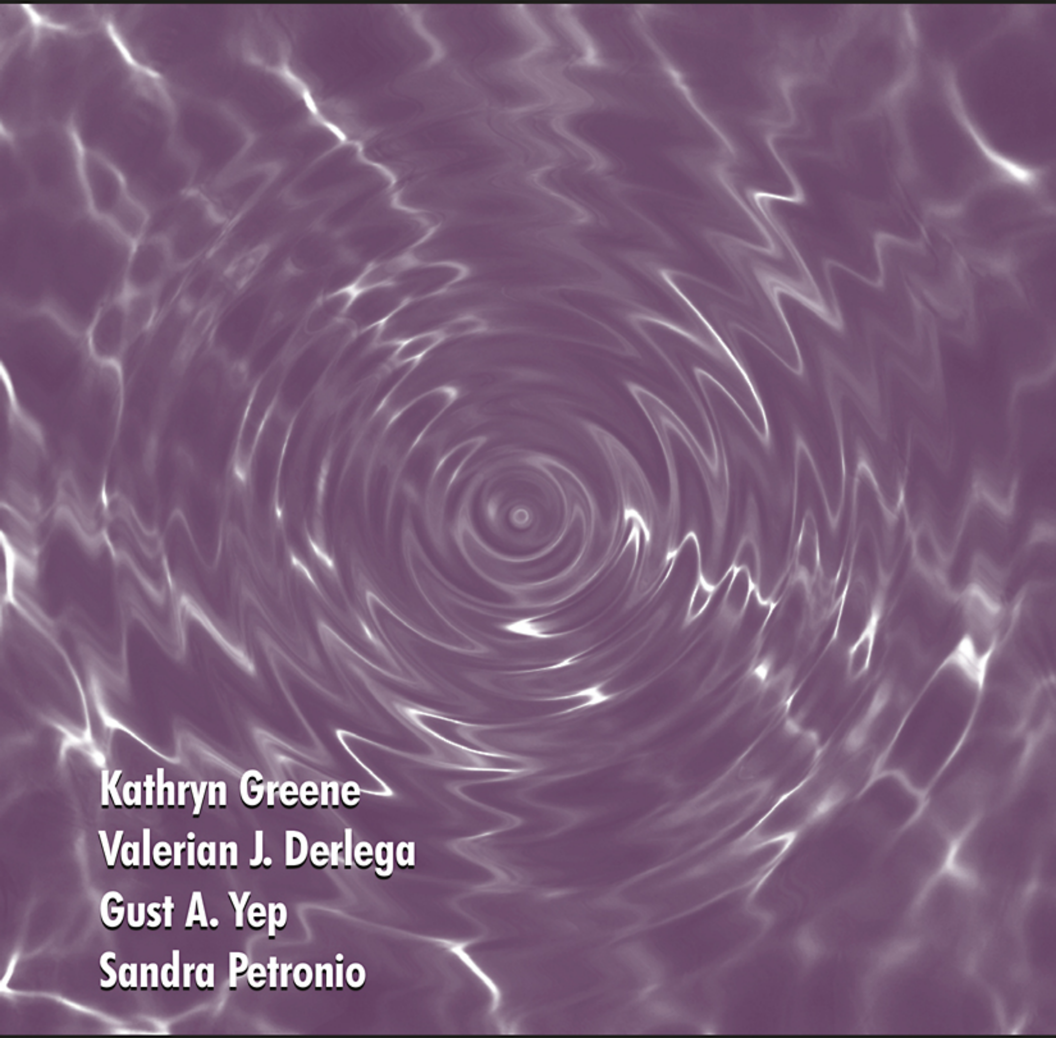
Privacy and Disclosure of HIV in Interpersonal Relationships

A Sourcebook for Researchers and Practitioners



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HIV IN INTERPERSONAL RELATIONSHIPS

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For Sandie,
a courageous soul who left us too soon,
and everyone else whose lives are touched by HIV

Contents

Preface

Human immunodeficiency virus (HIV) is one of the most pressing health issues of this century. HIV also has ramifications for the relationships and daily lives of those infected and affected by the disease. One of the most widely recommended AIDS prevention options revolves around whether or not to disclose about one's HIV positive status to others—particularly to potential sex partners. In this volume, we consider the impact of HIV disclosure for AIDS prevention. Relying on a theory of privacy and communication (communication privacy management theory), we explore the impact of HIV disclosure for a wider range of issues including communication, social interactions, and the development and maintenance of personal relationships.

This book focuses on choices to disclose or not disclose an HIV positive diagnosis. These decisions about disclosure and privacy are critical for how people with HIV live and manage their relationships. Because the book pointedly focuses on disclosure of HIV infection, it is at once unique and yet of interest to a wide variety of related fields of study. The focus of this book is on private, voluntary relational disclosure (e.g., "Should I tell you about the diagnosis?") not on forced or public disclosure (e.g., "Information about my HIV diagnosis was divulged to others by a public health worker"). Disclosure is examined in a variety of social contexts, including in relationships with intimate partners, families, friends, health workers, and coworkers. Of particular interest is examination of decisions to disclose an HIV diagnosis (e.g., reasons for disclosure, stigma, and relational quality), disclosure message features, and consequences of disclosure of HIV infection (e.g., social support, physical health, sexual behavior, self-identity, relationships with family and others in one's social network).

This book has been in progress for several years. During that time, many changes have occurred in the HIV epidemic and in the lives of the authors. As we finish writing this book, the 14th International Conference on AIDS concluded in Barcelona, Spain (July 2002), and researchers continue to report studies of existing and new treatments as well as possible vaccines. HIV-related stigma is clearly still a problem, perhaps inhibiting HIV testing. For example, more than three fourths of young gay men in the United States who tested positive for HIV were unaware of their infection (MacKellar, 2002), much higher than previous estimates. A new rapid (20 minute) HIV test (OraQuick) was approved in November 2002 (see MMWR, 2002). This test is useful to reduce waiting time (previously 2 weeks) but also to address concerns about nonreturns (people who are tested but never pick up results).

Antiretroviral therapies have drastically changed the health prognoses for many with HIV. Although the price for antiretroviral therapies has decreased dramatically, for many (most in many countries) they are unavailable. The majority of those with access to the best treatments (antiretrovirals) live in high-income countries. For example, in the United States treatment for a person with advanced AIDS currently costs more than $34,000 per year.

The report by the joint United Nations Program on HIV/AIDS (UNAIDS) released in July 2002 contradicted prior predictions that the epidemic would peak in many countries around the year 2000. We have, however, not seen a leveling off of infections at this point. In contrast, the epidemic is expanding rapidly, with 95% of people with HIV living in the developing world. The epidemic continues to rise dramatically in Africa, Asia, the Caribbean, and Eastern Europe. In Africa, for example, 2.2 million people died of AIDS in 2001 (Kresge, 2002). AIDS is the fourth leading cause of death worldwide (see UNAIDS, 2001) and the leading cause of death in some countries. It is predicted that there will be more than 65 million deaths in the next 20 years. Thus, there is a call for increased prevention programs.

This book project developed over several years. The people we interviewed about HIV disclosure affected us profoundly. Many who gave their time, energy, and spirit have since died or have advanced AIDS. These people shared themselves, the good and the bad of HIV, with grace and humor. The resilience of these wonderful people serves as a continued inspiration to us. Beyond talking with people with HIV, their partners, families, and friends were also open to describing accounts of struggles with disclosing about HIV. Finally, during this project, we talked with many people who work with those with HIV (e.g., therapists, social workers, and health practitioners) who contributed their experiences.

A word of caution is worthwhile about language used to refer to someone with HIV and/or AIDS in this book. The use of terms related to HIV infection have changed and will continue to change, and this is as much a reflection of social changes as politics. Early epidemic terminology used phrases like "GRID" (gay related immune deficiency) or even "gay plague." Later phrases were developed to focus on "people living with HIV" ("PLWHs") or "people living with AIDS" ("PLWAs") or some combination such as "people living with HIV or AIDS" ("PLWHAs"). Others have taken an approach utilizing "HIV and/or AIDS" to emphasize that some people live with both HIV infection and AIDS, whereas others live with HIV infection but not AIDS. We have consciously adopted phrases such as "individuals with HIV" to refer to all people with HIV (including someone with AIDS) and phrases such as "individuals with AIDS" to refer specifically to people with an AIDS diagnosis. On the other hand, we have avoided phrases such as "persons with HIV/AIDS" because it may incorrectly imply that all persons with HIV also have AIDS. *HIV* (human immunodeficiency virus) is the term used to describe the disease associated with HIV infection, and *AIDS* (or acquired immune deficiency syndrome) is the final stage of HIV-related infection associated with physical symptoms (e.g., recurrent pneumonia, HIV wasting syndrome) of severe immune deficiency. We have also used care with language related to sexuality, choosing to focus on behavior (e.g., men who have sex with men or MSM) rather than identity (gay or homosexual) where possible. We hope this language provides one mechanism for sensitivity to these issues in this book.

The four authors of this book represent different areas of expertise related to HIV and disclosure. Kathryn Greene's research in communication focuses on both disclosure of HIV and risk prevention messages, primarily with adolescent populations. Val Derlega's research in social psychology explores the role of disclosure in relationships. Gust Yep's research in communication focuses on the role of ethnicity in health decision making. Finally, Sandra Petronio's research explores how privacy is managed in everyday life. The multidisciplinary approach to the topic provides a unique way to explore how disclosure is managed in the lives of those with HIV.

Kathryn Greene thanks the many people with HIV and their families and friends who participated in the interviews reported in the book. The HIV service organizations in eastern North Carolina were instrumental in this project (namely Pitt County AIDS Service Organization [PICASSO], Eastern North Carolina HIV / AIDS Coalition [ENCHAC], Pitt County Health Department, East Carolina School of Social Work, and East Carolina School of Medicine Department of Pediatrics). Several departments provided support for my research during this project: East Carolina University Department of Communication, University of Wisconsin–Madison Department of Communication Arts, and my current academic home, Rutgers University Department of Communication. I extend gratitude to my parents, Jim and Judy Greene, who provided guidance and support for my education, and encouragement for my career. I also thank my sisters, Karen Dinicola and Kristen Greene, for their humor and tolerance of my passions about my work. I thank Nancy and Ken Church, who lost a daughter to AIDS early in the epidemic, for sharing their experiences (and they express gratitude to Sheila Kay, Karen Person, Curtis Buttenheim, Archie Hahn, Tom Shell, Mimi Davis, Hollywood Helps, the fourth floor nurses at Midway Hospital, and Elizabeth Taylor for funding a room). I am indebted to Don Rubin, Lynda Walters, and Jenny Krugman, who each encouraged me in a unique way to become a more thorough scholar. Thanks are due to the wonderful friends who have listened tirelessly about this and other projects: Jane and Sam, Marina, Rhonda, Karen, Judy, Harrell, Sandra, Stacey, and Yolanda. I express thanks to the Highland Park crew for their humor and support in exploring ways to enjoy such a terrific place to live. I also recognize and thank those who worked on the book project: Angel, Kelly, Susan, Keith, Karen, and Andrea. While this book was in progress, my spirited companion, Ashley, died; Lucy and I miss her presence.

Finally, I extend my gratitude to my fellow aikidoka for gently encouraging me to explore other paths.

Val Derlega expresses thanks and gratitude to the many persons with HIV who participated in interviews reported in the book and to the HIV service organizations in southeastern Virginia (Tidewater Aids Crisis Task Force, Full Circle, Candii House, Peninsula AIDS Foundation, AIDS/HIV Service Group of Charlottesville, Virginia, Fan Free Clinic, and International Black Women's Congress) that have provided assistance in many ways. In particular, thanks are due to Ramona Smith, Gloria Valentine, Jim Spivey, Irma Hinkle, Al Torres, Chris Wilson, Vega Ova, Vann Massie, Alicia Devine, William Devine, Andrew Sterling, Charles Ford, Mitch Rosa, Willliam Ka Agyei, Jimmy Vines, and Reverend Jim Downing. I also express thanks to the faculty and staff at the Center for Comprehensive Care of Immune Deficiency at the Eastern Virginia Medical School, including Edward C. Oldfield III, Sharon Hopson, LuAnn Gahagan, M. Randy Smith, Julie Turner, and Mary Virginia (Ginny) Sealey-Bobby. I also extend thanks to Xiushi Yang at Old Dominion University and for financial support provided by Grant R01DA13145–01A1 from the National Institute on Drug Abuse of the National Institutes of Health. Thanks are also due to Anita Barbee at the University of Louisville's Kent School of Social Work. Gratitude is also due to Robert B. Hays for his generosity and interest in our research. Robert Hays was a brilliant researcher on the social ramifications of living with HIV. Robert Hays passed away recently. I also thank my family, Barbara Winstead, John Derlega, Ann Winstead-Derlega, and Christopher Winstead-Derlega, and the folks in the West Belvedere neighborhood who have given much support and encouragement, particularly Iva Robinett and Bill Robinett. During the time period of working on this book, much good and some pain occurred in my family, including the passing of a gracious and loving person, Lois Winstead.

Gust Yep expresses the following thanks. Many people contributed to my commitment, knowledge, and experience about the daily realities of people living with HIV and AIDS. Because the disease is still a highly stigmatizing one, I do not name them individually. I thank the people on the San Francisco Noe Valley meal delivery route. As a volunteer for Project Open Hand, I brought meals and groceries to you every Monday night for over a year, and you generously shared your lives and stories with me. You made HIV and AIDS very real. Through these visits I learned about the struggles, suffering, joys, courage, and love of people living with this disease. I wish to thank Mark, Emma, Beth, Karen, Amy, and other members of my "family of choice," and Cindy Yep. Your support and love make my life and my work real and meaningful. Finally, I thank Michael, a friend who has lived with HIV for more than 15 years, for showing me how to live with grace, optimism, humor, peace, and love in spite of physical challenges and social adversities. You are truly a role model.

Sandra Petronio wishes to acknowledge a number of people for their thoughtful insights to this volume. Books are written with the knowledge that scholarship from others helps shape and influence the ideas by considering, questioning, and digesting their work. My colleagues have recognized many of those people. I would like to contribute the name of Irwin Altman whose work gave me foundational concepts for the theory of Communication Privacy Management. A hearty thanks to the graduate students I have been fortunate enough to work with over the years at the University of Minnesota, Arizona State University, and Wayne State University. A number of these valued students are now professors in their own right using the CPM theory and illustrating its worth. Dawn Braithwaite at the University of Nebraska, Mary Claire Morr at the University of Denver, Susanne Jones at the University of Wisconsin, Milwaukee, and Jack Sargent at Kean University. Current students who are using CPM at Wayne State University include Laura Andea, Mihaela Gherman, Peggy Reganis, and Jeffrey Younguist who are finishing their PhD degrees. These professors and students are just a few who have contributed to the ideas in found in CPM theory. I would be remiss if I did not thank my friend and husband, Charles R. Bantz for his perceptive and astute comments and my daughter, Kristen E. Petronio who always keeps me anchored. Finally, I am indebted to all of those who have applied CPM theory to significant problems like HIV / AIDS and continue to illustrate that this theoretical base gives us a practical way to approach an understanding of privacy management.

The authors would like to recognize the staff at Lawrence Erlbaum Associates, Inc., in particular Linda Bathgate, the acquisitions editor, for her commitment to this project. We also recognize the contributions of three anonymous reviewers who provided helpful and detailed feedback on drafts of this book. A not so anonymous person who provided feedback on the manuscript with his usual insightful style and wit was Bill Elwood. Jenny Mandelbaum also provided helpful input for chapter 4. Kathryn Greene thanks her friends (Mark, Ben, Yolanda, Eugenio, Stacey, Jan, Judy) for their patience and careful editing. Finally, Kathryn Greene would like to thank her co-authors for their thoughtful insights to this volume.

—Kathryn Greene
—Valerian J. Derlega
—Gust A. Yep
—Sandra Petronio

CHAPTER ONE

Introduction

The HIV epidemic has now entered its third decade. Being diagnosed with HIV in 2003 is not the same as in 1983 or even 1993 (e.g., Vázquez-Pacheco, 2000). There have been many changes in the medical management of HIV since the outbreak of the epidemic (e.g., Catz & Kelly, 2001; Sepkowitz, 2001), including the introduction of new combination therapies with promising effects (Bartlett & Gallant, 2001; Hammer, 2002). Yet there is still no vaccine available in the immediate future (Haney, 2002). Individuals infected with HIV with access to combination drug therapies have increased life-span estimates when compared with early epidemic figures, but these drugs may have serious side effects, do not work for all patients, and are not widely available in many countries (Epstein & Chen, 2002). This book is particularly relevant in describing what occurs in countries where the combination therapies (including protease inhibitors) became widely available in the mid to late 1990s and as a consequence where there has been a significant decline in AIDS deaths and reduction in physical symptoms associated with HIV disease. Despite these encouraging medical advances, an HIV diagnosis creates significant anxiety and distress about one's health, self-identity, and close relationships (e.g., Chesney & Smith, 1999; Holt et al., 1998; Winstead et al., 2002).

The profile of persons with HIV has changed, but stigma linking HIV to groups such as men who have sex with men (MSM) and injection drug users (IDUs) continues to persist despite changes in the profile of the epidemic and extensive educational campaigns addressing transmission (Herek & Capitanio, 1999; Herek, Capitanio, & Widaman, 2002). Today, most HIV infections in the world derive from heterosexual transmission, "a fact that is still overlooked by many" (Sepkowitz, 2001, p. 1765). Academic research and health outreach efforts have turned to the personal relationships of people with HIV and to their social interactions with others (see Derlega & Barbee, 1998a; Derlega, Greene, & Frey, 2002; Greene, Frey, & Derlega, 2002). This research and outreach work certainly connects with existing educational campaigns, for example, those targeting transmission routes and stigma, but it differs importantly in its focus on the quality of the interpersonal relationships of those with HIV (see Derlega & Barbee, 1998a; Greene & Serovich, 1998).

One key feature that needs to be understood to address HIV issues is the process of disclosing about an HIV diagnosis. People report great stress around disclosure decisions (e.g., Holt et al., 1998), and the actual revelation itself can become an added trauma (Limandri, 1989). Vázquez-Pacheco (2000) described the dilemma:

> So when exactly do you bring it up? When do you talk about serostatus? Is there ever a good time to talk about it? … When to have that disclosure discussion remains one of the most difficult decisions for an individual to make in this epidemic. (p. 22)

Not all people with HIV disclose their infection (see chap. 3), but failure to disclose has potential to harm the self, others, and close relationships. Disclosure of HIV status is crucial for both the individual's health and broader health prevention efforts. The goal of this book is to bring together a wide spectrum of information from research literature and organize it into a cohesive framework to generate new questions and identify critical issues about HIV disclosure. One way to provide an organizational structure is to use a theoretical formulation to synthesize research findings in a systematic fashion. We depend on the theory of communication privacy management (CPM) in this book to give us a way to understand the choices that people diagnosed with HIV make about disclosing this information to others (Petronio, 2002). Using a theoretical foundation gives us a way to organize existing information in a more meaningful way to establish additional paths for new research endeavors and more fully understand the existing information. By doing this, we can help those with HIV and those who try to help people with HIV come to some understanding of practical approaches they might take to cope with this disease. This introduction reviews HIV and AIDS statistics, addresses what constitutes disclosure, describes the importance of disclosure, overviews the chapters in the book, and finally reviews the interviews used for the book. First, we turn to a profile of the epidemic worldwide and in the United States.

WORLDWIDE PREVALENCE OF HIV AND AIDS

The United Nations Program on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) reported that through the end of 2001 there were an estimated 40 million people living with HIV around the world (UNAIDS/WHO, 2001). The majority of these HIV cases are in developing countries (95%). There were nearly 3 million AIDS-related deaths estimated in 2001, with nearly 22 million people worldwide who have died from AIDS (Sepkowitz, 2001). Despite earlier estimates predicting the HIV epidemic would peak by 2000, the latest calculations announced at the XIV annual Conference on AIDS in Barcelona, Spain in July of 2002 indicated AIDS will cause an additional 65 million deaths by 2020.

This figure is more than three times the number who died in the first 20 years of the epidemic, reflecting the underestimate of rapidly expanding HIV in many developing countries.

AIDS is the leading cause of death in sub-Saharan Africa, and HIV infection is rapidly increasing in both South and Southeast Asia (particularly China), Europe (particularly Russia), and the Caribbean and Latin America. In some countries, more than 30% of adults are infected (UNAIDS, 2001). There is great diversity in how countries are affected, some with more than 10% of their population with HIV, but many countries with less than 1% seroprevelence. The differences in location or specific populations at risk vary by country. However, there is similarity in infection in young people ages 15 to 24 in most countries. The profile of those infected currently highlights dramatic increases in infection in Asia and Africa and is roughly equal by sex (48% of adult infections worldwide are in women). The U.S. HIV/AIDS profile differs significantly, as we describe next.

PREVALENCE OF HIV AND AIDS IN THE UNITED STATES

This book focuses primarily on experiences with HIV in the United States. Statistics related to HIV change rapidly. Currently, the two best sources for HIV statistics information are available at www.cdc.gov/hiv/pubs/mmwr.htm (MMWR-Morbidity and Mortality Weekly Report) and www.cdc.gov/hiv/stats/hasrlink.htm (HIV/AIDS Surveillance Reports). We highlight recent figures here but encourage people to review updated figures. Sepkowitz (2001) provides two useful tables describing the chronology of the AIDS epidemic in the United States.

The U.S. Centers for Disease Control and Prevention (CDC; 2002) revealed that a total of 816,149 AIDS cases had been reported in the United States through December 2001. AIDS-related deaths in the United States total 467,910. To put this in perspective, this number is more than the total number of Americans who died in World Wars I and II combined (see Sepkowitz, 2001). AIDS cases have decreased dramatically since 1996 (when highly active antiretroviral therapies, or HAART, were introduced), but the rate of decline has slowed considerably in the past 2 years (HIV/AIDS Surveillance Report, 2002). As a note, these cases are for AIDS, not HIV infection, as criteria for HIV reporting to the CDC varies by state. The demographics of these reported AIDS cases in the U.S. included 82% men and 1% children under age 13. Among those who have been diagnosed with AIDS, 42% are White, 38% are Black, 18% are Hispanic, and lower percentages from other ethnic backgrounds. Of the people known to have AIDS, 45% were men who were infected when having sex with another man (MSM); 25% were infected by sharing needles when engaged in injection drug use (IDU).

The face of the HIV epidemic in the United States changed dramatically in the 1990s (CDC, 1999). Specifically, data indicate a growing proportion of HIV cases among Blacks and Hispanics and in women and a decreasing proportion among men who have sex with men. There are also trends indicating increasing infections in adolescents. Specifically, persons aged 13 to 24 accounted for 15% of reported HIV cases in 1999. There has been a sharp decline in perinatal transmission in the United States in the 1990s, possibly linked to increased testing in pregnant women or new delivery protocols for women with HIV or both. Particular attention has also been focused recently on new infections in minority women. Women accounted for 32% of HIV cases reported in 1999 (CDC, 1999), with Blacks and Hispanics comprising 77% of cases in women and 59% of cases in men. Thus, the U.S. profile shows increases in adolescents and minority (especially Black and Hispanic) women, with continued infection in MSM and IDUs.

These figures alone, worldwide and in the United States, indicate many people are affected and will be affected by HIV. One significant issue these people must confront is whether and when to share this information. This book focuses on that process, often labeled *disclosure.*

WHAT IS DISCLOSURE?

These alarming figures both in the United States and worldwide illustrate the obvious need for a better understanding of ways to assist people with HIV in coping with the disease and to stop the spread of HIV. One prominent public health recommendation for people with HIV is to disclose or tell others about their diagnosis, especially their sexual partners (see Rothenberg & Paskey, 1995). This longstanding disclosure recommendation has not been without controversy. In particular, many states have adopted laws encouraging or mandating notification of sexual partners (see Burris, 2001; Rothenberg & Paskey, 1995), and this is a major component of the public health response to the HIV epidemic.

People do not indiscriminately reveal private information, however, because doing so would make them feel too vulnerable (Gilbert, 1976; Petronio, 2002). People more than likely calculate how much they want to tell, when they want to tell, and who they want to tell for the very reason that the information is risky (Petronio, 1991, 2002). Often, when people consider disclosure of HIV status, they are dealing with a decision to allow access to the information to someone and to deny access to others. Consequently, when people refer to "private information," they mean that the information is based on facts and feelings to which others would not normally have access (Derlega, Metts, Petronio, & Margulis, 1993). CPM theory (Petronio, 2002) helps one see that regulating access is important because people often think about private information as something that belongs to them, and in conjunction with the possibility of feeling vulnerable, they want to control who else is privy to the information. When people disclose private information, they may do so by giving complete access through making a full disclosure, giving partial access (selectively disclosing), or restricting access by keeping the information secret (Bok, 1984; Kelly, 2002). It is useful to note here that information about the HIV diagnosis may be considered either private or secret. Private information refers to information about oneself that others might not normally have access to but that is not actively hidden from them, whereas secret information is actively withheld from most others. In this book, we use the term *private information* as an overarching concept that includes secrets (see Bok, 1984; Derlega et al., 1993; Kelly, 2002; Petronio, 2002).

The privacy and disclosure process consists of at least two individuals engaged in a social interaction, each with her or his own feelings, beliefs, attitudes, values, and expectations, and the behavior of both persons is affected by the social, psychological, relational, and physical context. Personal or private information is shared by one person to another specific person or persons. This distinguishes self-disclosure from public disclosure. In public disclosure, for example when the tennis star Arthur Ashe[1] announced via a press conference that he had AIDS (Ashe & Rampersad, 1993; Winston, 1992; Wright, 1999) or Mary Fisher (1992, Fisher is an AIDS activist) announced that she had AIDS at the Republican National Convention, the recipient of the information is difficult to identify (the "general public"). These public disclosure decisions are broad and sweeping, with little control over who knows the information. Self-disclosure, on the other hand, involves intentionally sharing one's private or intimate information with another person (or several people; Dindia, 1997). Disclosure is also generally considered voluntary, that is, a person makes a choice to tell another (without undue threat, coercion, deception, reading a diary, overhearing, etc.). *Disclosure* or *nondisclosure*, as we use the terms, focus on people choosing to share or not share personal information with others.

Disclosure may be relatively infrequent in naturally occurring conversation (Dindia, Fitzpatrick, & Kenny, 1997), yet it carries tremendous relational consequences and is crucial in relational development and maintenance (e.g., Dindia, 2002; Omarzu, 2000). For relationship development, disclosure serves to help get to know another person, and for relational maintenance disclosure allows people to "catch up" with one another. Self-disclosure was originally seen as a trait (e.g., Jourard, 1971); that is, some individuals simply like to share personal information about themselves with others more and some less. An alternative view is that self-disclosure is affected by situational and social contextual factors (e.g., Altman & Taylor, 1973), such as the place where people are interacting (at home or in a public setting), community or cultural attitudes about appropriateness of disclosure, as well as the type of relationship between the discloser and the potential disclosure recipient (e.g., friends, lovers, parents and children, coworkers, health professionals and their clients). Although we do not want to underestimate the possible

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[1] In the early 1990s, after Magic Johnson announced his HIV infection, tennis star Arthur Ashe went public with his infection. For some time after his diagnosis, Ashe told only those close to him (to avoid any stigma for his family, particularly his young daughter). In 1992, Ashe discovered that *USA Today* was planning to run a story about his HIV infection and he went public at that point. This case, different from Magic Johnson and Mary Fisher, focused on mode of infection. Ashe received blood transfusions during heart bypass surgeries in 1979 and 1983 (prior to mandatory testing of donated blood that began in 1985). In 1988, Ashe went in for further surgery and discovered his HIV infection.

impact of traits and temperament on self-disclosure (see Kelly, 2002), we emphasize in our book the role of situational and social contextual factors affecting HIV disclosure.

The content of disclosure can reflect a direct message (e.g., "I have AIDS") or more indirect messages (e.g., "I'm sick," or leaving medical reports for another to see; Derlega et al., 1993; Petronio, 1991; also see detailed discussion in chap. 4). Disclosure of private information can include what medical professionals may term "disclosing a diagnosis," specifically, physicians telling patients about their condition. However, the nature of disclosure in the physician's case has to do with revealing a diagnosis by someone who is not personally affected by the disease. Consequently, although the physician tells the patient pertinent information that is more relevant to the patient than to the physician personally, the information belongs to the patient and not to the physician. A medical disclosure of this type poses a unique situation in which the information actually belongs to the patient, but the physician is included because he or she is instrumental is making the patient aware of the condition (Petronio, 2002). Many times people share information that is relevant to others personally. As a result, although these people are messengers, they know something private about others and people with HIV want them to help control further dissemination. To do that, people typically rely either on implicit professional expectations about doctor–patient confidentiality or explicitly negotiate privacy rules for revealing and concealing medical information such as HIV status. Although this type of disclosure condition occurs with people who have HIV, much of our discussion about disclosure focuses on how individuals manage their own telling about the diagnosis or collectively work with friends and family to manage other people knowing their diagnosis.

With advances in the treatment of HIV using protease inhibitors and combination therapies (e.g., Bartlett & Gallant, 2001), there has been a sharp drop in the number of people dying from AIDS-related illnesses. As a consequence, people with HIV (and their loved ones) are focusing more on how to maintain close relationships and to initiate new relationships with others. This increased focus on close and personal relationships is reflected in an upswing in research on close relationships among individuals living with HIV (e.g., Derlega & Barbee, 1998a; Greene et al., 2002; Kalichman, 2000; Winstead et al., 2002). This book integrates literature on disclosure with relationships of people living with HIV. The distinctive role of HIV disclosure, which involves whether or not to disclose to others about a potentially life-threatening disease that is often associated with stigma and prejudice, is the central topic of this book. This book captures the distinctive role of HIV disclosure and offers some insights into the way researchers can address a critical need for those infected by the virus and those affected by people with HIV. As such, this book exclusively concentrates on disclosures about an HIV positive diagnosis and not about disclosure issues of people who are diagnosed as seronegative after testing. The latter topic also is important and there is a lot of decision making about this sort of HIV disclosure, too. However, this book is about living with HIV and its disclosure ramifications.

THE IMPORTANCE OF HIV DISCLOSURE

HIV disclosure as a research and media topic has received increasing attention over the last decade. First, there are possible advantages to the person with HIV and to significant others associated with choosing to disclose.

- Individuals living with HIV who disclose to selected target people may gain access to social support. To receive assistance (e.g., access to money for medication, child care when ill, or transportation to a physician's office), it may be necessary to disclose. Beyond these instrumental or tangible support needs, an individual with HIV also may want to talk about the illness or plan for the future, and disclosure is necessary to obtain this support as well. Hence, by having others to confide in, infected individuals can build a social support system (Remien, Rabkin, Williams, & Katoff, 1992; Serovich, Brucker, & Kimberly, 2000).
- In the case of sexual partners, HIV disclosure can provide others with information that allows both the person with HIV and his or her sexual partner to make choices that could lower the risk of HIV transmission. There are instances in which not knowing a person's HIV status could put another at risk. For example, if a sexual partner (current or potential) were told about the HIV diagnosis, then one or both parties could use condoms (or dental dams, gloves, finger cots) or choose to modify sexual risk behavior. Following HIV disclosure, the sexual partners might also choose not to be sexually intimate, not to engage in specific behaviors, or not to share needles.
- Disclosure can provide direct health benefits to the discloser. People with HIV are at greater risk for contracting sexually transmitted diseases due to compromised immune systems (Kalichman, 2000). Thus, if disclosure of HIV status results in condom use (or other protective behaviors), this provides direct health benefits for the person with HIV as well. Even couples in which both partners live with HIV can infect each other with modified strains of HIV (Kalichman, 2000). Also, if others are aware of an individual's HIV status, they may be able to warn the infected person about potential health threats such as possible exposure to someone who has chicken pox or another virus.
- People who disclose their HIV diagnosis may also obtain more appropriate medical treatment. People who have not told medical personnel about their HIV status may complicate medical management of other illnesses. This can even extend to not sharing what medications are taken with all physicians, with possible drug interaction effects (Bartlett & Gallant, 2001).
- Disclosing an HIV diagnosis could potentially reduce stigma associated with HIV and AIDS. To date, changes in public perception of the epidemic have been slow at best. Many people still report not knowing anyone with HIV (e.g., Greene, Parrott, & Serovich,1993, reported that less than one fourth of their sample of college students, parents of young children, and parents of college students, indicated personally knowing a person with HIV), although most likely they do know people with HIV and are unaware of it.

- A person could decrease his or her stress by disclosing to a trustworthy confidant. Keeping secrets may be stressful (Lepore & Smyth, 2002; Pennebaker, 1995), and worrying about to whom and when to disclose about the HIV diagnosis may be an additional psychological and physical burden. HIV disclosure to supportive disclosure recipients, other things being equal, has the possibility of increasing life span and improving mental and physical health (e.g., de Vroome, de Wit, Stroebe, Sandfort, & Griensven, 1998). This idea is based on research suggesting that holding in thoughts and feelings might lead to chronic stress and in turn to weakened immune system functioning (e.g., Booth & Petrie, 2002; Cole, Kemeny, Taylor, Visscher, & Fahey, 1996; see also Lutgendorf & Ullrich, 2002).
- Disclosing may bring the person with HIV into a closer relationship with others. Although there are possible risks associated with HIV disclosure, someone who is told about the diagnosis might feel trusted, bringing him or her closer to the person who disclosed. People who are not told may view HIV nondisclosure (once they find out the information) as a violation of the relationship (especially family, friends, and intimate partners; see, e.g., Greene & Faulkner, 2002). People who find out about the diagnosis may also feel they should have been told earlier. The overlap in concerns about HIV disclosure and close relationships is explored throughout this book.

SUMMARY OF HIV DISCLOSURE

Although reasons for HIV disclosure may be compelling, there are also possible disadvantages (and risks) to the person with HIV and to significant others associated with HIV disclosure (Derlega, Lovejoy, & Winstead, 1998; Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Greene & Serovich, 1996; Kelly, 2002; Petronio, 2002). Documentation of risks (including discrimination, violence, and rejection) for people who disclose their HIV diagnosis is extensive (e.g., Leary & Schreindorfer, 1998), and many individuals with HIV report negative responses to at least some of their disclosures. Table 1.1 presents a list of some reported negative and positive consequences of disclosing HIV status. This list is derived from interviews described later in this chapter and from other research.

Because it is clear that those who do not disclose and still participate in sexual and drug related risky behavior can spread HIV to others, one way to further prevent the spread of HIV and possibly increase life quality for individuals with HIV is to understand why people are reluctant to reveal their status (or not disclose). For some persons with HIV, there is a code of silence around HIV (Elwood, 2002; Vázquez-Pacheco, 2000) in which some do not want to know their HIV status (and would not know what to do if positive) so they even avoid HIV testing (or disclosing if they are infected with HIV). Numerous factors contribute to the reason people may seek to withhold information about their HIV diagnosis from others. The difficulty arises when protection of a person's status potentially contributes to the spread of HIV and can also threaten the infected individual's health. In both cases, there are risks and benefits to consider, and many individuals report great

TABLE 1.1

Some Reported Negative and Positive Consequences of Disclosing an HIV Diagnosis

Negative	*Positive*
Ostracism	Relationship became closer
Physical violence	Educated others
Blaming	Others were tested
Relationship ends (also divorce)	Practiced lower risk behaviors
Cannot see children, nieces, nephews	Able to talk about stresses
Lost housing, evicted	Reminded to take medications, eat well
Fired from job, not hired	Others prepared meals, helped around the house
Lost insurance	Assisted with child care
People do not speak to you	Financial assistance (rent, meals, medication)
Asked to leave church (and other groups)	Met others with HIV
Disowned (by parents/family)	Received help with filling out forms, using Internet
People will not eat food prepared	Joined support group, visited AIDS service organization
Do not want to burden other	

Note. These descriptions are derived from interviews reported in this book and other research (e.g., Derlega et al., 1998; Greene & Faulkner, 2002; Greene & Serovich, 1996; Hays et al., 1993; Marks et al., 1992; Marks, Cantero, & Simoni, 1998; Serovich, Kimberly, & Greene, 1998; Simoni et al., 1995; Winstead et al., 2002).

distress around decisions to conceal or reveal their illness (e.g., Greene & Faulkner, 2002; Holt et al., 1998; Winstead et al., 2002). Thus, disclosure is a critical issue to investigate, as this book illustrates.

CHAPTER OVERVIEWS

After this introductory chapter, the second chapter presents an overview of CPM theory (Petronio, 2002). The third chapter examines predictors of disclosure or what variables influence decisions to disclose or not disclose an HIV positive diagnosis. The fourth chapter describes the features and content of the HIV disclosure messages along with examination of timing and setting of these disclosures. The fifth chapter explores the consequences of HIV disclosure and nondisclosure decisions. The sixth chapter is the epilogue, which looks to the future of HIV disclosure issues. The appendix provides exercises, measures, and practical applications of disclosure research for individuals with HIV and those working with clients with HIV and their families.

Chapter 2: CPM and HIV Disclosure

In this chapter, the theory of CPM is presented (Petronio, 2002). As a practical theory, CPM is used in this book to organize the existing research literature on disclosure and HIV. Given the disparate nature of the research, this theory provides a core set of concepts from which new ways of understanding the problems associated with HIV disclosure emerge. This theory is predicated on the notion that people believe private information is something that belongs to them. Individuals want to control the flow of that information because they perceive that they own it, and revealing private information often has the potential to make them feel vulnerable. Consequently, we can more easily think about this information if we first use a boundary metaphor to illustrate the parameters that people set around their private information. Next, if we consider that people regulate the flow of their information through privacy rules, or what CPM calls a rule management system, we are able to see the way that people control that flow to others. Cast in this way, we can begin to envision how people with HIV tend to manage the dialectical tensions of privacy and disclosure by the way they control revealing to or concealing their HIV status from others.

Chapter 2 articulates the fundamental structure and processes of the CPM rule management system. Because the rule system is the key to grasping the decision criteria for telling HIV status or concealing it, knowing the underlying judgment heuristics people use when they develop privacy rules is critically important. In this chapter, we learn how privacy rules are formulated, adjusted, and changed when they are no longer function. For many who learn of their HIV status, the rules used to judge the level of privacy they wish to maintain often change. They may no longer feel comfortable talking to their partners or spouses about their health. Consequently, they may need to change an old rule (they always tell their partner about health problems) to a new privacy rule that limits what they tell their partners or spouses about health issues. We also learn that the theory provides a way to understand the fact that when individuals disclose private information, they link other people into their private boundaries. Doing so means that individuals make others co-owners of the information. As such, they need to negotiate or coordinate which privacy rules they will use to regulate third-party disclosures or which rules are used to restrict others from knowing.

Boundary coordination takes place once people disclose and others are linked into the privacy boundary. Coordination represents the process of negotiating privacy rules. When successfully agreed on rules become synchronized among the co-owners, the coordination process to run smoothly. However, we do not live in a perfect world; as a result, we also face boundary turbulence. Turbulence reflects situations when the negotiation of privacy rules managing the boundaries around private information fail to work. This failure may occur because co-owners or confidants violate a trust, mistakenly use the wrong rules, have difficulty because the rules are ambiguous, the original disclosers believe that confidants are capable of keeping confidences (and they are not), confidants misjudge the rules, or they completely ignore their agreement to abide by mutually negotiated privacy rules.

Boundary turbulence suggested by CPM has significant consequences for both the owner of private information and the confidant. Particularly when we examine the communicative interactions between individuals diagnosed with HIV and family members, partners, and / or friends, finding themselves in a turbulent situation regarding the disclosure of their HIV status can be traumatic. This chapter acquaints the reader with CPM theory as it is applied to the disclosure process for people with HIV. The theory offers a way to grasp how individuals grapple with regulating the revealing and concealing of their HIV diagnosis.

Chapter 3: Decisions to Disclose or Not Disclose About an HIV Positive Diagnosis

This chapter explores what predicts or explains decisions to disclose (or not) about the HIV infection to another. These explanations reflect the tension and uncertainty (whether or not to tell someone, how to tell someone) about finding out about the HIV diagnosis. Disclosure of HIV status is a complex communication event involving high levels of vulnerability and risk, and these decisions are processed carefully.

We first explore how HIV-related stigma affects HIV disclosure decisions. The perceived risk from HIV stigma stems from perceptions of possible negative emotional reactions, fear of infection and contagion, disapproval, and failing to contribute. For any of these aspects of stigma, if individuals with HIV anticipate a stigmatizing response, they likely will not choose to disclose.

The next portion of the chapter explores differences in motivations for disclosure based on self-, other-, and interpersonal-gain. People often disclose to gain some benefit for themselves. In the context of HIV, self-gain motivations include catharsis and seeking help. However, people also disclose based on what the other might gain. For individuals with HIV, other-gain motivations include duty to inform and educating others. People also disclose based on interpersonal considerations. Interpersonal motivations include testing others' reactions, establishing emotionally close and supportive relationships, and common experiences. These self-, other-, and interpersonal-based criteria can serve as motivations to disclose, but people also have motives for nondisclosure or maintaining privacy. Decisions to disclose an HIV diagnosis also include privacy protection. Hence, we explore motivations for nondisclosure including third-party leakage, self-blame or self-concept difficulties, fear of rejection or being misunderstood, and protecting others.

The final section of the chapter examines the relational influences on disclosure decisions. First, anticipated response can explain disclosure decisions. If people think a recipient may respond poorly to a disclosure, they would be less likely to share an HIV diagnosis. Next, strength of relational ties might explain disclosure. That is, the role may be important in deciding whether to disclose. Chapter 3 describes disclosure decisions in eight specific targets or roles: partner or lover, parent(s), siblings, children, friends, family, coworkers, and health care workers. Disclosure decisions may also be affected by past discussion of HIV in which a person who has discussed these issues previously might be more inclined to share an HIV diagnosis. Individuals with HIV may also choose to bring up the general topic of AIDS to see the reaction before they decide to disclose. Perceived relational quality may also influence disclosure decisions beyond strength of relational ties. People who are close to their mothers may be more likely to disclose a diagnosis to them sooner because they are close, beyond simply the mother's role as a parent. The discloser's past experience with sharing the diagnosis may also affect decisions. If people had difficult episodes in the past (e.g., a bad reaction such as violence or gossip), they may be less willing to disclose. Finally, culture may influence disclosure decisions, specifically gender and ethnicity.

Chapter 4: Features of HIV Disclosure Messages

In this chapter, we focus on the actual disclosure process and messages once a decision has been made to share the HIV diagnosis. We explore both verbal and alternative disclosure messages. The major areas covered in this chapter are mode of communication, context, and message features.

We first examine the communication mode or channel. These include differences between face-to-face and non-face-to-face disclosure. Specifically, people may disclose in person in the same room or they may send a letter, e-mail, and so forth. These choices of mode affect the message itself and how the recipient can respond. Additionally, this chapter examines third-party or indirect disclosure, both voluntary and not. For instance, perhaps a person's sister revealed the brother's diagnosis to their mother, and this could have been requested or not.

Next, the chapter looks at contextual considerations, specifically effects of the setting and timing on HIV disclosure. The setting (such as the physical context of the disclosure) affects perceptions of privacy and appropriateness, and the discloser may select a more equivocal message in public but a more direct message in private. Timing of disclosure can also be a factor in disclosure messages. For instance, disclosing about HIV status on a first date may be perceived as appropriate or inappropriate, but in another situation it might be a practical assessment of relational potential. Three aspects of timing are explored: when to disclose after learning a diagnosis, whether it is spontaneous or preplanned, and when within a conversation to disclose.

The chapter then examines specific HIV disclosure message features including directness, length, and content. The directness section includes discussion of the level of specificity or abstractness of the disclosure message. Messages can also vary in length from extremely brief to long and involved. Finally, the disclosure message content may contain information in addition to the HIV diagnosis, such as unknown sexual partners, sexual orientation, or drug use. That is, a person may share that he or she was diagnosed with HIV but also choose to share past sexual history in addition to the diagnosis.

The last section of the chapter explores what may be modes beyond verbal disclosure for revealing one's HIV diagnosis to others. The chapter discusses, for instance, the role of body language (e.g., physical symptoms such as "wasting") or of providing environmental props (e.g., leaving medications in view in the bathroom or refrigerator) to disclose about the HIV diagnosis.

Chapter 5: Consequences of HIV Disclosure and Nondisclosure Decision Making

The decision to disclose or not to disclose to others about the HIV diagnosis can have numerous outcomes. The chapter begins by summarizing reports of actual responses to HIV disclosure. Many of the responses to disclosing an HIV positive diagnosis may be helpful and supportive, yet there may be adverse social consequences of self-disclosure of the HIV diagnosis. Individuals—or their loved ones—may be shunned, discriminated against, or blamed for what happened. In some cases, individuals with HIV may be subject to verbal and/or physical abuse (see van der Straten, King, et al., 1998; Vlahov et al., 1998).

Next we examine the relation between disclosure and social support by looking at types of social support, coping, satisfaction, support groups or activism, and identity. One's role in a social network is significant for both physical and mental health. One possible outcome for those who disclose is accessing this social support to assist in coping with the disease; however, not all support is helpful.

We then turn to one especially difficult outcome of HIV disclosure: stigma. Many people with HIV report experiences with stigma, although the extent of these experiences varies a great deal. For some individuals, stigmatizing responses (including being treated differently) are the dominant outcome of disclosing, but for others these responses are more isolated (see Alonzo & Reynolds, 1995; Derlega et al., 2002; Fife & Wright, 2000; Greene & Faulkner, 2002). Our discussion of HIV stigma examines outcomes based on misinformation, group bias, and courtesy stigma.

The final section on consequences of HIV disclosure decisions looks at the outcomes of disclosing on close relationships. First, we look at how HIV disclosure affects relationship closeness, as disclosing can increase, decrease, or have no affect on the quality of the relationship. Then we look at how significant others can be caregivers, including promoting medication adherence and providing daily assistance. Next, we explore one specific relationship consequence—relationships with children after HIV disclosure. Finally, we examine how HIV disclosure affects safer sex and other risk behaviors in intimate relationships.

Although much of this chapter focuses on the impact of disclosure for persons with HIV, we also consider the impact of the decision to disclose or not disclose on others. People also choose to maintain privacy or not disclose, and this has consequences. Individuals with HIV report conflicted feelings about others' right to know the diagnosis. They may also see nondisclosure as a form of informational control, and this control at times breaks down if others share the diagnosis. Finally, nondisclosure can be a form of psychological inhibition.