor will get another questionnaire every six months to assess your progress.

ASSURANCE OF CONFIDENTIALITY

To protect your confidentiality, what you tell us will be locked in a file at IICP If you decide to be a part of this study, you will be assigned a number from IICP that will be used instead of your name. All the questionnaires you fill out will have this number on them. Researchers at ISU will not record your name on any of the survey forms you return. Because this study will collect data every six months over a long time, and because you will be paid to be a part of it, it will be necessary for IICP to know:

(1) your name, address, and telephone number;
(2) names, addresses and telephone numbers of other individuals who will know where you can be reached over time;
(3) the name, address, and telephone number of your care coordinator (if you have one);
(4) the name, address, and telephone number of your primary mental health counselor (if you have one).

BENEFITS

You may feel good knowing that you are adding to what we know, which will help us better serve those affected by HIV/AIDS. What you tell us can help us learn how people can stay healthy in the face of HIV disease. This should help provide service and care.
The study will not cost you anything but your time. You will receive $25.00 each time you return a set of completed questionnaires.

RISKS AND DISCOMFORTS

You may find that some of the questions are personal. A question might ask if you are a man "who has sex with other men?", or "Have you ever shared needles?". If any of the questions cause you to feel discomfort, you may call IICP at (800) 381-3688. They will either help you, or get you the name of someone who can.

WITHDRAWAL FROM THE STUDY

You are choosing on your own to be a part of this study. You are free to leave the study at any time. There is no penalty if you decide to leave.

ANSWERING QUESTIONS

If you have any questions, please ask. If you think of questions later, or if you have questions about your rights or the study in general you may call the Indiana Integration of Care Project (IICP) at (800) 381-3688.

VOLUNTARY CONSENT

I voluntarily give my consent to become a part of this study. I know that I may withdraw at any time without penalty. For each set of questionnaires I complete I will be paid $25.00. I agree to tell IICP of any change of address and to provide the names, addresses, and phone numbers of three people who will always know where I can be reached.
I also agree to provide the name, address, and phone number of my care coordinator (if I have one) and mental health counselor (if I have one) and give my consent for them to provide requested information about my case for this study.
All information related to my being a part of this study will be strictly confidential.

YOU ARE VOLUNTARILY DECIDING WHETHER OR NOT TO BE A PART OF THIS STUDY. YOUR SIGNATURE INDICATES YOU HAVE DECIDED TO BE A PART OF THIS STUDY, HAVING READ ALL THE INFORMATION. SIGN ONE COPY AND RETURN IT IN THE POSTAGE-PAID REPLY ENVELOPE. KEEP THE OTHER COPY FOR YOUR FILES.

_____ _____
Your Signature Date

_____
PRINT Your Name

Date Entered - _____
Initials - _____
Date Verified - _____
Initials - _____
For Office Use Only

Research Numbers
PN - _____
CCN - _____
MHCN - _____
TN - _____

SOCIAL SUPPORTS QUESTIONNAIRE

Survey of the

Indiana Integration of Care Project

Indiana State University

Forth Edition

For Office Use Only — Six Month Period
( ) Initial ( ) 6 month ( ) 12 month ( ) 18 month ( ) 24 month ( ) 30 month ( ) 36 month

Instructions: Please read the following questions and respond by choosing the best answer. Instructions for different sections are located throughout the survey. In some instances, you will be asked to elaborate in the space provided. When you have completed the questionnaires, please return them in the enclosed postage-paid envelope. All information is strictly confidential. If you have any questions or would like to discuss this survey, please call the Indiana Integration of Care Project (IICP) at:

1 (800) 381-3688

We are interested in learning who are currently the most important people in your life. Please use column 1 of the chart on the next two pages to write the first names or initials of the people you currently consider to be the most important people in your life. By important we mean:

1) the people with whom you discuss important matters, including your physical health and mental health; and

2) the people on whom you feel you can really depend for help if you need it.

These individuals can be anyone: family, friends, co-workers, or people who have been really helpful to you. They are the people that you are most likely to talk to about important matters in your life -- whether they live nearby or far away.

PLEASE WRITE THE FIRST NAMES OR INITIALS OF EACH OF YOUR MOST IMPORTANT SUPPORTERS IN COLUMN 1 OF THE TABLE ON THE NEXT PAGE:

IMPORTANT NOTES:

We are asking for these names or initials simply to help you in completing the next two pages. **WE WILL NEVER CONTACT OR IDENTIFY THE PEOPLE YOU LIST!**

We have provided nine lines for you to use. **YOU DO NOT NEED TO USE ALL OF THE SPACES PROVIDED. PLEASE LIST ONLY THOSE PEOPLE YOU CONSIDER TO BE MOST IMPORTANT TO YOU. IF THERE ARE MORE THAN NINE, PLEASE LIST ONLY THE FIRST NINE.**

INSTRUCTIONS: Please answer the questions in columns 2 through 11 for each of the people you named in column 1.

(1) FIRST NAME OR INITIALS	(2) SEX	(3) AGE *	(4) RACE	(5) SEXUAL ORIENTATION	(6) Who is this person in relationship to you?	(7) How close are you to this person?	(8) How often do you see or talk with them?	(9) About how many miles away do they live from you?	(10) How supportive are they with your situation with AIDS?	(11) Does this person also have HIV/AIDS?
X1	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X2	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X3	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X4	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know

* If age is unknown, estimate it using your best judgment.

(1) FIRST NAME OR INITIALS	(2) SEX	(3) AGE *	(4) RACE	(5) SEXUAL ORIENTATION	(6) Who is this person in relationship to you?	(7) How close are you to this person?	(8) How often do you see or talk with them?	(9) About how many miles away do they live from you?	(10) How supportive are they with your situation with AIDS?	(11) Does this person also have HIV/AIDS?
X5	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X6	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X7	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X8	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know
X9	M F	0-9 10-19 20-29 30-39 40-49 50-59 60-69 70 & up	1 White 2 Black or African-American 3 Hispanic 4 Asian 5 Other	1 Straight/ Hetero-sexual 2 Bisexual 3 Gay/ Lesbian 4 Don't Know	This person is my:	1 Very 2 Somewhat 3 Not very	1 almost daily 2 at least once a week 3 at least once a month 4 less than once a month	1 Lives in same house 2 0-5 miles 3 6-20 miles 4 21-75 miles 5 75 miles or more	1 Very 2 Somewhat 3 Not very 4 They don't know about it	1 Yes 2 No 3 Don't Know

* If age is unknown, estimate it using your best judgment.

IF YOU FEEL YOU HAVE MORE THAN NINE IMPORTANT PEOPLE, PLEASE ANSWER THE FOLLOWING QUESTION:

How many additional supporters do you have that are **NOT LISTED ABOVE?** _____

Think of the people you just listed and any other supportive people in your life. In general, how would you describe this group of people?

(•) Very supportive
( ) Somewhat supportive
( ) Somewhat unsupportive
( ) Very unsupportvie

IF YOU HAVE ANY QUESTIONS ABOUT COMPLETING THIS SURVEY, CALL:

1 (800) 381-3688

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