Expanding the Boundaries: Using Communication Privacy Management Theory to Explore the Disclosure of the Diagnosis of a Chronic Illness by Pediatric Healthcare Providers and Parents to Adolescent Patients

by

Anna Marie Campbell

A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved March 2021 by the
Graduate Supervisory Committee:

Janet Alberts, Chair
Paul Mongeau
Cady Berkel

ARIZONA STATE UNIVERSITY

May 2021

ABSTRACT

This qualitative study explores communication privacy management processes around disclosing a child's Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV) status within a pediatric healthcare relationship. The pediatric healthcare relationship is a triadic one composed of providers, parents, and patients. The literature from the fields of medicine, psychology and communication was used to explore disclosing HIV status by seropositive positive adults to others and by providers and parents to HIV positive children. Data for this study was collected from a hospital-based clinic using a 3-part protocol that included transcripts and information from a 6 member focus group interview, 42 patient medical charts, and two parent interviews. Datum was analyzed using thematic analysis. The results indicate that both providers and parents consider these adolescent behavioral indicators that disclosure is necessary: question-asking about medications and the need for medical appointments, the initiation of dating and sexual behavior, cognitive maturity, and chronological age. Providers and parents negotiate when and how the disclosure will occur and the providers perceptions of the permeability of the family privacy boundaries influence the negotiations. An adolescent's failure to properly adhere to the medication regimen and the initiation of and engagement in sexual behavior are catalysts for immediate disclosure. Finally, a clinical tool is proposed to assist providers and parents in their negotiations around disclosing the child's HIV status.

DEDICATION

This work is dedicated to the devoted and compassionate providers, brave patients, and parents of the Lewin Clinic who graciously shared their stories with me.

ACKNOWLEDGMENTS

I would like to thank my academic mentors, Dr. Pamela Shockley-Zalabak, Dr. Sherwyn Morreale and the late Dr. Michael Z. Hackman for seeing the scholarly potential in me and supporting me by offering their time, friendship, and words of encouragement as I struggled through this program.

I am grateful for the kindness, the humor, and the encouragement of my family and friends. My sister and brother-in-law, Annette and Chip Maxson, for their love and support of a sibling who thought getting a Ph.D. was a good idea for her later years. My late uncle, Dr. John Shybut, whose stories about his personal experiences in a Ph.D. program made for good conversation during the last years of his life. Dr. Dan and Mary Kopacz for the beers and cheers over the years.

My daughter, Sarah, whose love and friendship have sustained me throughout this journey. We both started our respective graduate school experiences in August 2014. My beautiful girl blossomed into a kind, insightful, and thoughtful young woman whose clear-eyed comments about the academic life were always uplifting. I treasured our short breaks together as a family in Phoenix as we watched you grow into the adult you are today and of whom I am enormously proud.

My husband, Andrew, for loving me for who I am and letting me go do the work I always wanted. Not many men are willing to let their wife traipse 800 miles away from home to attend graduate school for five years in the Arizona desert. Our love and life together have always been a home base for me. Your patience, gentleness, sense of humor, and intuition about working with people are characteristics I truly cherish about you. We share in the honor of finishing this program and getting this degree as I truly could not have earned it without your deep love and support of me.

I am deeply grateful to my dissertation committee who supported this complex research project. Dr. Janet Alberts whose leadership, compassion, and talent for guiding graduate students helped get this project to the finish line. Dr. Paul Mongeau for his insight into interpersonal communication theory and his dry sense of humor that always made me smile. Dr. Cady Berkel taught me the importance and pitfalls of doing research in real world settings and gave me the opportunity to complete this research. I am grateful to have worked with a talented group of academicians. Thank you for your guidance, dedication, and patience during this process.

Finally, I would also like to thank the following organizations for their generous support of this research project: Wellington Hospital Learners Research Council, the Hugh Downs School of Human Communication, and the Arizona State University Graduate Professional Student Association.

TABLE OF CONTENTS

CHAPTER Page

APPENDIX

LIST OF TABLES

LIST OF FIGURES

Figure Page

CHAPTER 1

BACKGROUND

Pediatricians in the United States are the primary health care providers for children and adolescents under the age of 19 years (American Academy of Pediatrics & Health, 1988). The relationship a parent develops with a child's primary care physician is one that lasts until the child matures to adulthood. This trusted professional helps parents assess and respond to their child's health care and developmental needs. Some children require specialized care, particularly if the child has acquired a chronic illness at birth or perinatally. One perinatally acquired illness that requires special care is the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome ("HIV/AIDS"). This illness, once a deadly and fatal disease, is now controlled using powerful antiretroviral medications designed to keep the virus from replicating in the human body (Hatfield-Timajchy et al., 2016). The medication regimen allows people living with HIV/AIDS to lead healthier, more productive lives (Control, 2019). For the first time in over three decades, people diagnosed with HIV/AIDS are now living with a treatable chronic illness (Control, 2019; Scandlyn, 2000; Siegel & Lekas, 2002).

Currently, over one million adults, adolescents, and children in the United States are infected with HIV/AIDS (Control, 2019). Approximately 12,310 adults, adolescents and children have contracted HIV/AIDS perinatally which means the virus was transmitted to them through pregnancy, childbirth, or breastfeeding (Centers for Disease Control, 2018). The current rate of perinatal transmission of HIV/AIDS in the United States is less than 2 per 100,000 people (Centers for Disease Control, 2018; Nesheim et.

al., 2017). Of the 12,310 people perinatally infected in the United States, approximately 6,953 people are adolescents ages 13 to 19 years old (Center for Disease Control, 2018). Young people have benefitted from the advances in antiretroviral medications that allow people living with HIV/AIDS to live longer, healthier lives. As these young people mature to adulthood, they will need to learn about their HIV status so they can manage their own health care needs and understand the implications of living as an adult person with HIV/AIDS (Hatfield-Timajchy et al., 2016).

The implications of living as a person with HIV/AIDS in the United States are the medical, social, emotional, relational, (Helms et al., 2017). The medical implications include the person's ability to maintain their good health by faithfully adhering to the antiretroviral medication regimen and regularly accessing health care services to ensure continued good health (Helms et al., 2017). The social, emotional, and relational implications are related to the stigma of living with a chronic illness (Chambers et al., 2015). In the United States, HIV/AIDS is a stigmatized illness, and these attitudes are still prevalent in many communities (Helms et al., 2017). The stigma related to HIV is "the prejudicial feelings, stereotypical perceptions, discriminatory behaviors and actions, or social devaluation of HIV infection, HIV/AIDS related illnesses, the activities associated with HIV-infection, and people with HIV" (Chambers et al., 2015, p. 849). Parents of pediatric patients infected with HIV/AIDS face the dual challenge of protecting their child's sense of self as a member of a family and a community while navigating the negative attitudes towards PLWHA in their community (Chambers et al., 2015).

A person's HIV status is private information (Greene et al., 2003), and most people living with HIV/AIDS ("PLWHA") keep this information well-hidden from others because of the stigma associated with it (Greene et al., 2003). They realize that if their HIV status becomes known, they could suffer ostracism or discrimination from their family and community, so PLWHA learn under which circumstances they should inform others of their status and also when disclosure of this information is not appropriate (Greene et al., 2003). Managing the dialectical tensions between revealing and concealing this information requires discretion and judgment, as well as an understanding of the relational contexts in which this disclosure should take place. Since children and adolescents are not able to manage these issues for themselves, parents and health care providers must manage the information about HIV status until these patients are old enough to understand how to manage privacy boundaries around their illness.

Context: The Pediatric Healthcare Relationship

Parents raising a child with perinatally acquired HIV/AIDS utilize health care services from pediatric healthcare providers who specialize in infectious diseases (Committee on Pediatric AIDS & Adolescence, 2001). The child's health care needs require them to see the provider frequently, and the parent and the child form a relationship with the provider and their clinic staff. This relationship is a triadic one in which the provider, parent, and child are connected communicatively because of the child's need for healthcare services (Damm et al., 2015; Olson, 2005). This triad also is comprised of three dyadic relationships within the three-person group. Three dyads exist:

parent-child, provider-parent, and provider-child. Each person within the triad performs a role and shares information with the other members about the child’s healthcare needs.

The first dyad is the parent-child relationship. A parent and a child share private information about their family group and the information within their own relationship (Petronio, 2002). Parents also are responsible for socializing their children about the family privacy rules and boundaries (Petronio, 2010). Within the pediatric health care relationship, particularly when a child is very young, a parent acts as a proxy for their child, sharing information about the child’s health and relevant family issues with the provider (Rafferty et al., 2019). In this role, parents are both gatekeepers of family information and stakeholders in the relationship with providers regarding the child’s health care (Petronio & Reierson, 2009).

The second dyad is the provider-parent relationship. As medical professionals, healthcare providers solicit information from the patients and parents within their practice and ensure that information about each patient remains confidential, as required by the ethical, professional, and legal standards within the medical profession (Petronio & Reierson, 2009). The provider is a stakeholder in the healthcare relationship with the parent and has an ethical and professional responsibility to treat the child’s health care condition (Petronio & Reierson, 2009). Working with parents in this relationship requires the provider to coordinate the child’s health care needs with the parent’s ability to meet their child’s medical needs.

The third dyad in this triad is the child-provider relationship. When a child is young, their parent acts as their proxy when communicating with the provider (Rafferty et al., 2019). As the patient matures to adolescence, they begin communicating with the provider during appointments. Once the patient reaches adolescence, they can communicate independently with the providers about their health needs. Adolescence also can bring communication challenges to the parent-child dyad as the child moves toward adulthood and independence and begins to seek control of their private relationships and information, including their health information (Ebersole & Hernandez, 2016). Providers may also serve as the adolescent's confidant for disclosure of information about risky behaviors the adolescent may keep hidden from their parents.

Research Problem: Disclosure of HIV Status

An adolescent who is HIV positive must be informed of their diagnosis and learn how to manage their health condition responsibly as they grow to adulthood. However, initiating this conversation can be a difficult one for parents (Keating et al., 2013) because as HIV positive adults, they are faced with explaining to their perinatally - acquired HIV positive child that they have a chronic, stigmatizing illness. The disclosure also means that a parent no longer maintains complete control information about their illness; now their adolescent also co-controls and co-manages this information about themselves and their family members (Petronio, 2010). On the other hand, despite potential family concerns or hesitations, healthcare providers are required to inform a patient, at an appropriate age, of their illness and the treatment needed to manage the illness (Petronio & Reierson, 2009). The question of when and how providers and parents should disclose HIV status to adolescent patients is a fraught one, and this question forms the basis for the study.

This qualitative study uses thematic analysis to investigate how providers and parents negotiate the disclosure of their status to an HIV positive adolescent. Through the framework of Communication Privacy Management theory (Petronio, 2013), the study examines how providers and parents manage and coordinate complex privacy boundaries around both the child's and-the parent's-HIV status. The crux of these difficult conversations for providers and parents lies with the need for the adolescent to become a responsible owner of their own health information without also being informed of their parent's status. Because providers and parents may have differing expectations around ownership and control of the HIV status of both the child and their parent, disagreement between can arise (Petronio & Reierson, 2009).

Significance

The significance of this study is twofold. First, it adds to our understanding of how boundary management occurs in complex privacy- regulation situations as well as contributes to the theorizing about the explanatory value of Communication Privacy Management theory in healthcare settings (Petronio, 2002) by applying it to a pediatric healthcare context. In addition, the study contributes to the literature focused on the disclosure of HIV status to HIV positive adolescents by healthcare providers and parents (American Academy of Pediatrics, 2013; Weiner et al., 2009).

Second, this study provides a starting point for the development of a parent-education tool for those who generally find the disclosure process stressful. A parent education tool will address families' values and beliefs around health and illness as well as the parent's willingness to discuss these issues amongst themselves. This tool will be designed to help educate parents about the HIV disclosure process and facilitate parent-provider discussions so that that providers are aware of the values and beliefs that influence a parent’s behavior and decisions about disclosing status to their child.

Informing an adolescent of their HIV status is an important milestone in the development of a young adult. However, the decision-making processes that lead to disclosure can be contentious, drawn out, and delay the event to the detriment of the child. Understanding the points of contention in the process as well as what conditions lead to smoother, more timely disclosures will benefit these young adults’ health as well as improve relationships within affected families and between caretakers and healthcare workers. The young adult also must learn how to balance the dialectical tensions in revealing and concealing stigmatizing private information as they enter sexual and romantic relationships in the future. Communication Privacy Management theory (Petronio, 2013) helps explain how, when, and why PLWHA disclose their HIV status to others. In the chapter to follow, the tenets of Communication Privacy Management theory (Petronio, 2013) are discussed and applications of CPM to healthcare relationships and family relationships are discussed.

CHAPTER 2

LITERATURE REVIEW

This study focuses on parents and pediatric healthcare providers' management and coordination of privacy boundaries around an adolescent patient's HIV status within the context of a pediatric health-care relationship. The study uses Communication Privacy Management theory ("CPM") (Petronio, 2013) as the theoretical framework for explaining how complex privacy boundaries are managed and coordinated by providers, parents, and patients. More specifically, it examines the decision-making process they use to determine whether an adolescent is prepared to manage this often-stigmatizing health information and to set boundaries around its disclosure. A brief discussion of adolescent development and their age-appropriate need to establish personal privacy boundaries is reviewed. The role of healthcare providers as deliberate confidants is proposed, and a discussion of how healthcare providers balance privacy boundaries within their professional relationships is introduced. Finally, the research questions guiding this work are presented.

Research into HIV Disclosure

The disclosure of HIV status is a well-researched topic by medical researchers, psychologists, and communication scholars (Brackis-Cott et al., 2003; Butler et al., 2009; Gerson et al., 2001; Greene et al., 2013; Greene et al., 2003; Li et al., 2017; Omarzu, 2000). As medications for treating HIV advanced over the years, medical researchers have investigated disclosure processes used by pediatric healthcare providers who faced challenges around disclosure to adolescent and young adult populations. One issue faced by medical researchers is the age at which disclosure should occur. The American Academy of Pediatrics (2013) recommends that disclosure occur early in adolescence because adolescence is the period of human development in which young people begin to experiment with “risky sexual and drug use behavior which may further the transmission of the disease” (Mellins et al., 2002, p.111). Second, providers also consider the child’s developmental capacity to engage in abstract reasoning to both understand their health condition and, the implications of HIV-related stigma in relationships with family and friends (Calabrese et al., 2012; Mellins et al., 2002). Finally, the child’s ability to adhere to the medication regimen is a major clinical concern for providers because the adolescent must be able to responsibly follow the medication regimen to ensure their good health (Brackis-Cott et al., 2003).

Research by psychologists has focused on the difficulty people living with HIV/AIDS (“PLWHA”) have in disclosing their status to another person. Their research has led to the development of models based in theories of self-disclosure (Chaudoir & Fisher, 2010; Li et al., 2015; Omarzu, 2000). The Disclosure Decision Model, developed by Omarzu (2000), seeks to explain how people disclose information and proposes that in order to achieve specific relational goals with an intended partner, a person considers the depth, breath, and content of the information to be disclosed (Omarzu, 2000). Another model, the Disclosure Process Model (Chaudoir & Fisher, 2010), proffers that when disclosing HIV status, four factors influence the disclosure process: antecedents, disclosure event, mediating processes, and feedback (Chaudoir et al., 2011). When determining whether to reveal their HIV status to another person, PLWHA also consider “motivations for disclosure, confidant serostatus, and relationship” to the recipient (Chaudoir, et al., 2011, p. 1626). Li, Qiao, Harrison and Li (2017) argue that the Disclosure Process Model (Chaudior & Fisher, 2010) should also include these concepts: uncertainty and information seeking behavior. Furthermore, they suggest two interpersonal communication theories be incorporated—Communication Privacy Management theory and Social Exchange Theory--to more fully explain the connection between the psychological and communication processes about disclosing HIV status (Li et al., 2017).

Communication scholars also have contributed extensively to the literature about HIV disclosure. Using CPM theory (Petronio, 2013) as a theoretical foundation, communication scholars have examined the HIV disclosure process, including how adults disclose their HIV status to relational partners and family members (Greene et al., 2013; Greene et al., 2003; Petronio, 2002) and the impact of HIV-related stigma on the disclosure process (Catona et al., 2016). The research using CPM has centered on the following: exploring factors adults use to determine when to disclose their status to another adult (Derlenga et al., 2004; Greene et al., 2003); how HIV positive parents inform their HIV-negative children about the parent’s HIV status (Catona et al., 2015; Tenzek et al., 2013), and how HIV positive African American adolescent females inform parents and other adults about their HIV status (Greene & Faulkner, 2002).

Family communication scholars have examined privacy management by families around health information, including disclosure by HIV- positive mothers to their HIV-negative children (Kennedy-Lightsey & Frisby, 2016; Mazur & Hubbard, 2004; Petronio, 2002, 2010; Serewicz et al., 2007). Ebersole and Hernandez (2016) investigated how parents and their adolescent children share health information and found that both parents and adolescents use the strategies of humor and topic avoidance to protect personal privacy boundaries, avoid stress and solicit social support. In a meta-analysis, Tenzek, Herrman, May, Feiner and Allen (2013) investigated the impact of an HIV positive mother disclosing her status to her HIV negative children. The findings were inconsistent in that the quality of the parent-child relationship improved; however, the child's negative feelings and emotions increased after disclosure because they felt unsure how to handle the need to keep the information secret from others (Tenzek et al., 2013). In response, the researchers proposed that parents help children construct and manage privacy rules around the newly disclosed information about a parent's HIV status (Tenzek et al., 2013).

Communication scholars also have used CPM to investigate how privacy boundaries are managed in healthcare relationships (Lewis et al., 2011; Petronio & Gaff, 2010; Petronio et al., 2004). Bute, Petronio, and Torke (2015) found that surrogates faced privacy dilemmas in determining how much information to disclose to health care providers when communicating the health care needs of older adults who are unable to communicate their concerns. Petronio and Sargent (2011) examined privacy predicaments nurses face when asked to reveal health information to family members who lacked the patient's consent.

In addition to research focused on the adult patient-provider relationship and adult privacy boundaries management, communication scholars have studied the communicative processes used by pediatric healthcare providers and parents. Duggan and Petronio (2009) investigated how parents manage family privacy boundaries when interacting with medical staff in emergency situations. Petronio and Sweeney-Lewis (2011) examined providers, patients, and families' use of privacy management processes related to cancer diagnosis. They found that each member of the triad regulated control over the information around the diagnosis. Furthermore, parents viewed their role as guardians and co-owners of the child's information and felt they should control the amount of information disclosed to their child (Petronio & Sweeney-Lewis, 2011).

Thus, CPM frequently has been used to explore HIV/AIDS disclosure and privacy boundary management in health settings and is, therefore, an appropriate theoretical framework for investigating the disclosure process for informing perinatally-acquired HIV positive adolescents of their health status. This study extends previous research in that parents and the providers have a long-term relationship in which they manage and coordinate boundaries around their co-ownership of health information while the true owner of the information, the adolescent patient, is unaware of the nature of their diagnosis. It thus explores the communicative processes used by providers and parents when adolescent behavior triggers the need to inform an HIV positive adolescent of their illness fully and completely. Second, this study furthers research into the theoretical concepts related to privacy management by examining how one dyad, provider and parent, determine when a child is ready for disclosure, how they negotiate the disclosure, and the conditions that may hasten the disclosure process.

Because as adolescents mature to adulthood they must learn to manage their own health condition, they need to know how and when to disclose their HIV status to others, including future relationships with sexual partners, employers, and adult healthcare providers (American Academy of Pediatrics, 2013; White et al., 2018). Pediatric healthcare providers and parents are aware of HIV-related stigma, and this awareness is a backdrop against which their decisions and conversations occur about fully informing an adolescent of their HIV status. Thus, an understanding of HIV-related stigma and its implications for PLWHA is the starting point for this analysis.

HIV-Related Stigma and Secrets

Disclosing HIV status is a difficult conversation for PLWHA. The stigma around HIV status runs deep within American culture (Kalichman et al., 2017). This type of stigma is defined as "the shame or disgrace attached to this disease and expressed through negative social reactions towards people infected with the virus" (Darlington & Hutson, 2017, p. 863). An example of HIV-related stigma is found in the number of people in the United States who feel uncomfortable working with HIV positive individuals and those who believe that a person who is HIV positive is personally responsible for contracting their illness (Catona et al., 2016). The negative social attitudes encountered by PLWHA may enhance their feelings about a loss of social support, increase a risk of depression, engage in risky behaviors, and have poor medication adherence (Catona et al., 2016).

Prior research into HIV-related stigma suggests that PLWHA face three different kinds of stigma: internalized, anticipated, and enacted (Kalichman et al., 2017). Internalized stigma is "a sense of being less worthy or inferior to others due to having

HIV" (Kalichman et al., 2017, p.1). Internalized stigma impacts the level of self-esteem held by a PLWHA and can contribute to depression (Kalichman et al., 2017). Anticipated stigma is the anxiety a PLWHA may experience because they expect to be viewed differently because of their HIV infection (Kalichman et al., 2017), and enacted stigma is the overt discriminatory actions taken against a PLWHA by others because of their HIV status (Catona et al., 2016; Kalichman et al., 2017). When a PLWHA anticipates or experiences a negative reaction from people within their family and community, they experience one or more of the types of stigma, which creates a heightened sense of vulnerability and insecurity for them.

When personal information about oneself is stigmatized, it can create a sense of vulnerability that leads people to desire to keep this fact well-hidden and secret from others, including family members (Afifi et al., 2005; Piazza & Bering, 2010; Vangelisti et al., 2001; Vangelisti, 1994; Vangelisti & Caughlin, 1997). In a study of individuals' need to hide distressing secrets from others, evolutionary psychologists Piazza and Bering (2010) propose that humans, when seeking social interaction, make choices about other people as relational partners based on the cues they receive from that person. Piazza and Bering (2010) posit that humans evaluate cues from others related to "three universal domains of social interaction: dyadic cooperation, parasite avoidance and coalitional exploitation" (Piazza & Bering, 2010, p. 290). In dyadic relationships, humans tend to avoid "characteristics that suggest one might make a poor interactive partner in a social exchange (e.g., … violent, in debt, dishonest) or as a mating partner (e.g., unfaithful, unpredictable, inexperienced)" (Piazza & Bering, 2010, p. 290). Parasite avoidance is defined as “characteristics that suggest one might possess a communicable pathogen or be vulnerable to such pathogens” (Piazza & Bering, 2010, p. 290). Coalitional exploitation is defined as “characteristics that suggest someone is an exploitable outgroup member” (Piazza & Bering, 2010, pp. 290-291). According to the authors, humans have developed psychological mechanisms for both hiding traits perceived as undesirable in a relational partner as well as psychological mechanisms designed to detect these weaknesses in other people.

Humans hide damaging information from others when engaging in a variety of social relationships, and Piazza and Bering (2010) propose that secrecy is “the active suppression (from public awareness) of information detected in oneself or one’s kin that is consciously registered as reputationally damaging or (more distally) fitness damaging” (p.303). A person who has a stigmatizing illness that could damage the reputation of their partner presents a fitness cost to their potential mate (Piazza & Bering, 2010). Therefore, stigmatizing information is well-hidden, so one is not perceived as an undesirable relational partner or family member.

The psychological energy needed to keep the information secret is burdensome (Kelly & McKillop, 1996) and involves balancing the dialectical tensions in revealing and concealing private information (Altman et al., 1981; Petronio, 2002). For this and the reasons above, revealing one’s HIV status is a challenge for many PLWHA (Greene et al., 2003). Self-disclosure involves cognitively making choices about the amount of and the kind of private information to communicate to another person. Psychologists who have studied self-disclosure (Derlenga, 1987) and the consequences of revealing secret information (Kelly & McKillop, 1996) acknowledge that the psychological release of telling a secret is beneficial; however, they also argue that disclosure of detrimental information about oneself can lead to social isolation and rejection (Derlenga, 1987; Kelly & McKillop, 1996).

Communicatively, disclosure of a person's HIV status is the revelation of a stigmatizing health condition that requires a PLWHA to balance the personal and relational risks and the benefits of revealing their health condition to another person (Derlenga et al., 2004; Greene et al., 2003). Adult PLWHA consider their social environment and relationship to the recipient, the person's need to know the information and whether the disclosure is a form of catharsis for the PLWHA before deciding to disclose their health condition (Derlenga et al., 2004; Greene et al., 2003). These factors help the PLWHA carefully consider whether the disclosure should occur.

One's kin group or family may also keep secrets about a variety of topics (Vangelisti, 1994). Secrets are defined as information that is purposefully hidden or concealed from others (Vangelesti & Caughlin, 1997). Secrets can be information that is a taboo topic is one that emphasizes "activities or events that are stigmatized or condemned by the family and the larger society" (Vangelisti & Caughlin, 1997, p. 683). Because HIV/AIDS carries a negative connotation that other chronic pediatric illnesses, such as cancer, juvenile diabetes, and asthma, do not have (Eaton et al., 2017), families may classify HIV status as a taboo topic to protect the family group and the family member from discrimination and being ostracized within the family or community (Greene et al., 2003).

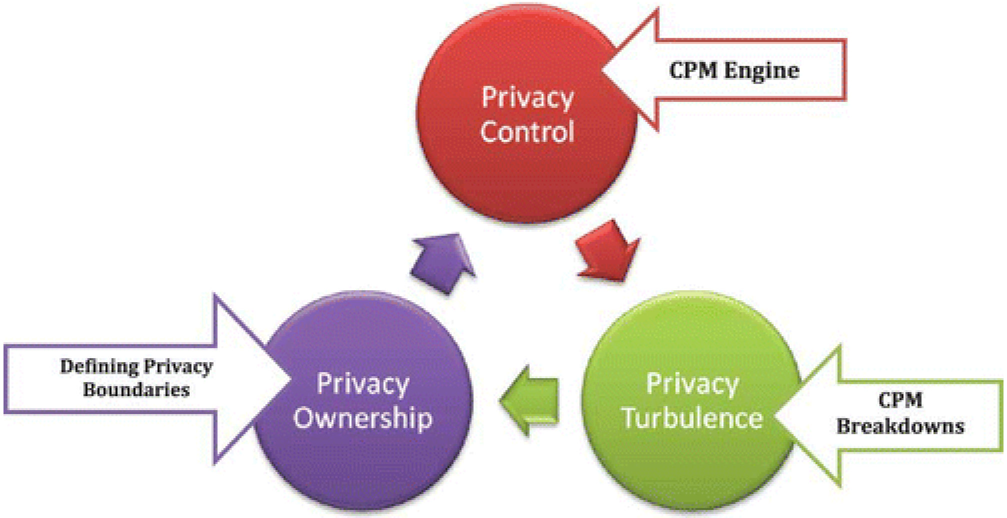
When seeking health care services for their HIV positive children, parents may be challenged by a healthcare provider to disclose information they have deemed to be private and kept secret from the rest of their extended family (Duggan & Petronio, 2009). This situation, therefore, can create a privacy dilemma for the parent in their role as guardian and co-owner of their child's health information (Duggan & Petronio, 2009). The pediatric healthcare provider co-owns the secret of the child's chronic illness with the parent, but also has a responsibility to eventually share the full and complete information about the child's HIV status with the child (Duggan & Petronio, 2009). Communication Privacy Management theory (Petronio, 2002, 2013) help explains how providers and parents, despite potential differences, decide when and how to reveal an adolescent patient's HIV status

Tenets of Communication Privacy Management Theory

Communication Privacy Management theory ("CPM") is an interpersonal communication theory developed to explain how people manage the dialectical tensions between revealing and concealing private information with others (Petronio, 1991, 2002, 2010, 2013). This interpersonal communication theory helps explain the internal psychological process people use to control access to their private information and to manage private information they own about other people (Petronio, 2002). The theory is best explained using a boundary metaphor that demonstrates the idea that people believe they own and control their own information (Petronio, 2002), and they create privacy rules for managing the boundary around their private information (Petronio, 2002). The theory also explains how co-owners of private information manage and coordinate the privacy boundary around shared information as well as how breaches to the privacy boundary are managed and recalibrated (Petronio, 2002).

The original elements of CPM have been streamlined for better understanding of the main tenet of the theory, which emphasizes how the communication privacy management system operates (Petronio, 2013). The revised theory is organized around the original three main components as well as eight axioms that discuss how people see ownership of their information and how they regulate access to that information (Petronio, 2013). The three main elements are Privacy Ownership, Privacy Control and Privacy Turbulence (Petronio, 2013). Figure 1 shows the relationships between the elements. To gain an understanding of the operation of the system and its application to the pediatric healthcare context, a discussion ensues about each of the three elements and the axioms that support the elements.

Figure 1
Communication Privacy Management System (Petronio, 2013, p. 8)



Privacy Ownership

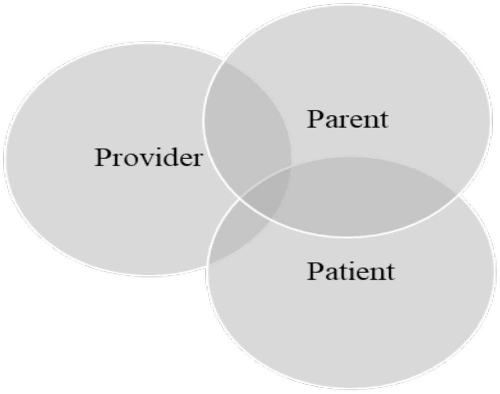
Privacy ownership is the starting point for understating how CPM operates. Privacy ownership consists of two axioms that predict people believe they own their private information and how they regulate the ownership of that information (Petronio, 2013). A core principle of CPM is Axiom 1, which states that people believe they own and have the right to control or deny others the right to access their information (Petronio, 2013). As an owner, a person makes choices according to their own set of decision criteria about how much information will be shared, with whom the information is shared and, if the information is shared, what the conditions are under which the co-ownership of information will be managed (Petronio, 2002, 2013).

Axiom 2 governs the sharing of private information by the original owner with another person (Petronio, 2013). The recipient becomes an "authorized co-owner" of the information (Petronio, 2013, p. 9). The authorized co-owner has a fiduciary responsibility to protect the information that has been shared with them (Petronio, 2013). A fiduciary responsibility to protect the information means that the authorized co-owner must treat the information carefully and regulate access to the information in accordance with the privacy rules established by its owner (Thompson et al., 2012). Furthermore, should the authorized co-owner decide to disclose the information to someone who is not an authorized owner, the authorized co-owner must suffer the consequences of that decision (Thompson et al., 2012).

Axiom 2 also is applicable to groups of people who share private information (Petronio, 2013). Within a group, multiple people can own information, and one's linkage to the group may be long term or temporary (Petronio, 2013). Members of the group also may create “privacy boundary cells” where members pair off and create a sub-group within the larger group privacy boundary (Petronio, 2013). The privacy cells serve a specific purpose for the members during the length of their relationship (Petronio, 2013).

An example of a privacy boundary cell is found within the pediatric healthcare relationship. A provider and a parent create a privacy cell around their shared information about a child’s healthcare needs within the larger group privacy boundary of the healthcare, parent, and adolescent relationship. The parent and the child also have a privacy boundary cell around private information they share about their relationship and their family. Finally, a third privacy boundary cell is the provider and the patient, particularly as the child matures and begins to communicate directly with the provider. The provider and patient create a privacy boundary cell around the sharing of the child’s health information. Thus, within the pediatric healthcare relationship there are three privacy boundary cells: provider-parent; parent-child, and provider-patient (Figure 2).

Figure 2
Pediatric Healthcare Relationship



Privacy Control

Petronio (2013) proposes that the second main element of the communication privacy management system, Privacy Control, is the “engine” that drives the system (p. 9). Axiom 3 proffers that because people believe they own the information, they also feel they have the right to control their information, even if is shared with other people (Petronio, 2013). Co-owners of private information manage and coordinate privacy boundaries using privacy rules that dictate who else can know their information (i.e. linkage), the rights of each co-owner around this information (i.e. responsibility of ownership,) and how much information the co-owner can share (i.e. permeability) (Petronio, 2002).

Axiom 4 proposes that when sharing information with others, people create and use privacy rules for controlling the flow of the information (Petronio, 2013). These privacy rules include conditions for allowing others to know the private information and the creation of the privacy rules involve decision criteria for sharing information by the co-owners (Petronio, 2002, 2013). The decision criteria for establishing the rules are based on the motivations of the co-owners, situations, cultural needs and the risk-benefit of revealing the information (Petronio, 2002, 2013). These criteria may be implicitly or explicitly stated between the parties when the private information is shared by the co-owners (Petronio, 2002). Each co-owner takes responsibility for managing the privacy boundary using the rules.

Petronio (2013) suggests that people organize their decision criteria into two categories: core criteria and catalyst criteria. Core criteria are the “stable gauges used to make choices about privacy rules" (Petronio, 2013, p. 10). An example of a core privacy rule created within a healthcare relationship is the one between a pediatric provider and a patient. A pediatric provider is bound by the ethical considerations and legal obligations of the medical profession to keep a patient's information private (Duggan & Petronio, 2009). When a patient discloses their health information to the provider, both the provider and the patient generally understand that the provider will not share this specific patient's information with other patients or other people not authorized to have this information (Duggan & Petronio, 2009; Wager, 2013).

Catalyst criteria change core privacy rules (Petronio, 2013). A catalyst generally involves a critical incident which changes the situation in which the core privacy rule is used (Petronio, 2010). The situation presents owners with an immediate need to evaluate their motivations for revealing or concealing the information and to calculate the risk-benefit of revealing or concealing the information (Petronio, 2013). Catalysts help owners recalibrate privacy boundaries around private information because immediate circumstances required a change in the rule (Petronio, 2002, 2010, 2013).

An example of a catalyst is an adolescent who begins engaging in risky behaviors such as substance abuse. An example may be when a parent receives a call from the police that their teen has been arrested for drunk driving. Parents may have been unaware that their teen was drinking and driving the car, and now parents must face inquiries from family, friends, and others about the teen's behavior. Parents may then renegotiate family privacy boundaries regarding the teen's behavior and the consequences to the adolescent's and the family's reputation within their community. Thus, the situation created by the drunk driving arrest changes the way the family handles information about their teen's behavior and the repercussions from such behavior.

As privacy rules and boundaries change, Axiom 5 predicts that people will successfully continue to coordinate and re-negotiate "privacy rules with 'authorized co-owners' regarding third party access" (Petronio, 2013, p. 10). Once the link to the private information is established, co-owners must decide how accessible the information should now be, or how permeable the boundary is around the shared information. Petronio (2002) describes boundary permeability as a range "from open access (thin boundaries) to closed access (thick boundaries)" (p. 31). Owners use privacy access rules or privacy protection rules to determine the permeability of the privacy boundary (Petronio, 2002). Privacy access rules may depend upon the nature of the relationship between the owners and the general amount of disclosure about the topic between the owners (Petronio, 2002).

Privacy protection rules, on the other hand, guard against the disclosure of the information (Petronio, 2002). The owners of the private information determine that disclosure of the information could bring great risk or substantive harm to the owner of the information if someone became an unauthorized owner. Private information that is well-hidden through a privacy protection rule may be considered a secret and may be avoided as a topic in conversation (Petronio, 2002).

Axiom 6 predicts that "co-ownership leads to jointly held and operated collective privacy boundaries where contributions of private information may be given by all members" (Petronio, 2013, p. 10). As an example, when a family member is diagnosed with a chronic illness, family members discuss and negotiate what and how much information members outside of the family will be given about the illness. Each family member may contribute to the discussion about the privacy rule around such information and how the privacy boundary will be managed. This axiom allows for the collective boundary to be managed by all members of the family group.

Axiom 7 is the final tenet for privacy control. This axiom states that "collective boundaries are regulated through decisions about who else may become privy, how much others inside and outside the collective boundary may know, and rights to disclose the decision" (Petronio, 2013, p. 10). In the example of a family who has learned of a family member's chronic illness, not only does the entire family group manage and coordinate the group boundary, but they also manage and coordinate who else outside of the family may know, which family member has the rights to disclose the information, and how much information will be disclosed. This axiom also regulates the flow of information between the members of the larger group regarding the rights and responsibilities of owning this private information.

Privacy Turbulence

The final component of privacy management is privacy turbulence. Privacy turbulence occurs when the expectations or understandings of how the private information was to be managed is disrupted (Petronio, 2013). Axiom 8 predicts that "privacy regulation is often unpredictable and can range from disruptions to complete breakdowns" (Petronio, 2013, p. 11). Privacy turbulence also occurs when an information owner or co-owner faces a decision to disclose the information or is the recipient of information they do not want to know (Petronio, 2002). An example of privacy turbulence can be found in the example of a young married couple who are expecting their first baby. If a mother-to-be discloses to her friend at work that she is pregnant and asks her friend to keep the information private, but her friend discloses the information to their supervisor, the unauthorized disclosure creates turbulence in the privacy boundary around information. Such breaches often are addressed between the co-owners.

A privacy predicament is considered to be a situation in which the owner or co-owners find themselves working with dissimilar expectations and definitions of the privacy boundary around the information (Petronio, 2002). The mismatched expectations and privacy orientations about the privacy boundary cause turbulence. The co-owners must change the privacy rules for managing the boundary due to the turbulence.

Family Communication and CPM

Communication Privacy Management theory has been used extensively to analyze family groups and how its members regulate private information (Kennedy-Lightsey & Frisby, 2016; Petronio, 2002, 2010; Serewicz et al., 2007). The dialectical tensions involved in balancing openness and privacy are important to understanding how each member of a family group retains their own autonomy, yet stays connected to the family group (Petronio, 2010). Within a family group there may be many levels of privacy and multiple co-owners of private information about each member of the family group and private information about the group as a whole (Petronio, 2010). The family system is also comprised of a web of relationships between family members and others (Petronio, 2010), including marital dyads, sibling relationships, and parent-child relationships (Petronio, 2002).

The three key components of CPM function within family groups. A family who believes private information must be highly controlled and who limits the sharing of private information believes the boundary around the information is thick and impermeable (Petronio, 2010). This family could be seen as having a closed boundary around information, meaning family members do not share private information with others (Petronio, 2010). Families who believe little control needs to be exerted over private information have thin and permeable boundaries (Petronio, 2010). Varying degrees of permeability exist, depending on the family's need to control access to the information (Petronio, 2010).

The idea of thick and thin privacy boundaries apply to the group as a whole and to the individual members of the family (Petronio, 2010). Within family groups, two kinds of privacy boundaries exist (Petronio, 2002, 2010). Exterior boundaries protect private information the family considers to be owned as a collective or "whole family privacy" (Petronio, 2010, p. 183). Co-ownership of private information for the family group is tantamount to guardianship "in which there an expectation of members protecting the dissemination" of information to people inside and outside of the family (Petronio, 2010, p. 177). Parents function as guardians of private information about the family and socialize children to the privacy rules around information (Petronio, 2010). The maintenance of such exterior privacy boundaries for the family allow the family to function as a whole and to work together to maintain the boundary (Petronio, 2010).

Within the family, interior privacy boundaries are created through relationships among individual family members (Petronio, 2010). The relationship between two or more of the family members who manage private information create a privacy cell (Petronio, 2010), and its members negotiate the rules for managing the private information (Petronio, 2010). The internal privacy cells are created and disbanded based upon the members need for access to the information and for the duration of the relationship (Petronio, 2010). An example of the family privacy cell can be found in the parent-child relationship and adolescent dating relationships. As a child matures to adulthood and can understand more complex information about romantic relationships, parents may change the level of permeability around their own private information related to dating and romance and share a certain amount of the information to help their child understand these relationships (Coffelt & Olson, 2014).

Parents socialize children by teaching them what counts as private information and about the privacy rules for protecting or granting access to it (Petronio, 2010). When children grow into adolescence, they begin to differentiate themselves from the family group, and begin to construct their own boundaries around their private information (Petronio, 2010). Adolescents may not always share private information with their parent and may keep certain kinds of information very private, such as sexual behavior, substance abuse, and other risky behaviors (Ebersole & Hernandez, 2016; Hawk et al., 2009; Petronio, 2010). When adolescents do not share private information with their parent(s), they may become frustrated and begin invading the adolescent's privacy by asking questions and demanding answers (Hawk et al., 2009; Mazur & Hubbard, 2004).

In response, adolescents may engage in topic avoidance and other strategies to avoid their parent's attempts to ferret out their private information (Mazur & Hubbard, 2004). These frustrating experiences for both the parent and the adolescent can lead to a high level of tension between them, which can cause a breakdown in communication.

Thus, CPM has been used to study the ways family groups manage private information as a collective and how individual members manage their own private information (Petronio, 2010). The family group manages a collective, exterior privacy boundary that encompasses private information about the whole family and each member is responsible as a co-owner of the information about the group (Petronio, 2010). Individual members form relationships within the larger group and create privacy cells around the private information each individual shares (Petronio, 2010). The exterior and interior privacy boundaries have varying degrees of permeability (Petronio, 2010). Family privacy boundaries change when children grow to maturity as adolescents begin to create and manage privacy boundaries around their private information (Petronio, 2010).

CPM and Pediatric Healthcare Relationships

Pediatric healthcare relationships differ from the provider-patient relationships found within the adult healthcare system. The modern pediatric practice is built upon the concept of a medical home for the child (Noble, 2014; Sia et al., 2004), and the pediatrician is trained to form a relationship with and communicate with parents and the child to address the child's healthcare needs (Grover, 2014; Levetown, 2008; Olson, 2005). The pediatric healthcare relationship is dissimilar to the adult healthcare system in that the parents, as surrogates and proxies, are the primary source of health information about the child, particularly when the child is in infancy and unable to communicate directly with the healthcare provider (Damm et al., 2015; Duggan & Petronio, 2009; Young et al., 2003). As children mature, the patient begins to take a more active role in communicating with the provider; however, the parent retains the role of legal guardian of the child until the child reaches early adulthood (Damm et al., 2015; Garvie, 2017). The pediatric healthcare relationship remains a triadic one until the child reaches young adulthood and transfers to the adult healthcare system (American Academy of Pediatrics, 2013; Damm et al., 2015).

Pediatric healthcare providers also must learn to work with the family's life circumstances. Providers face challenges as they treat the children of parents stressed by poverty, substance abuse, mental health issues and their own reluctance to discuss HIV related issues with their own support systems (Brackis-Cott et al., 2003; Lichtenstein et al., 2010). Medication adherence becomes problematic when the child's home environment is chaotic and unpredictable due to a parent's inability to provide food, shelter, and other necessities for the child to survive (Brackis-Cott et al., 2003). A parent's substance abuse or mental health problems can present additional stressors for the child as these issues may break apart families and the child may live with other relatives who provide care and supervision to the child (Lichtenstein et al., 2010).

Within the pediatric relationship, the healthcare provider and the parent form a relationship in which each one plays a role. Both the provider and the parent are stakeholders in this healthcare relationship (Petronio & Reierson, 2009). A stakeholder is a confidant who is given specific private information because of the “functional role” that confidant performs (Petronio & Reierson, 2009, p. 373). The parent shares the child’s private health information with the provider so the pediatric healthcare provider can perform the role of providing medical care to the child (Petronio & Reierson, 2009). Parents perform the role of primary caregiver and legal guardian of the child, and they are responsible for the overall well-being of the child, which includes coordinating medical appointments, ensuring the child receives medication, and advocating for their child with providers (Haskell et al., 2012). Each partner in the relationship performs their role with the child’s best interests in mind and trusts the other to do the same (Petronio & Reierson, 2009).

As stakeholders, parents and providers are co-owners of the child’s health information, and they have a fiduciary responsibility to one another for protecting access to this information (Petronio & Reierson, 2009). Consequently, they negotiate and synchronize privacy rules around health information, such as HIV status, because each party has moral and ethical obligations as owners of this information (Petronio & Reierson, 2009). Failure to understand these obligations can cause boundary turbulence and unwanted breaches of patient and family privacy (Petronio & Reierson, 2009). Thus, as co-owners of the child’s stigmatizing health information, the providers and parents develop a level of trust in one another as stakeholders and co-owners of this information.

Providers perform two roles within the pediatric healthcare relationship. First, as confidants of parents and patients, the providers are stakeholders in the pediatric health care relationship. The parent forms the relationship with the provider because their child needs health care services, thus, the providers perform “functional roles, providing the original owner a needed outcome” (Petronio & Reierson, 2009, p. 374). The goal and overall outcome is a healthy child and both providers and parents have a stake in ensuring the child reaches adulthood as a healthy person.

Second, the providers are considered deliberate confidants of parents and children within the pediatric healthcare relationship (Petronio & Reierson, 2009). A deliberate confidant is someone who gains access to private information by asking the owner “directly, indirectly, or asking for permission to know this information” (Petronio & Reierson, 2009, p. 374). Providers ask parents directly for the information about the child’s health care needs they are seeking. The provider may also gain indirect access to the health information through the reports they receive from various medical tests they order for the child’s health status (Petronio & Reierson, 2009).

Parents also choose how much of the child’s private health information they will share with the provider, and if the parent attempts to “thwart the efforts of the confidant’s inquiry,” the provider will ask the parent because they believe they have a right to know the private health information of the child” (Petronio & Reierson, 2009, p. 374). Failing to be forthcoming in sharing health information with a provider can be detrimental to the child’s health (Petronio & Reierson, 2009).

Parents are proxy owners of their child’s health information and as such, they have the right to control information about their child and family (Duggan & Petronio, 2009). Provider’s typically hold beliefs about how permeable family privacy boundaries around the child’s health information, though they are not always accurate (Duggan &

Petronio, 2009). Families who are seen as having thin privacy boundaries around health information may be perceived as "open" and those whose privacy boundaries are perceived as thick may be perceived as "closed" (Duggan & Petronio, 2009; Petronio, 2002, p. 31). Throughout the duration of their relationship, pediatric healthcare providers and the parents navigate the complicated nuances of privacy boundaries around the child's healthcare needs.

Pediatric healthcare providers and parents of children who are HIV positive face a challenge when a child must be informed of their HIV status. Part of a provider's responsibility to a patient is to fully inform the patient about their illness (Petronio & Sweeney-Lewis, 2011). Full disclosure of a patient's diagnosis and their illness is defined as the provider's "tendency to disclose complete details of a patient's condition" (Petronio & Sweeney-Lewis, 2011, p. 273). The pediatric provider must inform patients about their HIV status and educate them about the need for treatment and medication as well as explain the stigma associated with this illness. Parents, as proxy owners and gatekeepers of the family's private information, face the decision whether to allow their child to assume these responsibilities: to become fully informed about their illness, become a responsible participant in their own health care decisions, and become a responsible person when informing others of their illness.

The overarching question in this study centers on the process used by providers and parents to discuss and negotiate the timing for opening their dyadic privacy boundary around the child's HIV status to include the child as a fully informed responsible co-owner of this private information. Providers and parents may have similar or different motivational and situational criteria that they use to determine when the timing is appropriate for disclosing HIV status to a child. Furthermore, providers and parents within their respective roles may use a variety of communicative strategies to negotiate the disclosure of HIV status to child, and finally, the conditions around disclosure may affect the timing of the disclosure event. Using Communication Privacy Management theory (Petronio, 2013), this study investigates the disclosure process used by providers and parents when the need arises to fully inform a perinatally-acquired HIV-positive adolescent of their HIV status.

Research Questions

RQ 1: During the decision-making process related to disclosure, what criteria do parents and/or providers consider as they negotiate changing the privacy rule around disclosing HIV status to an HIV+ adolescent patient?

RQ 2: What communicative strategies do parents and/or providers use to negotiate new privacy rules for coordinating the privacy boundary around disclosing HIV status to adolescents?

RQ 3: How do disclosure conditions affect the communicative strategies parents and/or providers use to negotiate the opening of the boundary to give the adolescent ownership of his or her HIV status?

CHAPTER 3

METHODS

Statement of Purpose

The primary purpose of this study is to explore the management and coordination of privacy boundaries by parents and providers as they decide to disclose an adolescent's HIV status to them. Communication Privacy Management theory (Petronio, 2002) was used to explore how the private health information of both the biological mother and the adolescent are managed by the parent-provider dyad. The boundaries managed by the provider-parent dyad change when the decision is made to add the adolescent as a responsible co-owner of their private health information. This qualitative study specifically examines the criteria used by parents and providers to determine when an adolescent patient is ready for disclosure. Furthermore, the study examines the communication strategies used by parents and providers as they negotiate the timing of opening their dyadic communication privacy boundary around the child's HIV status.

This chapter reviews the qualitative research methodology used to investigate these communication phenomena. The following topics are discussed: my role as a researcher, the research design, the data collection processes, and the iterative process in applied thematic analysis used to develop the themes to code the data. Finally, the qualitative data reduction methods of role-ordered and event-listing matrices are discussed.

Research Design Rationale

Researcher Role

A qualitative inquiry was appropriate for this study, because I, as a researcher, sought to discover the range and depth of the participants' experiences regarding a specific phenomenon, that of disclosing HIV status to a pediatric patient within the context of a healthcare relationship (Patton, 2002). My approach to this study is that of an ethnographer, specifically a focused ethnographer which is defined as:

> a methodological approach to understanding human behaviors in social contexts that examines the lived experiences of the researcher and individuals of specific subsets or segments of a group in limited contexts, usually for limited amounts of time, and with a specific predetermined topic in mind (Simonds et al., 2012, p.157).

Focused ethnography allows for the researcher to investigate particular research problems through brief interactions and observations of a specific group of people and their relationships, behaviors and communication processes within a specific social context (Simonds et al., 2012). This method differs from ethnography in general because the researcher focuses the data collection on specific activities of the study participants and the research environment within a short time frame (Simonds et al., 2012).

A focused observer's status as a researcher is explicitly clear to study participants, and the data collection process has a "clear and structured agenda of what data to gather" (Tracy, 2013, p.112). The research setting for this study is a pediatric outpatient clinic, the Lewin Clinic, located on the grounds of Wellington Hospital, a pediatric healthcare facility located in a large metropolitan area in the United States. At the onset of data collection, I was introduced as a student researcher to the Lewin Clinic health care team, and I was introduced as a researcher to the patients' parents. Throughout the data collection phase, I kept notes related to my experiences and observations about the setting, the processes I observed, and the study participants. I also conducted semi-structured interviews of participants.

Data Collection Protocol

A three-part data collection protocol was used to collect interview data from a focus group and two parents. Patient medical charts were used to collect patient demographic data, information about the patient's family, and the disclosure process. Anecdotal data from provider notes about issues around disclosure of HIV status raised by patients and/or parent were also collected from the charts.

Phase 1- focus group. In this study's first phase, a focus group comprised of healthcare providers in the Lewin Clinic participated in a focus group. Because this study explores the experiences of disclosing HIV status by providers and parents, a focus group format was chosen. This method allows for a deeper understanding of the "practices and meanings of the participants in relation to the context in which they occur" (Kamberelis, Dimitriadis, & Welker, 2018, p. 698) by providing a "mini-window" into the social interactions between participants as they discuss a shared experience. These interactions construct meaning and provide insight into the phenomenon being studied (Morgan, 2012; Tracy, 2013). The Lewin Clinic holds an HIV clinic every week in which the six health care providers gather as a team as they eat lunch together. The focus group meeting was held as part of a regular weekly team meeting.

Phase 2- chart review. In the second phase, I reviewed patient medical charts in the form of written paper and electronic records. Inclusion criteria for this phase included patient age (≥12 years) and perinatal exposure. I collected demographic information and other data about the patient population. The documents contained historical/contextual information and provided details on the research setting and sample population (Schensul, 2008; Patton, 2002). Patient records are an integral part of clinical and administrative information related to the patient's encounter with the health care system (Wager, Lee & Glaser, 2013). The electronic medical charts contained specific information about the patient's health condition, such as the presenting problem, physical condition of the patient, laboratory results, consultations with other providers, and nursing notes (Wager, et al, 2013). Patient health records also contained administrative information, such as demographic information about the patient, the name and billing information for the patient's health insurance company, and notes made by nursing and other professional staff (Wager, et al., 2013).

In addition, medical charts were reviewed for anecdotal information regarding the disclosure process that appeared in progress notes, social work notes, and Disclosure Forms. Anecdotal information is additional non-medical, yet pertinent, information the patient or their parent discusses with a member of the health care team (Styron & Evans, 2016). This information generally is not recorded at every appointment, but the health care team will make a note of relevant non-clinical information that may affect the care and treatment of the patient.

Phase 3- parent/caregiver and adolescent interviews. The third and final phase of data collection was composed of semi-structured interviews with individual patients and parents. Standard in qualitative research methods (Marshall & Rossman, 1999; Patton, 2002; Tracy, 2013), a semi-structured interview is composed of questions used to guide the conversation between the researcher and the participant (Patton, 2002; Marshall & Rossman, 1999). As participants answer questions, however, the researcher asks unstructured follow-up questions to clarify or further explore specific responses to gain deeper understanding of the participant's perspective and experience with the phenomena (Patton, 2002). Eligibility criteria for adolescents in this phase included patient age (≥12 years), perinatal exposure, and awareness of HIV status. Eligibility criteria for parent interviews included being at least 18 years old and the parent or legally authorized caregiver of a perinatally infected adolescent. Exclusion criteria were limited to ability to speak English. Eligible participants were recruited by their provider at their regularly scheduled appointments; they were given a flyer describing the study (Appendix 3). Parents consented for themselves and their adolescents, and adolescents under the age of eighteen years old also assented prior to any interviews being conducted. In consideration of their time and effort, each interview participant received a $25.00 gift card.

Funding and IRB Approval

Funding for this project was provided by a Learner's Research grant awarded to the research team by Wellington Hospital's Learner's Research Council. The project received IRB approval from Wellington Hospital and the researcher's university prior to data collection. The researcher, their university, and the hospital completed a confidentiality agreement regarding the use of patient data prior to data collection.

Participants

Phase 1

Participants in Phase 1 include the six health care providers at the Lewin Pediatric Infectious Disease Clinic at Wellington Hospital, who functioned as a focus group in this project. Overall, the providers are an experienced, clinically diverse group of health care professionals. Table 1 indicates the name of each provider and their role within the clinic.

Table 1- Composition of Lewin Clinic Focus Group

(N=6)

Name of Focus group Member	Education	Role in the Lewin Clinic
Dr. Gates	M.D.	Medical Director
Mary Ann	D.N.P	Research Nurse
Rose	R.D.	Dietitian
Hope	C.S.W.	Clinical Social Worker
Clara	R.N.	Registered Nurse
Florence	R.N.	Registered Nurse

All six providers are women who range in age from 35 to 65 years old. Five providers identified as Caucasian, and one provider did not disclose her ethnic background. Providers' experience in their medical specialty ranged from 15 to 37 years (average number of years of experience =26.17, SD= 9.26). Each member of the focus group provides health care treatment to pediatric patients and guidance to patients and their families when concerning how to cope with a chronic infectious disease. The providers also work together as a team to inform each other about the needs and concerns of the patients and their parents who live with a stigmatizing chronic illness.

Phase 2

At the time of data collection, the Lewin Clinic treated approximately 70 children and adolescents (ranging in age from birth to approximately 21 years old) who were HIV positive. A total of 42 patients met the inclusion criteria and represent the final sample. Table 2 reflects the diversity of the patient sample in this study.

Table 2-Composition of Patient Sample

Phase 2-Patient Demographics
(N=42)

		N	Percentage
Ethnicity	Asian	5	12.2
	African American	18	43.9
	Non-Latinx White	10	24.4
	Latinx	4	9.8
	Native Peoples	1	2.4
	Other	3	7.1
	Missing	1	2.4
SES			
	Private Insurance	25	59.5
	Public Insurance	14	33.3
	Both Public& Private	3	7.1
	Missing	0	0.0
Immigrant Status			
	Non-Immigrant	11	26.8
	Immigrant	30	73.2
	Missing	1	2.4
Living Arrangement			
	Biological Parents	24	57.1
	Foster Parents	1	2.4
	Adoptive Parents	14	33.3
	Kinship Caregiver	3	7.1
	Missing	0	0.0
Disclosure Status			
	Fully Informed	34	81.0
	Not Informed	8	19.0
	Missing	0	0.0

Patient demographics. The 42 patients who comprised the sample for Phase 2 represented a diverse group. Patients ranged in age from 12 years to 20 years (average = 15.69, SD = 2.18). African American males comprised the largest group, both ethnically and in terms of sex, in the patient sample. There are slightly more males (55%) than females (45%) in the sample. Nearly one-half of patients in this sample were African American, and almost one quarter of patients are Non-Latino White. The socio-economic status of the patient is reflected in the kind of insurance program they utilize for health care services. Sixty percent of the patient group utilizes some form of public insurance. Public insurance programs, such as Medicaid, the Ryan White HIV/AIDS program, and the State Children's Health Insurance Program, are those that are funded by either the federal government directly or via a federal-state partnership (Uninsurance., 2002). Private insurance programs are generally provided through an employer, or a person can purchase insurance through a state insurance exchange (Raifman et al., 2018). More than one-third of the patients use private insurance to purchase health care services. The remaining seven percent of the sample utilize both public and private insurance.

Family composition and background. Many families were immigrants or were adoptive parents of immigrant children. Over 70% of the adolescent patients immigrated to the United States. Approximately 22% of the patients who are immigrants live with their adoptive families. Sixty-five percent of patients speak a language other than English as their native language. Forty-eight percent of them speak an African language, 40% speak a European language, and the remaining 11% of patients speak an Asian or other language.

Families who participated in the study were varied in size and composition. The size of the patient's families ranged from 2 people to 10 people (average size = 5.17 people, SD = 2.03). Twenty percent of adolescent patients have siblings that currently live with the family. Four pairs of siblings in this sample are HIV positive. Fifty-seven percent of the adolescents live with their biological parents and one-third live with adoptive parents. Approximately nine percent live with foster parents or kinship caregivers.

HIV status disclosure and disclosure process. Eighty percent of the sample were fully informed about their HIV status, and the remaining 20% did not know their HIV status. Of those participants who had been informed, disclosure occurred between 10 to 16 years of age (average = 13.29, SD = 1.63). Of the patients who knew their HIV status, 31 were informed by both the health care provider and their parent. Over 11% were informed by a health care provider only or by someone other than a parent. Unfortunately, fifty percent of the records belonging to adolescents who had been fully informed did not contain information about who informed them of their HIV status.

Phase 3

Participants for Phase 3 included patients and parents/caregivers. To be included in this phase, patients had to be age 12 years or older, been fully informed of their HIV status and speak English. Of the 42 patients in the sample, 25 patients met the criteria. Table 3 indicates the demographics of the Phase 3 participants.

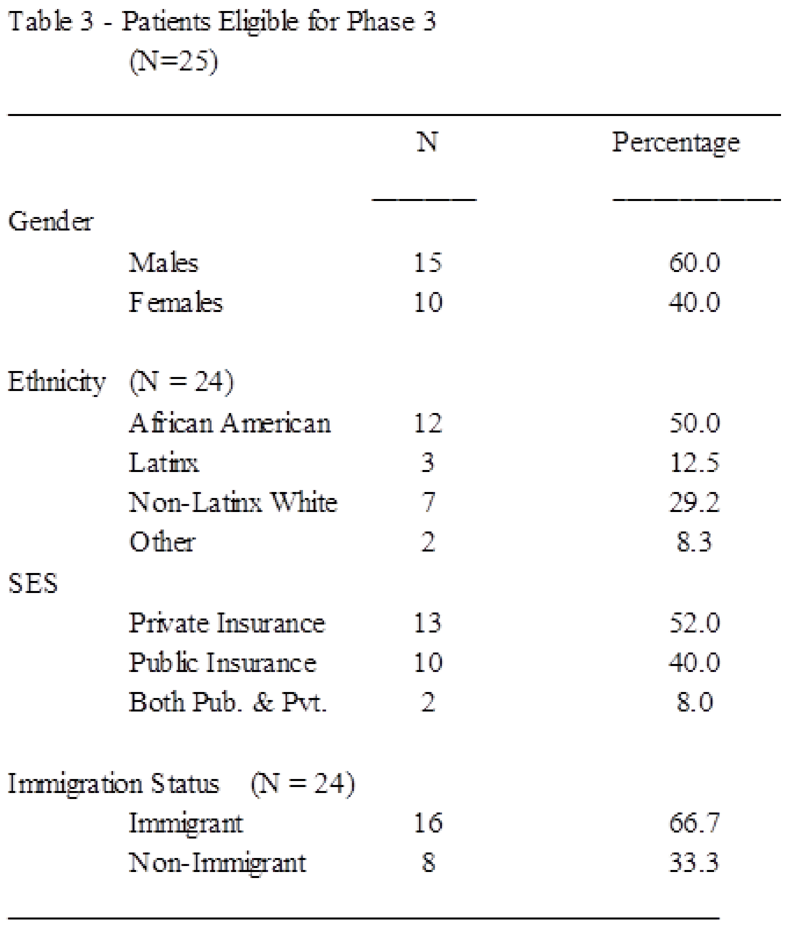


Table 3 - Patients Eligible for Phase 3
(N=25)

		N	Percentage
Gender			
	Males	15	60.0
	Females	10	40.0
Ethnicity	(N = 24)		
	African American	12	50.0
	Latinx	3	12.5
	Non-Latinx White	7	29.2
	Other	2	8.3
SES			
	Private Insurance	13	52.0
	Public Insurance	10	40.0
	Both Pub. & Pvt.	2	8.0
Immigration Status (N = 24)			
	Immigrant	16	66.7
	Non-Immigrant	8	33.3

Sixty percent of the eligible patients for Phase 3 were male and 40% were female. Over half of the patients in the sample were African American or Latinx. Almost one-third of the patients identified as Non-Latinx White, and slightly over 8% identified as Other. No patients eligible for Phase 3 identified as Asian or Native Americans. Over half of the patients eligible for the Phase 3 interviews utilized private insurance to procure health care services, and 40% utilized public insurance to obtain health care services. Only eight percent utilized both. Two-thirds of the patients eligible for Phase 3 were children who immigrated to the United States.

The parents of the 42 patients also were eligible to participate in the study. The eligibility criteria for parents for Phase 3 included the parent had to be 18 years of age and speak English. Of the 42 sets of parents, 25 sets of parents met the eligibility criteria for Phase 3. Most of the patient records from which the data were collected did not contain the parents' gender, age, or ethnic background, thus this information was not recorded.

Qualitative Research Approach

In this study, the general qualitative approach for data analysis is applied thematic analysis, which allows for the development of themes drawn from data collected from a group of study participants (Guest et al., 2012). Broadly defined, thematic analysis is "a type of inductive analysis of qualitative data that can involve multiple analytic techniques" (Guest, MacQueen & Namey, 2012, p. 4). Applied thematic analysis is a method that can be utilized by researchers with varying epistemological perspectives to answer a variety of research questions (Nowell et al., 2017). It has been used by communication researchers to explore the process of revealing and concealing health information between parents and adolescents (Ebersole & Hernandez, 2016) and to understand how people with eating disorders reveal their illness in an online community (Herrman & Tenzek, 2017).

Thematic analysis is best used for "examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights" (Nowell et al., 2017, p. 2). Thematic analysis also allows for "a rigorous, yet inductive, set of procedures designed to identify and examine themes from textual data in a way that is transparent and credible" (Guest, MacQueen & Namey, 2012, p. 15). Thus, applied thematic analysis gives qualitative researchers analytic tools to delve deeply into the textual data resulting from semi-structured in-depth interviews, focus groups, and other sources of data that help tell the story of the study's participants in a transparent and rigorous way (Guest, MacQueen & Namey, 2012).

Applied thematic analysis uses six criteria to ensure the rigor and trustworthiness of the data analysis procedure (Nowell et al., 2017). Generally, trustworthiness in qualitative research has six elements: credibility, transferability, dependability, confirmability, a clear audit trail, and researcher reflexivity (Nowell et al., 2017). A credible qualitative study is one in which the "fit between the respondent's views and the researcher's representation of them" are clear and recognizable (Nowell et al., 2017, p. 3). Transferability refers to the "generalizability of the study in the sense that the descriptions are thick and rich" so another researcher may use the findings in their own field site (Nowell et al., 2017, p. 3). Dependability requires that the research process is "logical, traceable and clearly documented" (Nowell et al., 2017, p. 3). Confirmability necessitates that the researcher's interpretations and conclusions are clearly derived from the data (Nowell et al., 2017). A clear audit trail ensures that a second researcher, unfamiliar with the study, can follow the decision trail regarding decisions made about the methodology used and the theoretical connections made in the study (Nowell et al., 2017). Finally, researcher reflexivity is required to record the researcher's personal reflections, values, and impressions that influence their perspective as an observer-participant in the study (Nowell et al., 2017).

One criticism of applied thematic analysis is the set of procedures used by qualitative researchers to develop the themes are not always clear and transparent (Xu & Zammit, 2020). Applied thematic analysis is a flexible methodology for data analysis; however, qualitative researchers have argued that too much flexibility in the development of themes causes uncertainty, confusion, and inconsistency if the procedures for the data analysis are not clearly described (Nowell et al., 2017; Xu & Zammit, 2020). The confusion, inconsistency and lack of clarity have resulted in many researchers suggesting that using thematic analysis in qualitative research creates ambiguity which leads to a lack of credibility and validity in a study (Guest, MacQueen & Namey, 2012). Thus, a researcher must clearly describe the coding procedures used to ensure consistency, clarity, validity, to supports the conclusions derived from the analysis.

The use of thematic analysis is appropriate for this study, a focused ethnography, because the purpose of the study is to examine the experiences of parents, providers, and patients as they manage and coordinate privacy boundaries around the patient's HIV status. Furthermore, the data set for this study is comprised of textual data from sets of semi-structured interviews, a focus group transcript, and anecdotal notes in electronic patient charts made by health care providers as they treat their HIV- positive adolescent patients. In sum, applied thematic analysis is appropriate to use to explore common themes found in the experiences of the providers and parents about the decision to disclose HIV status to the adolescent.

Methods for Data Collection

This focused ethnography used a quasi-mixed-methods approach in that qualitative and quantitative data were collected. The data collection had three phases that were implemented between August 2018 through May 2019. Final IRB approval from the Institutional Review board at Wellington Hospital was obtained in August 2018. This qualitative study generated five different data sources (Appendix 2). Two of the sources are the field diary and the field notebook used throughout the entirety of the study; the data collected in the diary and the notebook are considered “raw data,” which Tracy (2010) defines as the “first, unprocessed notations of the field” (p. 114). These notes also contain information protected by HIPAA that cannot be disclosed. The remaining three data sources are the IRB approved information gathered in three phases. These data are a combination of a focus group interview, semi-structured interviews, a compilation of anecdotal notes taken from medical charts, and the demographic data regarding the patient sample. These sources are summarized in Appendix 1. A complete description of the methods used in the collection of each data source follows.

Phase 1

Prior to meeting with the focus group, I met with the clinic research nurse, Mary Ann, to review schedules and obtain a general clinic orientation. On September 12, 2018, the focus group interview occurred. The Lewin Clinic healthcare providers completed a short demographic questionnaire beforehand. The semi-structured interview lasted 77 minutes and the meeting was recorded and transcribed. I reviewed the 36-page transcript for accuracy and completeness by comparing the transcript to the recording of the meeting. Pseudonyms were assigned to the pediatric hospital and the clinic. Each participant was assigned a pseudonym, and the corrected transcript was uploaded into an NVivo file (QSR International, 2020). I reviewed and entered the provider demographic information into an SPSS 24 (IBM, 2019). In NVivo (QSR International, 2020), I created a case classification called Providers, I uploaded the SPSS 24 (IBM, 2019) file into NVivo (QSR International, 2020), and I ensured that the attributes created in NVivo for each provider were correct.

Phase 2

Phase 2 of the data collection process was completed between September 18 and October 31, 2018. Phase 2 required Mary Ann to generate a list of patients that met the following three inclusion criteria: the patients had to be at least 12 years old, be perinatally infected with HIV, and speak English. The patient's parents were automatically included in the sample and had to meet the one inclusion criteria of being at least 18 years old. The final sample included 42 patients who met the inclusion criteria. I began the data collection in this phase with a review of the 42 individual electronic patient charts. I collected demographic data about the patients, information about their families, and the parent's age, ethnicity, and HIV status, if available. In addition, I catalogued information about the patient's disclosure status, how they were informed of their HIV status, and at what age the patient had been informed fully about HIV. This information was collected on the IRB approved data collection sheet (Appendix 4).

I also reviewed the 42 electronic patient charts to collect anecdotal information about disclosure issues from progress notes, social work notes, and the Disclosure Status forms created by the health care providers. I recorded the anecdotal information on the back of the demographic data collection sheet for each patient (Appendix 4). I recorded these data elements: the month and year of the clinic visit, whether the information was taken from a progress note, social work notes or from the Disclosure Form, and any anecdotal information about disclosure issues for each case. If a patient chart did not have any data regarding disclosure, I made the notation “normal” on the back of the form. Normal was defined as the usual and customary medical information about the patient that a provider recorded in the chart and that did not include any comments about disclosure issues. I compiled the data about disclosure issues taken from the patient charts into a table consisting of 133 entries for 37 of the 42 patient files. Six patient files did not contain any anecdotal information about disclosure issues. I reviewed the anecdotal notes for accuracy and completeness and uploaded the Word table into NVivo. Next, I created a case classification in NVivo titled Patients and created a case for each of the 42 patients. I then copied the data from the table for each patient and pasted it into the assigned correct patient case.

At the end of Phase 2, the demographic and other information about the 42 patients were entered into an Excel file. I used these data to prepare a list of potential patients and parents to participate in the semi-structured interviews for Phase 3. The inclusion criteria for an interview were that the patient had to be fully informed about their HIV status, and if the patient was under the age of 18, the parent had to consent to the interview of the adolescent. The patient had to assent to the interview as well. Patients over the age of 18 alone were required to consent to the interview. Parents were also required to consent for their own interviews. Additional IRB approval for the recruitment poster was obtained, and a list of 31 patients was prepared. The parents of the patient were also included as potential participants in the interview phase.

Phase 3

Prior to the beginning of Phase 3, Mary Ann and I reviewed the list of 31 patients who were eligible to participate in the interview phase. Four patients and their parents were removed from the list. These patients and parents included participants whose personal circumstances, such as involvement in the child protective services system, juvenile incarceration, and/or parent involvement in criminal behavior, excluded them from the interview process by Wellington Hospital policy. As of January 2019, the final list contained 27 patients and their parents as eligible for Phase 3.

I originally planned to include 15 semi-structured interviews of parents and patients in Phase 3. The 15 interviews were to consist of five parents whose child had been fully informed about HIV, five parents whose child did not know their status, and five patients who had been informed of their status. In this sample, there are 27 eligible patients for the interview phase. This set of patients have two sets of siblings, thus, there are 25 parents who are also eligible for the Phase 3 interviews. Parents of the 27 eligible patients were approached by the providers for participation in this study[1] between January 9 through May 10, 2019. Sometimes patients did not show for their appointments

---

[1] There were two sets of siblings eligible to participate in the interview phase. Each sibling set had one parent who was approached by the providers; thus 25 parents and 27 patients comprise the pool of eligible interview participants.

during this period. These “no-shows” created confusion in the record-keeping procedures and made tracking the recruiting process more difficult.

If the parent and patient attended the appointment and the parent agreed to an interview, I was provided the parent’s contact information. I then contacted the parent telephonically. Of the parents and patients approached by the providers, seven parents refused to participate and were given a code as “no” in the data set. Ten parents agreed to be interviewed, and eight parents tentatively agreed to participate in an interview. When I contacted this latter group of parents for an interview, none responded to the telephonic message. I called each parent at least twice. These participants were given the code of “maybe” in the data set.

Of the 11 parents who originally agreed to be interviewed, three parents changed their minds and declined to participate in an interview. One parent had tentatively agreed to an interview and when contacted said no, because he had changed his mind. Two parents who initially agreed to an interview changed their minds at the last minute and contacted me to inform me of their decision. Thus, the total number of parents who declined an interview is 11. Table 3 represents the results of the Phase 3 recruitment efforts.

The final interview sample totaled three participants; two parents who agreed to an interview and a patient. The two parents were not related. One parent was a male and the second parent was female. Each parent had adopted their respective child patient. The two parents and one patient were interviewed in April 2019, and the interviews were recorded. After each interview, the transcript was prepared, and I reviewed the transcripts for completeness and accuracy. A pseudonym was assigned to each interview participant. The patient interview was not recorded due to equipment failure. I kept notes during the interview and reconstructed the interview from those notes. The only demographic information collected for parents was gender and whether the parent was biological or adoptive. Neither parent consented to an interview of their child. Data collection for all phases ended in May 2019. All transcripts of the parent interviews were uploaded into the NVivo program for analysis, and the data from the Excel file was uploaded into SPSS in preparation for data analysis.

Methods for Analysis and Interpretation

Applied thematic analysis is the overarching analytic technique used to develop codes and themes and to create a codebook describing the experiences of the parents, providers, and patients in this study. Themes developed from the inductive process are "strongly linked to the data themselves and may bear little relation to the specific questions asked of the participants (Nowell et al., 2017, p. 8); they capture the essence of the data. However, themes must be created consistently to ensure enough codes to support a theme. Codes also are derived deductively; however, if a researcher utilizes too many codes derived from an deductive process, these predefined codes may be too numerous and may "leave researchers lacking any direction and feeling overwhelmed by the amounts of complex data" (Nowell et al., 2017, p.8). Codes and themes should be reflective of the experiences of the study participants.

A codebook is an essential component of applied thematic analysis (Guest et al., 2012). Coding is an iterative and messy process designed to create a result consisting of an organized set of codes and themes that are coherent, organized and have relevance to the phenomenon being studied (Guest et al., 2012). The purpose of the codebook is to help the researcher meet the "aims of thematic analysis…examining commonalities, differences and relationships"(Guest et al., 2012, p. 53). The codes and themes developed created a framework for comparing the experiences of the study participants and meeting the criteria for trustworthiness by accurately representing the experiences described with clarity and consistency.

Coding

The coding process included six steps: 1) the researcher became familiar with the data, 2) initial codes were generated, 3) codes were reviewed to identify themes, 4) themes were reviewed for consistency, 5) themes were defined, and 6) the report was produced. These steps are not completed in a linear fashion but rather performed in an iterative way to ensure the entirety of the data set is coded and categorized within a set of themes (Nowell et al., 2017).

I used this method throughout several rounds of coding. Most of the codes and themes used in this data set were derived inductively from the data using a first cycle coding process known as "In Vivo" coding (Miles et al., 2020, p. 65). In Vivo coding is used in qualitative studies, and in this first cycle of coding, the researcher uses words and phrases taken from the participant's own language (Miles et al., 2020). An example of this type of coding used in this study is the code developed for Age. Question 1 of the focus group questions asked providers at what age did they think disclosure would be appropriate. Age was a common-sense label to assign to providers' responses discussing the chronological age at which disclosure should occur. In Vivo coding was used to code the data set during the first cycle of coding.

Several codes and themes in this study were derived deductively from the theoretical constructs discussed in Communication Privacy Boundary Management theory (Petronio, 2002). For example, the theme, Family Privacy, was derived from concepts regarding how thick or thin a family's privacy boundaries are, in this case for HIV status. The codes, Open and Closed, indicate the provider's perceptions and working knowledge of how comfortable the family is in talking with one another about HIV issues. The theme, Stigma, is another example of a deductively derived theme and code, in that the academic literature on health issues, among other topics, uses the construct to describe feelings of shame or fear related to exposure of private information (Catona et al., 2016; Greene et al., 2003; Kalichman et al., 2017). Thus, the themes created in this study were initially developed using both inductive and deductive coding schemes.

Data Reduction Methods

Two other approaches help further refine themes found in a data set and ensure rigor and transparency of analysis. The first technique used to answer Research Question 2 is a role-ordered matrix (Miles, Huberman & Saldana, 2020). In this study, parents and providers play specific roles within the context of a health care relationship. Roles are comprised of "socially expected behavior patterns" associated with a function assumed or played by a person in a situation (Miles, Huberman & Saldana, 2020, p. 160). An example of a role in this study is that of the provider. A health care provider has a set of perceptions about the disclosure process that is gained through their experiences providing healthcare to patients within the Lewin Clinic. A parent also has experience in and perceptions about working with the health care provider in obtaining health care services for their child. A role-ordered matrix is a table that “groups, summarizes and compares different people’s role perceptions about selected topics or issues that enable the researcher to compare and contrast those perceptions” (Miles, Huberman & Saldana, 2020, p. 160). The use of a role ordered matrix is appropriate for comparing similarities and differences in the negotiation process used by parents and providers when deciding to disclose HIV status.

A second technique used to analyze and interpret the data from this study is an Event List Matrix (Miles, Huberman & Saldana, 2020). Disclosure of HIV status to an adolescent is not only a series of difficult conversations but contains an inherent timeline for when this event takes place. One way to organize data and reflect a process is through an Event List matrix (Miles, Huberman & Saldana, 2020). An Event List matrix allows the researcher to arrange “a series of concrete events by chronological time periods, sorting them into several categories” (Miles et al., 2020). An event matrix from these data plotted the individual events that lead to disclosure and the amount of time taken by providers and parents to negotiate the disclosure process. An event matrix may be helpful in identifying the factors that influence the amount of time taken to achieve the disclosure. An example may be the difference in the amount of time taken if a critical or non-critical disclosure event has occurred. This technique gives a more comprehensive picture of the length of time the disclosure process takes and allows for a deeper look into the process used by the Lewin Clinic when the need to disclose HIV status arises.

CHAPTER 4

FINDINGS

Introduction

This study focuses on parents' and providers' management and coordination of privacy boundaries around an adolescent patient's HIV status within the context of a pediatric health-care relationship. The research questions in this study sought to identify factors used by providers and parents to determine an adolescent's readiness to be informed about their health condition; how the provider and the parent negotiated the details of the disclosure event, and under what circumstances did the disclosure occur. This chapter presents the major findings for the three research questions posed in this study.

Research Question 1 investigated the criteria used by parents and provider to determine adolescent readiness for disclosure. The major findings are first, stigma is the backdrop against which parents and providers make decisions about disclosure as both are keenly aware of the association of stigma with this illness. Second, providers and parents agree that five criteria necessitate disclosure: medication adherence, an adolescent's dating and sexual behavior, an adolescent's question asking, an adolescent's cognitive issues and the child needs to know their status. The providers and parents differ on two criteria: the adolescent's age and their family situations. Parents also consider who else in the child's life may need to know such as future spouses and employers.

Research Question 2 examines the negotiation process used by providers and parents to determine when and how the disclosure will be made. The data analysis revealed that the relationship between the parents and the providers is built upon trust in one another as stakeholders in the relationship. The major findings indicate that the negotiations begin with the providers approaching the parent thoughtfully by using open ended questions designed to get the parents to engage and think about the disclosure event. Parents have both negative and positive reactions to the provider's initial approach. The parents then decide to either agree or disagree. Some parents feel empowered to initiate disclosure on their own. Some parents may disagree with the disclosure outright and some parents delay the disclosure. Should a parent delay disclosure for too long, the provider then counters the delay with an ultimatum.

Finally, Research Question 3 investigates the conditions under which disclosure are made. The most important finding for this question is that disclosures are made under three general conditions: Non-Typical, Urgent, and Typical. The first condition is a non-typical disclosure in which the disclosure is made outside of the Lewin Clinic provider-parent relationship and generally results in parents becoming upset about the way their child's HIV status was revealed. The second condition is an urgent situation in which the child's behavior (i.e., medication adherence and an adolescent's engagement in sexual behavior without the knowledge of their HIV status) presents a critical health incident in which a disclosure must occur. The final condition is a typical condition in which the Lewin Clinic providers and parents negotiate the timing and plan the disclosure event. This condition lacks an urgent situation in which disclosure must occur and depending upon the needs of the adolescent, he/she receives additional information about his/her HIV status and sexual health at future appointments as they mature to adulthood.

Research Question 1

Within the pediatric healthcare relationship, parents and providers work together to ensure the adolescent patient receives proper medical care for their illness and, as the patient matures and enters adulthood, that they understand how to independently take care of their health needs (Gerson et al., 2001). Furthermore, parents and providers work together to determine the appropriate time to fully inform an adolescent of his or her HIV status. They also negotiate the circumstances under which an adolescent will be informed. To better understand the disclosure process, Research Question 1 sought to identify the general criteria providers and parents use to determine whether the adolescent is ready for complete disclosure of his or her HIV status.

Providers and parents are aware of the societal attitudes and stigma around a person's HIV status, and their awareness frames the conversation about disclosure. Data analysis reveals that providers and parents share criteria around these issues: medication adherence, question asking about medications and provider visits, cognitive issues, and adolescent interest in dating and sexual behavior, to determine when the adolescent is ready to be fully informed about their illness. Data analysis also reveals differences between providers and parents in the criteria they use to determine when an adolescent is ready for disclosure. The providers also consider an adolescent's age and cognitive maturity to determine if an adolescent is ready for disclosure.

Parents and providers differ in their considerations of the impact HIV disclosure will have on a family. Parents think about the impact disclosure will have on upon the child, other family members, and people outside of the family, both now and in the future. Providers, on the other hand, are cognizant of the family's life circumstances and the impact of disclosure upon the family during times of instability.

Societal Attitudes and Stigma around HIV/AIDS

The need for patients to understand the social implications of the stigma around HIV is a backdrop against which the disclosure process takes place. Providers and parents are aware of the two categories of the HIV-related stigma, anticipated and enacted, that relate to others' potentially negative reactions towards PLWHA, thus, adolescents need to understand and manage complex private information around their HIV status. First, they must learn to manage medical information about their own health condition. Second, revealing a child's HIV status leads them to ask about the origin of their illness and, since HIV/AIDS is transmitted through pregnancy and childbirth, a mother's status typically is revealed. Hope explains "many times with maternal exposure you're also disclosing Mom's status as well, um, so it's a dual disclosure in a sense" (Focus Group Transcript, p. 2, ll. 26-28). For these reasons, an adolescent must have the cognitive ability and the emotional maturity to discern when the appropriate time is to reveal or conceal their, and their mother's, information.

Dr. Gates also described the need for HIV-infected adolescents to possess both cognitive ability and emotional maturity from this perspective. She said, "there are issues about how much a child would understand, and since this is a disease with a lot of stigma, um, confidentiality and knowing who to talk to or how to talk to people about it, have it come up, is a huge issue" (Focus Group Transcript, p. 2, ll.16-19). Hope pointed out that disclosure is like an onion, and stigma and societal attitudes towards HIV/AIDS are one layer of the onion.

> We also have some cultural issues where even though you multiply the stigma from families who are from Africa, um, 'cause they're much more stigmatized as well in Africa. So, I think that there's a lot of factors and it's like an onion, sort of peeling back each layer that you think it's gonna be alright but there's a different layer of something, um, that adds to it (Focus Group Transcript, p. 2, ll. 32-38).

These different layers of the onion, cultural attitudes towards illness and the patient's ability to understand and exercise discretion around revealing HIV status, create a stressful setting for revealing a chronic illness that has many cultural, social, and relational implications.

Providers also are aware of the role stigma can play within the dynamics of family relationships. As they interact with parents, providers often perceive a parent's reluctance to discuss HIV status with relatives.

> Rose: Anytime anything is hidden, there's just guilt. Like that's why I think it really – even if it's just the fact that there's a secret in the family, and if it wasn't even HIV, it was something else, it just kinda creates this, you know" (Focus Group, p. 30, ll. 27-30).

The provider's perceptions of the parent's feelings of shame and guilt help the provider respond to parents' feelings about sharing HIV status with family members and people outside of the family.

Parents also are cognizant of the stigma HIV status has in their communities and families. Family members may be afraid of the person who has HIV/AIDS because they do not know how HIV/AIDS is transmitted. One father of an adolescent son, whom he and his wife adopted, encountered this phenomenon within his community when the young boy first joined his family. The father recalls, "it's okay, he's not going to infect your kids. It's not dangerous. But yeah, there was a lot of education there that nobody knew. And you know, I'm telling them I was scared, too, until I learned the facts. I had no idea either" (Parent Interview# 2 Transcript, p. 9, ll. 2-7).

The father's extended family also had fears about interacting with a child who was HIV positive until the parents educated them about HIV/AIDS. The father stated,

> Yeah, … you could tell everybody was tense for a week or two, and then it was over, and it was done. It was past news. And my brother and his kids – it was past news. And by the time we moved back out here to be around our family, they had forgotten about it. So, you know, it never – no one has ever responded like, oh, sorry, I just can't be around him, you know? Like everybody got over their fear within a week or two, and it was done (Parent Interview # 2 Transcript, p. 10, ll. 33-37).

The father educating other family members about how HIV is transmitted helped them relax and interact with the child during the family's time together.

One mother experienced others' fear when her daughter was young. Her niece was afraid the daughter would transmit HIV to her new baby and refused to visit the mother and daughter, which infuriated the mother. The mother stated, "You know, I was really ticked. I was really quite angry. So when we came home, I gathered up information from the hospital there, and I sent it to her, and um, the next visit they did come over" (Parent Interview #1 Transcript, p. 3, ll. 34-37). This experience influenced how the mother helps her daughter respond to people who may not understand the nature of HIV. She told me,

> I did tell her 'But we're not gonna tell everybody,' and then I explained all that, how people react, and I told her about this incident with the cousin, and, um, you know, so we – we talked about all that, and so I said 'So it's better off if we just keep it to ourselves' " (Parent Interview #1 Transcript, p. 4, ll. 45-46; p. 5, 1-3).

The mother wanted her daughter to understand that people who are not aware of the way in which HIV is transmitted, may react negatively when hearing that someone they know is HIV positive. Thus, awareness of the stigma and social attitudes around HIV influence the experience of disclosure for providers, parents, and patients as the need to disclose HIV status becomes apparent.

Shared Criteria

Stigma provides a backdrop against which the disclosure conversation occurs; however, providers and parents share a set of criteria by which they determine that adolescent is ready for disclosure. The data analysis revealed parents and providers agree upon several criteria that indicates the adolescent is ready to be fully informed about their illness. The theme, Adolescent Readiness, represents five codes that are the criteria providers and parents use to determine the adolescent is ready for disclosure. These five codes are Medication Adherence, Adolescent Question-Asking, Cognitive Issues, Child Needs to Know, and Adolescent Dating and Sexual Behavior. Four of the codes describe an adolescent's behavioral and/or emotional level of maturity that indicates they are ready for disclosure. These criteria center around issues that impact the adolescent on an individual level and those concerns can impact other people.

Medication Adherence

The first criterion, medication adherence, ensures the adolescent stays in good health, and when adolescents struggle with medication adherence, the time may be ripe for disclosure. Hope explains, "we're having preteens or teens who are struggling with medication; we can have a conversation with parents about we probably need to tell them why they're taking their meds 'cause then hopefully they have a better understanding of why these medications are important" (Focus Group Transcript, p. 4, ll. 29-34). When an adolescent demonstrates they are not complying with the medication regimen, providers often recommend disclosure of HIV status to help the adolescent understand why the medications are necessary for their good health.

Taking their medication regularly is necessary to the patient's good health and wellbeing. Providers become aware of a patient's irregular use of medication by reviewing the lab results of blood draws when the patient attends the appointment. This clinical indicator is critical to assisting patients in managing the disease and helping parents and patients understand why taking the medication regularly is important. Providers also rely on parents to inform them if a patient is not complying with the medication regimen. The provider noted in one record, "Attended appointment with dad and sibling. Patient decided on her own that she did not need to take her medication. Parents became aware and notified the physician. Provider discussed HIV and the impact on the body. Discussed why medication is necessary and what the lab values mean" (Participant # 55). Finally, some patients are angry about having to take medication every day for the rest of their lives. A provider noted in a patient's chart, "Discussion with patient regarding medication adherence and anger issues related to med adherence" (Participant # 58). Getting adolescents and their parents to understand the need for following the medication regimen is key to controlling the effects of the illness. An adolescent's independent choice in not taking their medication and the adolescent's questions about the need for taking the medication may influence the decision by providers and parents to disclose HIV status.

Parents are also aware their children need to take the medications correctly. One patient had a medication regimen that required her to take three pills daily. For approximately two weeks, the patient did not take her medicine and threw away her pills in the bedroom trashcan, where her mother found them. The mother recalled the medical appointment at which her daughter's lab results for HIV in her system were high. She stated,

> I don't know how long she'd been doing that, but in essence it was two weeks, and her – next time her blood work was high, and she started to cry, you know, and I said "That's what we're trying to tell you. You know, you can't do that. It's not your decision to make. You have to take this pill every day." So she understood then how important it was, 'cause the facts are right there in front of her (Parent Interview #1 Transcript, p. 11,3-9).

Ensuring an adolescent understands the health care rationale for properly taking and complying with the prescribed medication regimen is one criterion upon which providers and parents agree merits disclosure of HIV status.

Adolescent Question-Asking

The second criterion providers and parents consider is Adolescent Question-Asking. This criterion is met when the provider or parent experiences an adolescent asking more in-depth questions about the need for medication or for medical appointments. The questions posed by an adolescent to a parent or a provider do not indicate directly that the adolescent is not complying with the medication regimen, but instead, these questions from an adolescent are an indicator that they may be ready for more in-depth information about HIV status. Dr. Gates pointed out "I think some of the common issues that come up when families start to think about, uh, disclosure is when the child starts asking a lot of questions, starts questioning why they're taking their medication" (Focus Group Transcript, p. 2, ll. 17-20). Notations in patients' medical charts demonstrate the variety of questions adolescents pose when wanting more information. A provider noted that a patient asked, "why if she is well, does she need medication?" (Participant # 61). Moreover, questions about the illness indicate the adolescent's need for a more detailed explanation of the illness. The provider for another patient, wrote in the notes that she was asked "how patient contracted HIV and why the siblings do not have this disease. Provider discussed maternal transmission of HIV and perinatal protection" (Participant # 84). Overall, then, providers interpret question-asking behavior about medications by an adolescent patient as an indicator they may be cognitively ready for more in-depth information about HIV status.

Cognitive Issues

Some perinatally-infected HIV positive children suffer from developmental delays or have other underlying health conditions that impact their intellectual development. The child's lack of comprehension about their health condition is concerning to parents and providers. One father describes the challenges with his son, who is in early adolescence, and who does not fully comprehend his health condition. The father understood how important medication adherence was for his child; however, he was not sure how well the child understood his need to take the medicine daily. The father and Dr. Gates agreed to allow the child to manage his daily medications, but he expressed frustration about his child's inability to organize and to take his medication daily. The father said,

> You have to take it every day. And we've tried – he's getting older, so we've tried to let him organize his own pills. That didn't work because the brain function – we tried to let him – he does have a daily list, but we still have to check – did you take your medicine today? And then if he misses a day, then we really do – you have to understand that you could die. This is a disease than can kill you. And you know, we're not trying to be mean, but because that's all that he can understand, he needs to have that – In his brain that this is the most important thing I do every morning, is take these three pills (Parent Interview, #2 Transcript, p. 7, ll. 14-29).

In this case, the father did not believe disclosure necessarily would improve his child's adherence to the medication regimen given his cognitive deficits. Cognitive issues concern both providers and parents when a child is unable to understand the immediate need for medication adherence. The long term effect of the lack of comprehension by the child points to a potentially larger problem in that the child is not able comprehend health information about their HIV status. The long term inability of the child to understand his/her health condition, may also impact their ability to manage both their health condition in the future and how to handle the privacy boundary around their status in future relationships.

Child Needs to Know

In the code, Child Needs to Know, the parent agrees with the provider that the child needs to know that they are HIV positive. The provider and the parent agree the child needs to fully understand the implications of living as a person with HIV/AIDS. These implications involve two concerns; first, a child fully understanding their own health condition and second, the circumstances under which their HIV status should be shared. Part of the understanding involves the simple fact the child should be informed about their health condition. One mother, in response to a question about the benefits of knowing one's HV status, responded by stating "What benefits? Well, she has to know," (Parent Interview #1 Transcript, p. 4, l. 45. Her daughter learned that she was HIV positive at age 13. The mother talked with the daughter openly about HIV and explained to me,

> There – there – see, there wasn't one "Ah-ha" moment. I mean, you know, she's known that she has it, and we've been talking about it for years, so – Like I said, there wasn't in that – I didn't – there was no moment where I said "…, guess what? You have HIV." You know, there never was that" (Parent Interview # 1 Transcript, p. 4, ll. 29-31).

Once a child knows their status, the parent and the provider can more fully educate the adolescent about the illness and how best to manage their health concerns long term.

Another father, on the other hand, agrees that his adopted child needs to know his HIV status. The father is struggling to determine whether his child has a developmental delay which may compromise his adolescent son's ability to fully understand that he has a chronic illness. The father believes his child just does not understand he has a serious chronic illness. He stated,

> So, I mean when we got him, he knew he had HIV. He just doesn't have the comprehension to know what HIV is. And so we tell him over and over again when he asks, but he doesn't get it. And you know, so the main thing we push is since you can't understand what you have, if you don't take this medicine, you will die (Parent Interview # 2 Transcript, p. 7, ll. 8-16).

An adolescent's inability to understand his or her health condition can be a barrier to maintaining good health throughout their life. Furthermore, the inability of the adolescent to understand their own health condition may also impact relational partners the adolescent has in the future.

Adolescent Dating and Sexual Behavior

Another criterion used by providers and parents for determining whether a patient is ready for disclosure is the adolescent's involvement in dating and sexual behavior. Hope discussed the need for disclosure before ninth grade, because most adolescent begin to become interested in sexual activity at that time. "Oh, I was gonna say we talked about ideally before high school there's an age that we want to – we start hearing their interest in dating, boys, girls, or whomever. We wanna start having that disclosure earlier" (Focus Group Transcript, p. 4, ll. 19-22). For example, one patient, disclosed he was dating a girl but that they had not yet started a physical relationship (Participant # 77). Another patient expressed interest in dating, so the "Provider discussed sexual activity and the need for protection. 18 y.o. and is interested in dating" (Participant # 52). Because of the risk to other people, providers want to ensure that patients understand that sexual activity is one method of transmitting the virus and that they understand how to use condoms to prevent transmitting the virus before they become sexually active. One patient had started dating, and her provider noted "Patient is Dating; discussed condom use" (Participant # 65). Thus, a patient's involvement or interest in dating is an important criterion providers and parents use to determine whether a patient is ready for complete disclosure about their HIV status.

An adolescent who is dating may also be engaging in sexual behavior and, therefore, needs to know their HIV status. A provider noted this information in the chart for a patient, "Patient caught by father engaging in sexual activity with boyfriend. Provider discussed sexual activity with patient" (Participant # 73). A public health concern for both groups is that the adolescent patient understands the need to disclose their status to sexual partners and to protect their sexual partners to prevent transmission of the disease. During an appointment, a patient, discussed her dating experiences with the provider. In her notes, the provider wrote, “Patient has been kissing boys. One asked her for sex. Provider gave information to patient regarding need for protections and disclosure to sexual partners” (Participant # 69). Another patient disclosed to his provider that he was dating. The provider noted that they “discussed transmission of HIV virus during sex and emphasized condom use. Reassured patient to have sex ‘when ready as it is a decision not to take lightly’” (Participant # 87). Thus, parents and providers agree that adolescent dating and sexual behavior are part of the criteria for disclosing HIV status to the adolescent patient.

Provider Criteria

Although parents and providers agree on the factors that support Adolescent Readiness, they each also consider other criteria when deciding whether to disclose. Providers consider the chronological age of the adolescent and reflect upon what they know about the patient’s family as they determine whether the adolescent is ready for disclosure. The separate criteria for providers are captured under a sub-theme, Family Issues, which consists of three codes: Family Situations, Family Relationships, and Age.

Family Situations

Family Situations represents the direct knowledge providers have about the family’s life circumstances and their perceptions about stressors parents and the family may be facing. Housing, food, or employment insecurities can be added stressors for the parent and family as the time for disclosure of HIV status becomes apparent. Hope describes family situations as

> one of the things I was saying was when we think we're ready but then the parents aren't ready, or something happens in the house where maybe a sibling is acting up and then it's not the appropriate time to do a disclosure when there's other environmental or social factors of homelessness or food. So disclosure is important, but a parent loses their job or those other barriers that might happen, you know, critical events that need to be addressed before a disclosure even though it's important at that time when we think the child is ready (Focus Group Transcript, p. 3, ll. 30-38).

While disclosure of HIV status is important from a health care perspective, a family's life circumstances can create situations that are more pressing and urgent in the family's daily life. These situations may cause the disclosure to the adolescent to be delayed or ignored until the situation is resolved.

Family Relationships

The second code in this theme is Family Relationships. Providers are sensitive to the structure of the family group and who within the family knows the patient's HIV status. Sibling relationships and other family relationships are part of the equation when providers decide an adolescent patient is ready for full and complete disclosure. Some patients have siblings who are not HIV positive and parents who may be reluctant to share HIV status within the family. Clara pointed out. "It's also where the family is in sharing it with their family or, um, situational. It's all situational" (Focus Group Transcript, p. 3, ll. 5-6). Sibling relationships are considered by the providers because of the questions the adolescent may raise regarding their sibling's status. Hope explained "There are other factors that play into that, and I think siblings play a big part, too, because do you tell a sibling? Is that gonna change our relationship? Then it's, "Why does my sibling have it and I don't?" (Focus Group Transcript, p. 3, ll. 40-43). Thus, sensitivity shown by the providers towards the family's life circumstances and the family relationships are part of the criteria for providers in determining when an adolescent is ready for disclosure.

Age

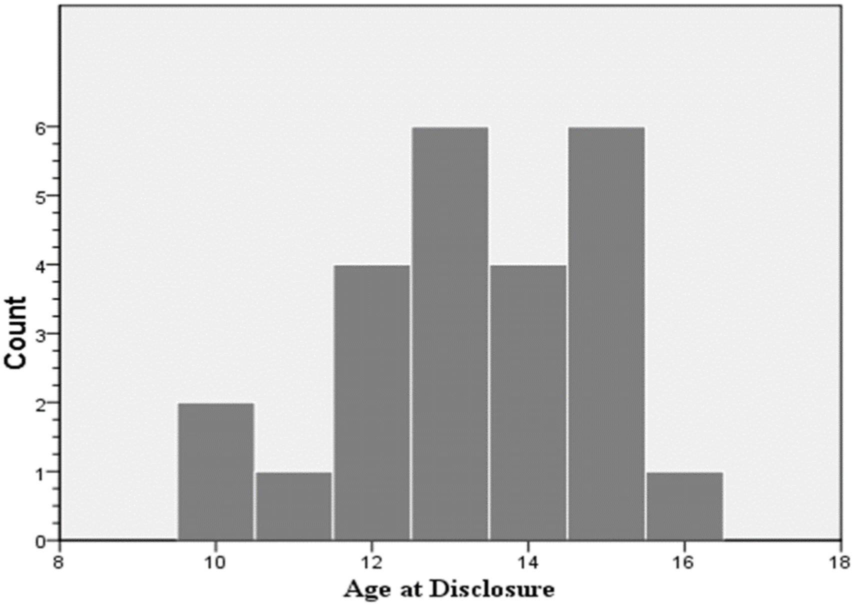
The final criterion that providers use to determine whether a child is ready for disclosure is their chronological age because the Lewin Clinic providers have an artificial age limit by which disclosure should take place. Chronological age is a flexible criterion for instigating the disclosure process because adolescents mature at different ages; however, as provider Mary Ann, points out, the Lewin Clinic staff generally target 15 years old as the age by which disclosure should occur. Typically, after disclosure occurs, at age 15 the adolescent receives a workbook at an appointment. The workbook provides information about HIV and other health-related issues to prepare the adolescent for transition to the adult health care system (Appendix G). A provider and the patient work together to review the information in the workbook. Mary Ann, explained,

> "I think, too, we try to do the workbook with most of the teens. I think 15 is the age. And so, when we notice someone is getting close to 15 and they still don't know, that's sort of an arbitrary or artificial trigger to if we haven't gotten there yet." (Focus Group, p. 4, ll. 38-42).

Figure 3 indicates the ages at which disclosure occurred in the Lewin Clinic patient sample. Twenty four of the 42 patient records reviewed contained data regarding the age of the patient at which disclosure first occurred.

Figure 3

Age at Disclosure (N = 24)



In these cases, the age at the time of disclosure ranged from 10-to 16-years old. The average age of disclosure for this sample was 13.29 years (SD = 1.63). The data indicate that the general practice of the providers at the Lewin Clinic is for disclosure to occur between ages 13 and 15 years old. Thus, providers consider chronological age as part of the criteria necessary for disclosure.

Parent’s Criterion

Parents also consider criterion separate from those considered by the providers. Parents look to the future and the relationships their children will be forming outside of the family. The code, Who Else Needs to Know, reflects a parent’s concerns about their child’s current and future relationships with others who may need to know their child’s status. Parents who were interviewed agreed that their child’s future spouse would need to know the child’s HIV status. I asked one mother about future romantic partners her daughter may have and should her daughter inform them about her HIV condition. The mother replied, “I would imagine she should tell like once she got married, you know, once she's engaged or whatever to tell the fella what it really is” (Parent Interview # 1 Transcript, p. 7, ll. 28-32). Another parent also suggested that his son’s future spouse would need to know. “That’s between you and yourself. I mean obviously your wife should know if you’re gonna get married” (Parent Interview # 2 Transcript, p. l5, ll. 4-5). Thus, parents see their child informing a future spouse about their HIV status as the spouse is someone a parent feels who need to know about their child’s HIV status.

One parent also pointed out that his child’s future employers do not need to know his HIV status. Depending upon the kind of employment the child may gain in the future, HIV status is not always necessarily disclosed to employers.

> But you don’t need to go to your job and say, hey, everybody, I have HIV. That’s not gonna help you out. They don’t need to know and it’s not – not their business. And legally, you don’t have to. So just go about your business and act like you don’t have it, as far as they know. The doctor needs to know, you need to know, your wife needs to know” (Parent Interview # 2 Transcript, p. 15, ll. 5-10).

Parents want their child to know about and understand their health condition, and they also want to help the adolescent understand how and to whom disclosure must and should be made. Parents agree that a future spouse needs to know the adolescent’s HIV status. One parent suggested that the adolescent needs to understand that an employer may not necessarily need to know their status. Thus, parents also use the criteria of other people such as future spouses and employers who may need to know in the future what is their child’s HIV status.

Research Question 2

Research Question 2 explores the communicative strategies providers and parents use as they negotiate opening and coordinating the privacy boundary around adolescent patients' HIV status. Within the pediatric healthcare relationship, providers and parents are the primary stakeholders and the negotiation around disclosing HIV status are conducted by these two people. Data analysis indicates that establishing trust was an important prerequisite for effective negotiations regarding the decision to reveal patients' HIV status. Furthermore, the parent develops trust in the provider's ability to keep the mother's HIV status as a secret from the adolescent.

Data analysis also revealed that the negotiations begin with a conversation between providers and parents when one or more of the criteria for opening the privacy boundary is present. The conversations begin as a series of questions posed by providers to parents about the disclosure event. Parents respond either positively or negatively to the questions posed by the providers. Providers are also aware of the family's privacy orientation around HIV status which may impact the negotiations around disclosure. The data indicate families are either very willing to discuss HIV information among family members or they are not willing to discuss it at all. These conversations allow parents and providers to discuss the adolescent's readiness to become a responsible owner of his/her health information and determine together how, when, and where the adolescent will be fully informed about their HIV status. Finally, it addresses how providers negotiated with parents enacted strategies to agree, delay or avoid disclosure.

Negotiations, Trust, and Secrets

Negotiations, by their very nature, are communicative acts. (Ury, 2007) defines negotiations as “the process of back-and-forth communication aimed at reaching agreement with others when some of your interests are shared and some are opposed” (p.4). As stakeholders in the healthcare relationship, the providers and parents build trust in one another’s knowledge of and ability to meet the child’s health care needs. Trust is built over months and years as they meet and is grounded in each side’s knowledge of the other’s concern for and ability to meet the child’s health care needs. The trust between providers and parents allows each party to express and explore their mutual and opposing interests around disclosing HIV status as they jointly decided how, when, and where the disclosure event would occur. The conversations around disclosure occur over time and reveal a process in which providers ask open-ended questions and provide emotional support to parents as the decision to disclose is reached (Lesch et al., 2007).

Trust and Secrets

One element of the trust between providers and parents is sharing a common goal: maintenance of the patient’s good health. Providers get to know and trust patients and their families as they consistently attend appointments during treatment. Part of the trust by the parent in the provider is knowing all members of the health care team have their child’s best interest at heart. Mary Ann explains, “I think most of them know that as a team we want the best for their children, and that's part of what their trust is about, is that they know that we're sincere in that effort” (Focus Group Transcript, p.14, ll. 11-15). Parents, in turn, develop trust in health care providers when they feel the information given to them about their child's health is reliable. As Rose stated, "But I think there's a lot of trust with the families and the team that, in terms of, you know, they think that they can trust what Dr. Gates is gonna say, that it's gonna be okay" (Focus Group Transcript, p. 14, ll. 1-3). Thus, trust within a parent-provider relationship is two-fold: it develops through consistent attendance at appointments by patients and their parents and due to providers' provision of trust-worthy information about the child's health needs.

Trust also arises from providers' willingness to keep the mother's HIV status hidden from the patient. The provider's ability to keep the mother's HIV status private and, when the time is right, to inform the child of his or her HIV status requires a delicate balance of the dialectical tensions between privacy and openness. Providers understand parents trust them with concealing the HIV status of the biological mother and the provider will protect the HIV-positive mother when disclosing the child's status. Mary Ann explained, "many of them know that we've kept the secret for a good long while now, so it's not that we can't keep the secret or don't want to keep the secret" (Transcript, p. 14, ll. 13-15). The trust created between provider and parent and the recognition that the child's HIV status must be disclosed provides a common ground for the provider and parent to begin their negotiations over disclosing HIV status.

Opening the Conversation: The Provider's Approach

Typically, disclosure negotiations are initiated when providers feel a child is emotionally, cognitively, and medically ready to become fully informed about and responsible for their HIV status. The Lewin Clinic team sees disclosure as a process that includes a plan for raising the issue of disclosure with parents that allows them time to process the idea their child will be fully informed about their illness. Clara explained,

> You also do it ahead of time. There's a plan in place. ‘Next time we're gonna talk to the family about disclosure.’ And then from there, there's a plan made about when you're gonna disclose to the child. And so, the parents have time to process it. I mean it may be three months at their next visit that you do the disclosure. So they have time to think about it and think about how they're gonna react to the reaction (Transcript, p.6 ll. 34-40).

Providers think carefully about how to approach parents and use their knowledge of the family’s life situation to plan for a disclosure event. They use a process that allows parents to help plan the disclosure event.

Providers begin the approach with parents at a regularly scheduled appointment. While the patient is involved in completing other routine health care tasks with the nursing staff, providers and parents have a private conversation. Providers engage parents in a discussion about disclosure by raising thoughtful and open-ended questions designed to encourage parents to begin thinking about disclosure. Dr. Gates explains,

> So it's something that we have to talk to the family about, and we separate them from the child when we're talking about it, and we just go over those issues. When is the right time to do this? Who should we have present? Who wants to be present? Are you comfortable doing that yourself? Do you want to do that? … Um, do you wanna do it in the home? Do you wanna do it in the clinic? Do you want us to take care of it? Do you wanna be present when we do it or do you not wanna be present? (Focus Group Transcript, p. 6, ll. 10-14).

These questions allow parents to begin to consider the idea of disclosure and to help plan how their child will be informed about their HIV status. During that process, parents often react emotionally.

Parents Reaction's to the Provider's Approach

Parents react in two ways to the provider's approach for disclosing HIV status. One reaction is a strong negative emotional reaction reflecting parents' anxiety and fear about disclosure of HIV status. Dr. Gates stated,

> those reactions I think are much more common when we're talking about doing the disclosure, 'cause I think parents have a lot of anxiety. They're very afraid many times. They're petrified. They're, um, embarrassed. They're, um, there's a lot of emotion for many parents around thinking about doing the disclosure (Focus Group Transcript, p. 7, ll. 1-9).

When parents respond negatively and emotionally, providers listen address parents' concerns. Dr. Gates offered her strategy for allowing parents to express their emotions

> Sometimes too when they're really anxious I just try to talk to them about, "What are you afraid is gonna happen? What is, you know, what is really causing the anxiety?" And let them talk about what they're most worried about and then share with them what usually happens and how it usually goes (Focus Group Transcript, p. 9, ll. 17-21).

Once parents express their emotional reaction to the idea of disclosure, they are then able to listen and engage more with the provider about the process.

The second reaction parents have to disclosure is question-asking. Parents pose questions about the disclosure process and how it unfolds. They want to know the type of information their child will be given and how providers will handle specific issues. Hope clarified how providers support parents,

> So just explaining that this is why it's important and we're gonna be here every step of the way while you're here, and you know, giving them, guiding them, "This is how it's gonna happen" and even interjecting that if a kid asks questions this is probably what we're gonna say, and giving them an opportunity to say, "I think they're gonna ask this" and we can tell them what we're gonna answer, how we're gonna answer, how they like us to answer that question (Focus Group Transcript, p. 9, ll.6-15).

Often, provider's responses help parents relax and feel supported as they decide whether they will agree to disclosure. Providers also are cognizant of the family's orientation to how private information is managed and communicated to other people.

Family Privacy Orientations

Parents are protectors of family members within their care. They also are gate-keepers of the family privacy boundary around HIV status and usually control the flow of private information about a child's condition. The codes, Closed and Open, represent family's privacy orientations around HIV status.

Open. An open privacy orientation indicates the family is willing to discuss HIV information within their family and possibly other people within their community. For example, one father stated, "But I mean we're very open with communication. We don't hide stuff with our kids" (Parent # 2, Interview Transcript, p. 2, ll. 43-44). He further stated that

> We talk about other family members if they're having health issues or whatnot. Um, all of our kids know what HIV is because of that. We've explained that – we do over and over, so that's – we're very open about that. Um, they know about all his health visits and what he's going through, and the brain issues, and all that. So we're very open (Parent # 2 Interview Transcript, p. 4, ll. 15-20).

Providers' perceptions about a family's privacy orientation about HIV status are noted occasionally in patient charts. One provider wrote, "Family has open discussions about safe sex and proper disposal of blood" (Participant #50). The willingness to discuss HIV information within the family is an indicator that parents may be more open to disclosing HIV information to their child, other family members, and possibly with others outside of the family.

Closed. The privacy orientation of closed indicates the family is not willing to discuss HIV information among themselves or with other people. Hope explains what many families like this tell their providers,

> A lot of our families will tell us, 'We don't think about it every day. We think about it when we come here every three months or when we take our meds, but otherwise we don't talk about it. We don't discuss it. It's not a part – it's a part of our lives, but it's not something we focus on'. So that's there as a reminder in a sense. There's always that fear that a sibling or somebody finding [the workbook] in the house. They're not an open family about status" (Focus Group Transcript, p. 16, ll. 13- 19).

Parents may keep a closed privacy orientation to protect themselves and their families from discrimination and ostracization due to stigma around HIV status within their family and community. Dr. Gates noted, "So it's all hidden because it's understood that it's supposed to be hidden" (Focus Group Transcript, p. 30. Ll. 20-21). Providers note in patient records that some families are very private about HIV information. One provider wrote, "Disclosure Form in file states family is very private" (Participant #71). Each of these privacy orientations becomes important when parents are asked to disclose their child's HIV status because it influences the communicative strategies parents use in response to the provider's approach.

Parents' Decisions

Once approached, parents must decide whether to agree to disclose their child's HIV status. Analysis revealed that when asked, parents responded in three ways: agreed to disclosure, initiated disclosure on their own, or disagreed with the request.

Agree

Parents agree to disclosure for a variety of reasons. When approached, some parents readily agree to the provider's request because they trust the provider. Dr. Gates noted, "I mean it's very different depending on the family. Um, we have some families where, and even culturally, you know, "You're the healthcare provider. You know what you're doing. Do your thing, whatever you wanna do" (Focus group Transcript, p. 12, ll. 37-40). A provider noted in a patient's file that they "discussed disclosure to patient with parent. Parent agreed to disclose" (Participant # 80). Some parents agree to disclosure but specify how much information they are comfortable their child knowing. For example, a provider recorded in a patient's chart "Parent told provider she wants 'little bits of disclosure'" (Participant # 62). Other parents agree due to the perception their children are ready for disclosure. In one case, a provider stated, "Disclosure discussed with mom today. Mom agreed to disclosure as patient's English language skills are improving" (Participant # 75). In several instances, parents recognized their children were maturing and needed to be able to communicate their health needs to current and future providers and, therefore, agreed to disclosure.

Parent Initiates Disclosure

Occasionally, parents initiate the disclosure discussion on their own after the provider has approached the parent about disclosing their child's status. In these cases, typically parents ask a provider how the disclosure will occur. Dr. Gates explained, "then many times there's a discussion about, this is how we usually do it. This is the discussion that we usually have. This is what it sounds like. These are the things that we're gonna talk about." (Focus Group Transcript, p. 6, ll. 19-22). After their questions and concerns are addressed, parents may feel supported and empowered to disclose HIV status on their own. Dr. Gates stated, “Sometimes we've done that and then the parent goes ahead and does it on their own because they now know what to do” (Transcript, p. 6, ll. 26-27). This process allows parents to disclose HIV status using information they feel comfortable discussing with their child. At other times parents and providers disclose together. A provider noted in a chart, “Initiated some disclosure with patient. Dad told patient he ‘had a virus’. Provider built on this message. Discussed blood disposal techniques” (Participant # 71). Once the parent had broached the Participant of HIV status, the provider was then able to provide more in-depth information to the patient.

At times, the conversation between a parent and child around HIV disclosure can be incomplete or confusing. Dr. Gates recalled,

> “I mean we had a family that we were planning to do the disclosure at the next visit and we were prepared to do it, so come to find out that the parents had done some discussing before and so I asked them what they were told and the patient said, "Well, the person told me that I might be fine or I might go to the hospital and get sick and die" (Focus Group Transcript, p. 34, ll. 6-8).

One parent informed his child on the way to the Lewin Clinic office for an appointment. The provider noted in the patient’s medical chart, “Patient moving away from area. Dad began conversation about HIV in the car on the way to the appointment. Provider disclosed during appointment” (Participant # 68). When parents agree the request to disclose and the providers discuss the disclosure process with them, they may feel comfortable enough to initiate the disclosure conversation with their child.

Disagree

Parents also disagree with disclosing HIV status to their child for several reasons. The code, Disagree, represents three communicative behaviors parents use when they disagree with the provider about disclosure: disagree without explaining why they disagree; disagree but provide a reason for the disagreement, and disagree by seeking to delay disclosure.

The first behavior parents display is a complete disagreement without any reason given for their choice. A patient may be ready for disclosure and the provider believes the child is ready, but the parent simply disagrees. A provider noted in a patient's chart "Provider approached parent as patient is asking questions; parent disagrees with disclosure" (Participant # 67). Parents also refuse to allow providers to disclose. In this instance, they directly tell the provider that they are responsible for disclosing HIV status to their child. For instance, a provider recorded in a patient chart "Mom does not want staff to inform patient about Mom's diagnosis. She will do it on her own. Patient is 14 y.o. and is not dating" (Participant # 57). These abrupt tactics make clear to the provider that the parent is responsible for disclosing status and the provider will not be involved.

Parents also disagree with disclosure requests if they feel their child is not ready to understand the implications of owning such information. Parents worry that their child may disclose information about HIV status to people whom the parent would prefer not to know this information. Dr. Gates observed "again they are scared their child is gonna tell everybody. Um, they're afraid they're gonna be stigmatized by people in their family or in the community" (Focus Group Transcript, p. 7, ll. 30-32). Providers hear the concern from parents about the child readiness. One provider noted in a patient's chart, "Mom disclosed to provider that she is scared that patient will discuss illness with patient's friends and patient would then become ostracized. Mom understands patient needs information about why patient takes medications" (Participant # 83). Thus, a parent's perception that a child is unable to keep the information private can lead them to refuse to discuss the disclosure process.

A child's cognitive inability to grasp the implications of the information being disclosed also is a reason parents oppose disclosure. When first approached by the provider, one set of parents resisted disclosure because they felt their child did not have the capacity to understand the illness. Instead, they wanted to disclose to his sibling. The provider noted in the record "Discussed disclosure with parents; Patient may not understand. Parents want to disclose to sibling" (Participant # 59). Three months later, the provider again approached the parent about disclosure and was rebuffed once more. The provider noted, "Disclosure discussed with parents regarding patient and sibling. Issue of driving was raised; patient's status may become known. Parents agreed to discuss and report back to physician. Plan to disclose to sibling" (Participant # 59). Nearly19 months later, the provider noted in the chart, "Discussed disclosure with parent. Parent claims 'patient does not understand.' Status discussed openly at home as sibling is now aware of patient's status. Parent claims patient does not comprehend" (Participant # 59). A child's cognitive issues can present a difficult situation for the family as they struggle to determine whether the patient can manage the information about their chronic illness.

Delay

Parents disagree indirectly with the provider’s request for disclosure and demonstrate this by using a delay tactic. Dr. Gates explained, “sometimes one parent doesn't wanna be involved and the other parent does. Sometimes both parents want to be very involved. Sometimes no parents want to be involved. So it's something that we have to talk to the family about” (Transcript, p. 6, ll. 7-9). Occasionally, when the request for disclosure is made, one parent tells the provider the other parent must be consulted without providing a reason why the consultation is necessary. A provider noted in a patient’s chart, “Provider spoke with mom alone about disclosure (15 year old). Mom is thinking about disclosure when the patient is 16. Mom wants to talk to Dad about disclosure” (Participant # 52).

Sometimes a conflict between individual parents over disclosure occurs. The conflict between the parents may be at what age each parent believes disclosure should occur and the conflict may also indicate a parent’s own emotions about their own HIV status. A provider reported in a patient chart, “Provider spoke with parent regarding disclosure. Mom feels shame about the diagnosis and mom was encouraged by the provider to discuss disclosure with Dad. Dad is against disclosure because of patient’s age. Provider informed parent disclosure is a process” (Participant # 71). The disclosure process involves several discussions with parents at appointments until disclosure is achieved, and parents who are uncomfortable in talking about their own or their child’s HIV status may use a delay tactic to avoid disclosure.

Provider Ultimatums

Finally, when providers feel parents have delayed disclosure long enough and the child is ready to receive full information about their health condition, they issue an ultimatum. Dr. Gates explained that some parents need to hear their children must have disclosure because they are becoming mature enough to understand the implications of living with HIV/AIDS. The need to disclose can become important since Lewin Clinic providers disclose HIV status to their patients by age 15. Patients are given an HIV workbook at age 15, and the patient and provider review the contents of the workbook at appointments. Dr. Gates explained the ultimatum the providers use with parents when disclosure must occur. She said parents are told

> ‘We need to do this. Your child is going to high school’ or whatever it is and, "They're gonna be dating and they need to know this information. We have this workbook and they're gonna find out about it when we do the workbook when they're 15 and go through the workbook.’ ‘That's happening. That’s the deal’ (Transcript, p. 10, ll. 9-14).

Dr. Gates also clarified that few parents need to hear the ultimatum. She explained, “not many parents require that, but sometimes we have to do it.” (Focus Group Transcript, p. 8, l. 34). This strong stance by the providers signals to parents that disclosure is inevitable regardless of their attempts to stall the disclosure process. One provider noted in the patient’s record, “Provider informed parents at age 15, patient will be given the workbook and he will be dating soon” (Participant # 71). During negotiations around disclosure, parents who use a strategy of delay are met with the strategy of an ultimatum. The result is disclosure by the provider of the child’s HIV status to the child patient around age 15.

Research Question 3

Research Question 3 examines how different disclosure conditions affect negotiations between providers and parents around the disclosure of HIV status to the adolescent. In essence this question aims to investigate the circumstances under which the disclosure event occurs. This question examines who, where, and when disclosure events take place and whether the specific circumstances under which disclosure takes place is hastened or delayed. The disclosure conditions involve meetings and/or appointments with a health care provider in which the child is fully informed about their HIV status.

Data analysis revealed three different disclosure conditions that impact the negotiations and the relationships between providers and parents. The three disclosure conditions are Non-Typical, Urgent, and Typical. A non-typical incident is one in which disclosure was completed but was most likely performed outside of the Lewin Clinic and did not involve Lewin Clinic providers. This condition can create tension between parents and the Lewin Clinic providers over how the disclosure was performed. An urgent situation is one that occurs within the Lewin Clinic and is completed by a Lewin Clinic provider, and most importantly, is in response to an adolescent's immediate health crisis. Due to the critical health situation, this condition shortens the amount of time the providers spend negotiating with parents. The final condition identified is a typical disclosure condition in which the Lewin Clinic provider and parent have negotiated when the disclosure will take place, and no other critical incident influences the decision of the provider and/or parent regarding disclosing HIV status to the adolescent.

Non-Typical Events

Lewin Clinic patients often have additional health conditions for which they seek health care services from other providers in the Wellington Hospital system. These providers work in the outpatient clinics at Wellington and inside the Wellington Hospital. Non-typical disclosure events occur at appointments or other meetings at which a non-Lewin Clinic health provider discloses a child's HIV status to them with little or no negotiation or preparation of the parent. The non-Lewin Clinic providers may be unaware of how to communicate HIV status to patients and their parents because they are not mindful of the privacy issues around HIV status within a family. The non-typical disclosure generally occurs in two ways: a Wellington hospital-based provider inadvertently discloses HIV status to the patient and his/her family during a visit with the patient and his/her family and friends who may not know the HIV status of the patient. The second manner in which non-typical disclosures occur are completed by non-Lewin Clinic providers within another outpatient clinic in the Wellington system.

Wellington hospital-based providers sometimes meet with patients when the patient's family and friends are visiting him/her. They converse with a patient about their health condition in front of the patient's family and friends. Dr. Gates explained,

> Some of the non-typical events are things that happen for example if a patient is hospitalized and they don't know their status, but then people in the hospital start talking about their status in front of them because they just don't think about that. If you're not working in the field, people are just not aware of the issue, and so they don't think about it (Focus Group Transcript, p.16, ll. 28-33).

The Wellington Hospital provider discloses the patient's HIV status during the conversation with the patient and in the presence of the patient's parents and other friends or family who are visiting. Dr. Gates described the conversation between the provider and the patient in this way. “The hospital provider might say to the patient and the other people in the room, ‘You have ulcerative colitis. I'm gonna talk to you about your ulcerative colitis, and you have HIV and I'm gonna talk to you about your HIV.’ They don't remember that that is a confidential issue, and so that can occur” (Focus Group Transcript, p. 16, ll.33-36). The lack of awareness by the hospital staff contributes to the tension between the parents and the Lewin Clinic providers regarding communication around a patient’s HIV status.

Another non-typical disclosure occurs in the non-Lewin Clinic outpatient clinics and the disclosure is made by the non-Lewin Clinic provider. When a Lewin Clinic patient needs to see another provider in the Wellington system, the Lewin Clinic providers try and prepare the parent about the possibility of this kind of disclosure occurring. Occasionally, these experiences are unpleasant, particularly when the provider abruptly discloses the child’s HIV status to the patient with minimal parental input. For example, a father whose child did not know their HIV status became belligerent when a non-Lewin Clinic provider inadvertently disclosed HIV status to his child.

> Mary Ann: “we actually had an incident in ABC Clinic where we had a patient about 11 or 12 that didn't know, and the, one of the providers in the ABC Clinic did that and the dad just immediately went ballistic, started yelling and screaming, partly because he wanted to totally deflect off of that and draw attention to himself” (Focus Group Transcript, p. 16, ll.38-42).
>
> Dr Gates: “And we pre-prepped them and everything. We had said we don't know if you have discussed this…” (Focus Group Transcript, p. 17, ll. 5-6).

The unplanned disclosure occurs despite some preparation; however, the amount of preparation by the provider does not always prevent unpleasant incidents. The parent’s behavior was an attempt to protect his child; however, his behavior created additional issues for the patient, himself, the Lewin Clinic, and the ABC clinic staff. The lack of awareness about the nuances of HIV status and family privacy about HIV status by non-Lewin Clinic providers can create additional concerns about stigma and privacy for the patient and the family.

Urgent Situations

Urgent situations are disclosure events that occur because of a child's immediate need to know they are HIV positive. The situation is such that disclosure must be made immediately and without hesitation by the provider and/or the parent. In these cases, negotiations tend to be brief, and providers inform parents of the urgent need to disclose. Data analysis revealed that two urgent situations require disclosure. First, the patient is not taking their medication, and the second situation is that the adolescent is sexually active and unaware of their HIV status.

Medication Adherence

Medication adherence was identified in Research Question 1 as a criterion for parents and providers to begin negotiating the disclosure process. If a patient fails to correctly follow the medication regimen, the amount of the HIV/AIDS virus in their body increases, thereby placing their health at risk (Hatfield-Timajchy et al., 2016). When providers receive lab results that indicate a patient is not correctly taking their medicine, it becomes necessary that their HIV status is disclosed to them, so they understand the need for medication. Hope explained,

> I think the other non-typical event, … if we have a teen who really is not taking their meds at all and we're watching the viral load and we basically have to talk to

> the parents like, "We need to do this now" and like this visit is where we have to talk about it because XYZ is happening, they're not taking their meds and they need to understand this…(Focus Group Transcript, p.18, ll. 6-15).

Under these circumstances, negotiations with parents are brief and to the point. Typically, Lewin Clinic providers attempt to prepare parents for the disclosure event; however, when the child's health is at stake, they react quickly.

These quick reactions are noted in patient charts. One provider recorded "Met with patient to discuss HIV/AIDs and need for strict adherence to medication; reviewed transmission methods: blood, sex, breast feeding. Important to use condoms" (Participant # 82). Another patient had serious issues with medication adherence, and the provider wrote in their chart, "substantive medication adherence issues with patient. Provider explained how people die of AIDs. Disease is treatable and patient has to take medication consistently" (Participant # 84). Thus, urgent situations around lack of medication adherence create a heightened sense of immediacy for the provider, and this critical incident may shorten the amount of time the providers generally spend negotiating disclosure of HIV status with parents.

Sexual Behavior

An adolescent's engagement in sexual behavior also was identified in Research Question 1 as a criterion for disclosure by providers and parents, and it constitutes another situation in which immediate disclosure is necessary. Hope explained,

> It's we have to tell them now because we have all these other, or we find out at the visit they're pregnant or they're sexually active or something *[laughs]* and we need to – I mean we've had where they're sexually active and we're like, um, we need to probably have a conversation …(Focus Group Transcript, p. 18, ll. 17-22).

Once a teen discloses to a provider, they are sexually active, that team member brings the information to the rest of the team. They immediately begin discussing disclosure with the parent. Hope further explained,

> Everybody feels comfortable with somebody on the team, so then they might not share it and then we have to come back and say to the team like we need to have a family conversation because they are sexually active and we need to get some condoms and disclosure on board now *[laughs]* (Focus Group Transcript, p.18, ll. 24-27).

In these instances, negotiations with parents, again, are brief, and the teen is informed about their HIV status and given information on how to prevent transmission of the virus.

Providers note these conversations with adolescents in patient charts. One provider recorded, “Patient is sexually active and discussed transmission of virus” (Participant # 73). Providers also remind patients that they must disclose this information to their partners. Another provider noted, “Sexually active; has one girlfriend; discussed disclosure to partners and ability to have children” (Participant # 79). Providers also educate patients about the use of condoms, so the patient feels comfortable discussing the need for and the use of this form of prevention against transmission of the illness. A provider noted, “Discussed condom use with patient and RN” (Participant # 67). Because of the consequences associated with poor medication adherence and sexual activity, urgent circumstances shorten the time for negotiations about disclosure between providers and parents.

Typical

Typical events occur when a Lewin Clinic provider and/or parent disclose patients’ HIV status to them. The negotiations between providers and parents occur over time and are conducted without a sense of urgency or a critical health incident that drives the need to disclose immediately. Throughout the negotiations, providers work continuously with parents to prepare them for the event and help them become comfortable with the amount of knowledge their child will be given about their illness. During the initial disclosure event, the provider explains generally to the patient the complete and full information about their health condition. Depending upon the adolescent's level of readiness, the providers may not include a lot of information about sexual behavior and the need for an adolescent to disclose HIV status to the sexual partner and to protect the partner from infection.

The provider gives the patient in depth knowledge about the diagnosis, general information about transmission of HIV, why medications are necessary and what the lab values mean. Providers prepare parents to respond to additional questions from their child about their illness. Dr. Gates explained,

> when we do the initial disclosure … everything isn't discussed at the first disclosure because it's just too much. It's overwhelming. So I do usually tell them that I'm gonna start talking about this, that, and the other thing, but I usually don't do sexual stuff and things like that in any detail in the first exposure because it's just too much, and then it becomes less of a concern for them at least for the initial disclosure. It's a process, you know? (Focus Group Transcript, p. 8, ll. 10-12).

The process is designed to allow time for an adolescent to adjust to knowing this information about themselves. The process also allows parents to become comfortable with their child knowing about his/her own health condition.

In these cases, providers comment on these discussions in the patient's chart. For example, one provider remarked, "Disclosed status to patient at home by staff. Patient's family was present (mom and sisters). Patient and family were given full disclosure and opportunity to ask questions (Participant # 73). During these events, providers also reinforce with the patient that HIV status is private information now owned by the patient and recommend the adolescent talk with his/her parents before disclosing this information to others. Another provider recorded, "Initial disclosure today. Provider provided information regarding virus and special meds; status is private health information and don't disclose information without talking to parents first" (Participant # 72).

When an adolescent is ready, the second part of the process involves a more in-depth discussion about sexual behavior and HIV status. Dr. Gates explained, "Kids do have to think about sexual stuff. So that has to be discussed at some point…" (Focus Group Transcript, p. 8, ll. 20-22). If a provider or a parent becomes aware that a patient may be starting to date, the provider discloses additional information about HIV status and sexual behavior. A provider noted in a patient chart, "More information regarding virus presented to patient. Discussed safe sex practices and disclosure to partner" (Participant # 73). A typical disclosure conversation also can include a comprehensive discussion of the patient's HIV status. The second disclosure event may include additional in-depth information about the complexity of the illness, the methods of transmission, the need for safe sex practices, and the patient's ability to have children in the future. The provider also reinforces the private nature of the information and that the patient should be aware of the stigma around HIV status. A provider noted in one patient's record,

> Disclosure event today. Provider disclosed HIV status; pathophysiology, transmission, methods: blood, sex, birth, breastfeeding. Safe sex practices discussed; patient can have children. Discussed privacy of health information and this information should be kept private because of ignorance in the community about HIV (Participant # 72).

Thus, providers ensure their patient has complete and full information about their health condition and the patient understands the stigma associated with HIV status and the overall need for keeping his/her HIV status private.

Conclusion

This chapter presented the major findings of the three research questions posed for this study. Research Question 1 identified the criteria that parent and provider use to determine if the adolescent is ready for disclosure about his/her HIV status. The major finding for Research Question 1 revealed that parents and providers are aware of the negative attitudes around HIV status that exist in their families and their communities, and this stigma is a backdrop against which the disclosure decisions are made. Providers and parents agree that these factors necessitate disclosure of HIV status: medication adherence, an adolescent’s dating and sexual behavior, an adolescent’s question asking, an adolescent’s cognitive issues and the child needs to know their status. Providers and parents also differ in the criteria they use to determine whether an adolescent is ready for disclosure. Providers consider what they know about the family’s daily living situation and the age of the adolescent when deciding whether to disclose. Parents, on the other hand, consider relationship they and their child may have with other people now and in the future as they determine whether the adolescent is ready for disclosure. These criteria, both shared and independent, are used by providers and parents as they begin the conversation about when, where, and how the disclosure will take place.

Research Question 2 addresses the communicative strategies used by providers and parents to negotiate opening the privacy boundary around HIV status. The trust built by parents and providers in their relationship is the foundation upon which the negotiations begin. Throughout their interactions with parents, provider's perceptions of a family's privacy orientations about HIV status influence their approach to the parents about disclosing HIV status. Providers engage parents by asking thoughtful, open-ended questions to involve them in the process of planning the disclosure event. Once approached, parents may respond emotionally to the idea of disclosure. When this occurs, providers react to the parents' anxieties and fears by gently probing the underlying reasons for their emotional reactions. In turn, parents may react by asking in-depth questions about the disclosure process. Throughout, providers support parents as they process the idea of disclosing HIV status.

Parents then must decide about disclosure. Some parents readily agree to disclosure while others decide that disclosure is appropriate and feel empowered to initiate the disclosure process themselves. Parents also disagree with the provider over disclosing HIV status because they feel their child is not yet ready for disclosure due to age or cognitive issues. Parents disagree by refusing to disclose or engaging in delay tactics to stall the disclosure process as well. Providers use ultimatums with some parents to signal that the child will learn of their HIV status at age 15 regardless of parents' disagreement with the need to disclose.

Finally, Research Question 3 examined the conditions under which the negotiations between providers and parents around disclosing HIV status are conducted. The first condition, Non-Typical, involves inadvertent disclosures by non-Lewin Clinic staff to the patient and other people. Parents may not be prepared for the disclosure event, and, therefore, may have a negative behavioral reaction to the disclosure. The Non-Typical condition can also affect the relationship between Lewin Clinic staff and providers in other parts of the Wellington Hospital system. The second condition, Urgent Situation, occurs when a critical health situation driven by the adolescent's behavior requires immediately disclosing the patient's status. Two urgent situations exist: when a teen is not correctly taking their medication and when a teen is engaging in sexual activity. The final condition, Typical, represents the general disclosure process utilized by the Lewin Clinic providers when disclosing HIV status to an adolescent. In these cases, they have negotiated with parents and agreed to when and how disclosure will occur. This process allows time for parents to become comfortable with the idea of disclosure and that the child is now becoming a responsible owner of their own health information. The Typical condition allows for the provider to support the parent during the negotiation process. The Typical condition also allows an adolescent to absorb the new information about their health condition and ask questions about their illness.

The results of this study present a complicated case of boundary coordination and management by one of the dyads in the pediatric health care relationship. In the chapter to follow, the theoretical implications of these results can help explain the process of how an adolescent child becomes a responsible owner of the information about stigmatizing health condition. When parents and providers decide to open the privacy boundary around a child’s HIV status, their decision is influenced by the shared and independent criteria they have identified. The negotiations conducted by parents and providers are in response to one of the conditions that hasten or delay disclosure in the need to inform a child of their HIV status. The implicit privacy rules around the secret of HIV and the disclosure conditions drive the privacy boundary management process in this triadic healthcare relationship.

CHAPTER 5

DISCUSSION

Introduction

This study sought to examine how providers and parents manage, coordinate, and determine when and how to open the privacy boundaries around a child's HIV status within a pediatric healthcare relationship. Disclosing HIV status to an adolescent within this context is an example of the complexities associated with managing and coordinating privacy boundaries around co-owned stigmatizing information within a healthcare relationship. The results of this study illustrate the process used by providers and parents as they maneuver through the necessary boundary management operations to determine ownership status, linkage, and permeability around disclosing pediatric HIV status. These boundary management operations lie at the core of the disclosure process.

Providers and parents use criteria specific to the context of a pediatric healthcare relationship to determine whether the adolescent is ready to become a co-owner and co-confidant of the information about their HIV status. The results indicate that emergent situations regarding medication adherence and adolescent risky behavior act as catalysts for the disclosure of HIV status. The results of this study also illustrate the challenges faced by adults who co-own stigmatizing information about a third person and the difficulties of negotiating the disclosure process when a parent resists the idea of informing their child about their own health condition. Providers and parents have similar concerns about the timing and the amount of information to be disclosed, yet they also hold differing views about adolescent’s age at disclosure and when others should know about the child’s HIV status.

Negotiating Decision Criteria

The results from this study illustrate how the three major components of Communication Privacy Management theory, privacy ownership, privacy control and boundary turbulence, (Petronio, 2013) operate within the context of a pediatric healthcare relationship. The first component, privacy ownership, theorizes that people own and control their private information (Petronio, 2013). Providers and parents co-own the information around a child’s HIV status. The second component, privacy control, discusses how the co-owners control access to the information and how they modify their privacy rules to add additional “authorized co-owners” by granting them access to the private information (Petronio, 2013, p. 9). When the time arrives to determine if the child is ready to become a responsible co-owner and confidant, the provider-parent dyad discusses how they will change their core privacy rule to allow the adolescent access to their boundary around the private information of HIV status. This determination is made using decision criteria for ownership of the information around HIV status. The results of this study suggest that within the context of a pediatric healthcare relationship, providers and parents use a set of shared decision criteria as well as individual decision criteria, to determine if the child is ready to become a co-owner and co-confidant of the information about their own and their parent’s HIV status.

Shared Decision Criteria for Ownership

The theme Adolescent Readiness represents the behavioral indicators and contextual criteria providers and parents use to determine when an adolescent is ready for disclosure of their HIV status. The analysis revealed that providers and parents both agree that the child's behavior, cognitive maturity, independent ability to adhere to the medication regimen, and an interest in dating are indicators that the child can and should be informed. As stakeholders in the healthcare relationship, the providers and parents share common goals in ensuring the child's healthcare needs are met, and both parties believe the child needs to know their HIV status (Petronio & Reierson, 2009; Greene, et al., 2003). Two indicators, a child's question asking behavior and cognitive maturity, represent the individual child's readiness for disclosure. A child's questions to providers and/or parents indicate to each party that the child may be ready for more in-depth information about their health condition. Providers and parents also share the criterion that cognitive maturity in a child must exist before disclosure is warranted. This criterion may reflect a child's development in understanding more abstract information, or the level of cognitive maturity may reflect the child's understanding of the need to exercise discretion around disclosing their health condition to others.

Another behavioral indicator that providers and parents share is medication adherence. The analysis revealed that a teen's non-adherence to the medication regimen for HIV is an indicator for disclosure. Providers and parents, as stakeholders, become concerned when they discover that the child is not properly taking their medication for their illness (Petronio & Reierson, 2009). This behavior by a child may indicate they are not verbalizing their questions regarding the rationale for taking the medication and may be jeopardizing their health by failing to properly take their medication. This non-verbal behavior by a child is an indirect signal by a child to indicate they need additional information as to why the medication is necessary for their good health.

Finally, the analysis reveals that providers and parents agree that a child's interests in dating are an indicator the child may be ready for more information. This indicator signals to providers and parents that the adolescent needs to understand when it is appropriate to disclose their condition to romantic and sexual partners (Greene et al., 2003). The providers and parents also share an interest in protecting others. They share a concern that the child fully understands the health and relational rationale behind the disclosure of their health condition to others before initiating a sexual relationship. The providers and parents also believe the child must understand how HIV/AIDS is transmitted and how to protect other people.

Separate Decision Criteria for Ownership

Providers and parents each have a set of separate criteria related to privacy ownership that they use to determine when a child is ready for disclosure of HIV status. Providers use chronological age and family issues as separate criteria to determine if the child is ready to become a co-owner of their HIV status. For example, the data analysis revealed that providers in this clinic disclose HIV status most frequently when a child is between 13 and 15 years old. These ages represent the stages of adolescent development in which a child's cognitive maturity and physical and emotional development allow them to understand information related to their health. Furthermore, at these ages, the child is able to understand the idea of discretion and possesses deeper understanding of how to determine when to disclose private information within the context of a romantic relationship. The providers also set age 15 years as an artificial limit for disclosure because adolescents often begin dating and sexual relationships around this age.

Providers also consider two family issues: the family's life situation and the family relationships. First, providers are aware of how the overall life situation of the family may impact the timing of the disclosure. Families who live with HIV/AIDS face externalized HIV stigma from their extended families and communities (Abdulrahman et al., 2017; Kalichman et al., 2017). Also, many families living with HIV/AIDS reside in high-risk communities where they face poverty, criminal behavior, addiction and other stressors that make daily life unpredictable (Lichtenstein et al., 2010). An additional stressor for a family living with HIV/AIDS is immigration status (Abdulrahman et al., 2017). Immigrants face challenges learning the customs and processes of many systems in their new country, including health care services, and they face greater challenges in terms of employment, transportation, food security, language acquisition, and education (Abdulrahman et al., 2017). Moreover, immigrants bring their cultural values and beliefs about health care to their new country; these values guide the parent's decision-making and thought process around disclosure of HIV status, which can conflict with the providers' decisions and desires to disclose adolescent patients' HIV status (Wyatt et al, 2012). Immigrants also bring cultural values around who within the family should know a person's health information (Wyatt et al, 2012). When determining the timing for disclosure, providers try to be cognizant and sensitive to these issues in their patient population and attempt to balance their desire to reveal HIV status against the family's daily life circumstances (Brackis-Cott et al, 2003).

Finally, providers are aware of the relationships the child has with other family members. Providers consider the family structure and cultural background when they consider disclosure. The analysis reveals that the providers think about the child and the number of siblings the child has within the family. Siblings may not be old enough to understand the child's illness or may also have perinatally acquired HIV but are not mature enough to understand the disease. In addition, providers are concerned about how disclosure may affect the quality of sibling relationships. Providers also consider what they know about the family's cultural background as it relates to who within the family may know about the child's health condition. Parenting roles within a family are structured around cultural beliefs and values related to gender roles within a family (Hong, 2017). The relationship between the child and their parents and siblings may impact the timing of the disclosure event and when the boundary opens.

The parent's stake in the relationship with the provider is twofold in that they want to ensure their child receives healthcare services to meet their needs, but the parent also has a stake in the social world of the family. Parents consider who else outside of the family may learn of the child's HIV status once the information is disclosed to their child. The analysis reveals that parents consider their child's future relational partners, such as spouses and employers, when considering whether a child is ready to receive full disclosure of their health condition. The parent must be able to trust their child to maintain the privacy rules around their HIV status. Inherent in the parent's trust is the notion that the child has the discretion to know when to disclose this stigmatizing information to others as this information may subject the child and/or the family to externalized stigma within the larger family group and community.

Thus, in this study, the theoretical construct of privacy control, a major component of Communication Privacy Management theory (Petronio, 2013), is demonstrated by the decision criteria providers and parents use to change a core privacy rule for boundary management around their co-owned information about HIV status. The decision criteria reflect the changes in the adolescent's behavior that providers and parents use to consider when adding the adolescent as a co-owner to the privacy boundary around HIV status. The shared criteria reflect the interests each stakeholder has within the pediatric healthcare relationship. Each stakeholder has separate interests that also influence their decision to add the adolescent as a responsible co-owner. After identifying the behavioral indicators that signal the time is ripe for the child to assume the responsibilities of ownership, the providers and parents negotiate the timing and permeability of informing the adolescent and allowing access to their co-owned private information.

Negotiating Disclosure: Dialectical Tensions, Permeability, and Resistance

Privacy control also involves negotiating changes to the core privacy rules that guide access to private information about HIV status shared by providers and parents throughout their relationship (Petronio & Reierson, 2009; Petronio, 2013). The analysis revealed that during their relationship, providers and parents develop trust in one another to manage the boundary around their co-owned information, and they are free to express their concerns and feelings during the negotiations. In this study, parents' emotional responses ranged from complete acceptance that the time was appropriate for disclosure to parents expressing high levels of anxiety and fear over the disclosure of HIV status. Parents expressed deep concern that their child may be facing externalized stigma and/or that the relationship between them and their child would be damaged. Providers recognize that high levels of anxiety and fear are common, and they work to help the parent reduce their anxiety and fear over disclosing HIV status to the adolescent.

In this study, the major issue for parents in the disclosure process is the provider's ability to balance the dialectical tensions in strictly keeping confidential the HIV status of the biological mother while revealing to the child only the information about the child's HIV status. Confidentiality of information that is disclosed to a healthcare provider is a major tenet of provider-patient communication (Petronio et al., 2012). Furthermore, confidentiality is co-ownership of a secret (Petronio & Reierson, 2009). The trust the parent has in the provider indicates that the provider has met the parent's expectations as a responsible confidant by keeping the mother's HIV status a secret from the child (Petronio & Reierson, 2009). The disclosure of perinatally acquired HIV status represents the dialectical tensions between a provider's ethical obligations to inform their patient of their health condition and the trust the provider has earned from the parent by keeping confidential the biological mother's HIV status. Thus, when the time for disclosure must occur, one factor that influences the parent's responses is the amount of trust they have in the provider.

Permeability

A provider’s perceptions of the permeability of the family’s privacy boundaries also are critical to understanding how the provider and parent balance the dialectical tension around revealing HIV status. As stakeholders, providers and parents co-own the HIV status information (Petronio & Sweeney-Lewis, 2011); however, parents and families create privacy rules around the family group’s information that the physician may not identify (Duggan & Petronio, 2009). Study results show that the provider’s awareness of family privacy boundaries can affect how the parent reacts to the idea of disclosure. A provider’s perceptions about the family’s willingness to discuss HIV issues within one another gives the provider a sense of the family’s privacy boundaries around HIV status.

Parents who maintain an open boundary around HIV status may feel they do not need to protect the information about the adolescent’s HIV status from other family members and do not feel challenged by the disclosure process (Petronio & Sweeney-Lewis, 2011). Parents who maintain a closed internal family privacy boundary around HIV status information likely feel their ability to protect of family privacy rules and boundary around the adolescent’s health is being challenged (Petronio & Sweeney-Lewis, 2011). When providers understand parents have open boundaries around HIV status, the negotiation process is more efficient. Conversely, when providers encounter parents who have closed boundaries and feel threatened by the disclosure process, they may not be able to navigate the negotiation process effectively. Providers recognize that parents are afraid of the changes to the family’s privacy rules and boundaries that disclosure of status may bring, and they understand parents are afraid of the externalized stigma they may face in their families and communities should the information about HIV status be revealed (Kalichman et al., 2017).

Parents who maintain an open internal family privacy boundary engage the provider in two ways. First, they may agree without question to the provider's request for disclosure. Second, in this study, parents who maintain open internal family privacy rules around HIV status asked open-ended questions of the provider to understand the disclosure process. These parents have a privacy rule around HIV status that permits access to the information and are willing to discuss HIV status within the family group. The parents whose internal family privacy rules around HIV status are accessible may not feel challenged by the disclosure of HIV status or by who outside the family may know this information. The family privacy rule is more open, and the parent is accepting of the disclosure process. Thus, parents may feel more comfortable with the disclosure process.

This study also suggests that parents whose family privacy boundaries are open may initiate disclosure of the child's HIV status to them. As the original owner of the child's HIV status and guardian of the child, the parent has the right to share this information with the child when they believe the child is ready to hear this information (Petronio & Sweeney-Lewis, 2011). The study also suggests that parents who maintain an open family privacy boundary around HIV status see the provider as an equal partner in the pediatric healthcare relationship; however, the parent retains decision-making authority around disclosure (Petronio & Sweeney-Lewis, 2011). After the parent's discussion with the provider about the disclosure event, the parent may feel empowered to conduct the disclosure event themselves, and if the child has additional medical related questions, the provider may answer those questions at the next appointment.

Resistance and Delay

Finally, confusion over the ownership of the HIV status information and who has the responsibility to inform a child of their status can result in parents' resistance to disclosure or use of delay tactics. Providers and parents co-own a child's health information; however, a power struggle can occur when the provider is unaware of the parents' need to own and control the health information (Petronio & Sweeney-Lewis, 2011). Parents who overtly deny the provider the permission to disclose the child's HIV status are exercising direct control over access to the information about HIV status. These parents often are explicit in their refusal to disclose. They see disclosure of HIV status as part of their role as the decision-maker and guardian for the child, and the parent may feel the right to own the information around HIV status and that it is solely within their control and discretion (Petronio & Reierson, 2009). This tactic is used as a protective strategy by the parent for the family's internal privacy boundary around HIV status (Petronio & Sweeney-Lewis, 2011).

Delay tactics used by parents to avoid disclosure may be a form of protecting their child from knowledge about their (Petronio & Sweeney-Lewis, 2011). Parents whose internal family privacy boundaries are closed may engage in delay tactics to further restrict access to the family's private information (Petronio & Sargent, 2011). This resistance may be the parent's way of avoiding the topic of disclosure with the provider to protect themselves from having to discuss the taboo topic of HIV status with their child. By engaging in delay tactics, the parent controls the timing of the disclosure; however, the use of delay tactics creates a disclosure dilemma for providers.

These behaviors create a predicament for the provider; they must choose to comply with parents' requests or to assert ownership rights over the information around HIV status (Petronio & Reierson, 2009). Because of their ethical obligations and duty to fully inform patients about their illness (Duggan & Petronio, 2009), providers may issue an ultimatum to resolve the disclosure impasse. The ultimatum may impact the quality of the relationship between providers and parents as parents may feel their rights as a stakeholder in the relationship have been violated (Petronio & Reierson, 2009; Petronio, 2002).

Catalysts

Petronio (2010) defines a catalyst as a critical incident that necessitates the disclosure of private information for the health and safety of the adolescent and/or others. The theme of Urgent Situations represents the catalysts that spur opening the provider-parent dyadic privacy boundary around the information about the child's HIV status. These situations occur when an adolescent is engaging in behavior that could cause harm to themselves or others, such as not adhering to the medication protocol and engaging in sexual behavior. A teen's non-adherence to the medication regimen can cause the virus to begin replicating rapidly, and reducing the increased viral load becomes a difficult clinical issue for the provider to manage (Hatfield-Timajchy et al., 2016). Providers must quickly exercise their duty to inform their patient to avoid imminent harm to the adolescent's health. In these cases, providers approach parents about disclosing the adolescents' status immediately to fully inform the adolescent about the need for the medication and the requirement that the medication be taken correctly, and negotiations most often are brief as parents recognize the potentially sever consequences their children face.

The second catalyst occurs when providers or parents become aware of the adolescent's engagement in sexual behavior. To prevent transmission of the virus, an adolescent must be fully informed about their status, so this critical situation prompts providers and parents to negotiate quickly regarding status disclosure. Once aware of the behavior, providers work with adolescents to ensure they understand how to care for themselves and their partners to prevent transmission. The catalysts create situations where privacy rules and boundaries may be quickly re-negotiated and implemented to ensure the health of the adolescent and that other people are protected (Petronio, 2010; Greene, et al., 2003). Thus, two urgent situations act as motivators for providers and parents to negotiate opening and linking the adolescent to the privacy boundary around their HIV status.

Triadic Boundary Management and Turbulence

The typical condition represents the general process used by the Lewin Clinic to give the adolescent co-ownership of their HIV status; link the child to the dyadic privacy boundary shared by the provider and parent around the adolescent's HIV status, and to open the boundary enough to allow the adolescent to fully understand and potentially share with the other two co-owners, provider and parent, the information about their HIV status. The catalysts require immediate opening of the provide-parent dyadic privacy boundary around the child’s HIV status due to situations that cause harm to the adolescent or potentially harm other people. In the typical condition, when the provider-parent dyad opens the dyadic privacy boundary around the adolescent’s HIV status, the dyad then becomes a triad. The triad now co-owns and manages a triadic boundary around the child’s HIV status. Until the disclosure event occurs, the provider -parent dyadic privacy boundary around the adolescent’s HIV status remains, and the provider and the parent manage the privacy boundary.

The theme of Non-Typical Condition represents the challenges of a parent in managing a complex privacy boundary within a pediatric healthcare setting. The difficult encounters occur when the parent-child dyad interacts with pediatric healthcare providers outside of the Lewin Clinic. These well-meaning providers may not understand the nuances of and implicit privacy rules for managing a complex privacy boundary around the information about the child’s HIV status. The parent assumes that the non-Lewin Clinic provider will treat the information about the child’s HIV status in the same manner as the providers at the Lewin Clinic. Instead, the parent may find the non-Lewin Clinic provider unaware that the child’s HIV status should be discussed openly in their appointment.

Boundary turbulence occurs when “the expectations of an original owner had for the way his or her private information would be treated becomes compromised” (Petronio & Reierson, 2009, p. 376). Turbulence also is introduced when providers who are not part of the Lewin Clinic disrupt privacy boundaries by discussing the child’s HIV status in front of the child without the parents’ consent. This situation arises when a non-Lewin clinic provider is unaware of the privacy boundary around the child's HIV status (Petronio & Reierson, 2009). Non-Lewin clinic providers maintain confidentiality of patient information as required by law; however, they may expect to be able to discuss all the child's medical conditions with the parent and the child together. Because Lewin Clinic providers and parents have long-standing arrangements about the privacy rules around the child's HIV status, parents may feel all providers should be aware of the privacy rule regarding the child's HIV status and are upset that the non-Lewin Clinic provider do not.

These mismatched expectations cause a breach in the triadic boundary when the parent becomes upset with the non-Lewin Clinic provider and complains to the Lewin Clinic provider about the other provider's failure to maintain the parent's expectations about the privacy boundary around HIV status.

Theoretical Contributions

This study contributes to the literature around Communication Privacy Management theory (Petronio, 2013) and to the literature around the disclosure of pediatric HIV status. First, this study suggests that the pediatric health care relationship is a triadic one in which the parent as a decision-maker and guardian of the child, acts as a proxy for the young child when communicating with the provider. This study explores how one dyad, provider-parent, within the triad manage and coordinate privacy boundaries around a stigmatizing chronic health condition. The relationship between the provider and parent is built on trust and is a long-term relationship, and this study extends the knowledge about Privacy Control and Privacy Ownership (Petronio, 2013) as it applies to a long-term triadic healthcare relationship among providers, parents, and pediatric patients.

Second, this study adds to the literature on how Communication Privacy Management theory (Petronio, 2013) operates within the health care context. The study investigates how providers and parents as stakeholders in their relationship carefully consider how to inform a child of their HIV status. This study expands the notion that providers play two roles within the pediatric relationship: deliberate confidant and stakeholder, in their relationship with the patient and their family (Petronio, 2002). Parents also play two roles within the pediatric relationship: guardian and decision-maker of the child's health care needs (Petronio & Reierson, 2009). Each party represents their interest in ensuring a child with a stigmatizing health care condition receives proper medical care and develops into a responsible adult.

Finally, the findings from this study can be used to develop a clinical tool to aid providers in managing the disclosure process. Prior research into this area has been focused on disclosure processes used by nursing staff (Gerson et al., 2001), the impact of informing the children of HIV positive parents (Tenzek et al., 2013; Wiener et al., 2007), and the psychological impact of informing HIV positive children of their diagnosis (Mellins et al., 2002). This study lays the groundwork for the development of a clinical tool that can be used by providers to initiate the difficult discussion with parents of when to disclose HIV status.

Practical Implications

An important practical implication of this study is that it provides pediatric healthcare workers with a clear presentation of typical roadblocks that occur as they negotiate the HIV-disclosure process with parents. This awareness would be especially beneficial for new providers, though even experienced providers likely would find it useful to understand the role that privacy rules play in disclosure negotiations. An additional, and related, practical implication is that the study lays the groundwork for the development of a clinical too that providers can use to start the conversation around disclosure with parents before their children enter puberty. The clinical tool could be used to facilitate conversations with parents and serve as a place to record specifics in the typical disclosure situation. As the child enters adolescence, the providers could use the tool to educate parents about the physical, social, and emotional challenges adolescents face as they grow to maturity; how the relationship within the parent-child dyad changes over the course of adolescence, and how parents can help their adolescent create their own privacy rules for disclosing status.

One behavior parents of HIV-positive children may notice is the repeated questions their child may ask about their need to take medication or see the healthcare provider. The parent education tool can suggest responses to the child’s questions and offer techniques for deflecting a child’s questions until a discussion with the provider can occur. Similarly, the tool could offer parents advice on how to teach the child about their medications and how to handle confrontations with their adolescent over medication adherence or other issues around healthcare.

Another portion of the parent education tool could advise parents how to communicate with their children about HIV status, sex, and romantic relationships. This topic is an awkward one for many parents, and the tool could suggest strategies for facilitating a dialogue with their teen around disclosure to partners and safe sex, thereby helping the adolescent to become responsible to future relational partners (Coffelt & Olson, 2014; Greene et al., 2003). The development of a non-threatening communication context by the parent also may allow the adolescent to be more forthcoming about concerns they have about their own experiences.

In families where the privacy boundary around HIV status is very thick, the tool could be used to help parents become more comfortable with the inevitability of disclosing HIV status to their child. Providers already ask parents about their level of anxiety when they raise the issue of disclosure. Activities can be developed to become less anxious about disclosure, such as asking them to reflect and write about their fears related to disclosure. The provider can then discuss these answers with the parents, which could facilitate their agreement to disclose to the adolescent.

In sum, based on this study's findings, a clinical tool can be developed that providers can use to help parents become comfortable with disclosure and their child's maturation to adulthood. This clinical tool also can help parents become comfortable talking about and accepting the idea that disclosure will occur and that their child will be responsible for maintaining personal and family privacy boundaries around HIV status.

Limitations

There are three limitations in this study. First, the final phase of the data collection protocol produced a small number of interview participants. The overall number of patients (N = 42) who were eligible for this study was robust; however, Phase 3 of the data collection protocol produced only two parent interviews out of 11 parents who had agreed to an interview. One possible reason for a small turnout is that parents were reluctant to discuss their private health information with someone they did not know very well. Despite all the necessary consent forms and the assurances that their identity would be concealed, the prospect of discussing stigmatizing information about one's child and family may have left participants feeling very vulnerable. Thus, the thick privacy boundaries parents maintain around a stigmatizing illness of a family member and/or themselves may have contributed to the small number of parents participating in the Phase 3 interviews.

The second limitation to the study is that data and results are taken from the experiences of only six providers and two parents in one clinic. In addition, the study lacks the participation of adolescent patients. Adolescents over the age of 18 could consent to the interview, but patients under the age of 18 must have the consent of their parent as well as their own assent. Given the boundary issues that exist, securing consent is likely to be difficult. The data generally demonstrate the process this clinic uses; however, without interviews from adolescent patients about disclosure, the description of the disclosure process is incomplete.

The third limitation is the lack of cultural and gender diversity among the providers who participated in this study. This sample contained a homogeneous group of Caucasian women who have been practicing medicine for many years. To gain a complete picture of how providers view and handle disclosure events, a broader sample that includes non-Caucasian male and female providers would provide a more diverse perspective of the overall disclosure process. Finally, providers who are early in their medical careers would add additional perspectives and data regarding how they view and experience negotiations with parents.

Future Directions

Future directions for this research lie in a deeper exploration of the motivators for disclosure. First, a larger number of diverse providers, parents and patients would allow for an in-depth investigation of the cultural values and beliefs that different groups and communities hold about privacy around health and illness. These values and beliefs held by a culture shape expectations regarding who within the family and the community should know about the illness and who should handle communications with the doctors and within the family about illness (Ngula & Miller, 2010). This line of research would reveal how privacy boundaries work in relationships with parents whose cultural beliefs or values about disclosing HIV/AIDS to their children are oriented towards a thick privacy boundary. This understanding may result in a different way to approach parents when the time for disclosure is near.

Future scholars should also consider a deeper investigation of how privacy orientations around specific chronic health conditions operate within the families with different communication patterns (Koerner & Fitzpatrick, 2002). Further research also could profitably include the development of practical trainings for providers by scholars in family, health, and intercultural communication around approaching and listening to families and patients whose cultural backgrounds differ from themselves. Additional research into health communication and families may also bring about a fuller explanation of how members of the family reveal or conceal information about chronic illnesses to others family members. Finally, more research into the perspective of perinatally acquired HIV-positive adolescents about disclosure and the development of their privacy access rules and boundary coordination--within both face to face and computer mediated relationships--would be of value. Answers to these questions would add to the literature in the areas of communication privacy theory, health, family, and intercultural communication.

Conclusion

This study proposes that a pediatric healthcare relationship is a triad of provider-parent-patient relationship. Within the triad are three dyads, and this study examined the way in which the provider-parent dyad creates privacy access rules to coordinate and manage the privacy boundary around both the mother’s HIV status and the child’s HIV status. This study examined the motivations of both providers and parents for opening the privacy boundary around the child’s HIV status and explored how provider-parent dyads negotiate the disclosure event.

The results of this study support three conditions under which disclosure of HIV status occurs. The typical condition is an evolving negotiated change to the privacy access rule used by providers and parents. The Urgent condition is driven by two behavioral catalysts, medication non-adherence and the adolescent's engagement in sexual behavior. The study also identified non-typical disclosure conditions in which non-Lewin Clinic providers create boundary ambiguity and turbulence when they discuss the child's HIV status with the child who does not know their status. These conditions present one clinic's process for disclosure. Future work should concentrate on delving deeper into the disclosure process for fully informing adolescents of their chronic illness and helping them to mature to be self-reliant, independent health adults.

REFERENCES

Afifi, T. D., Olson, L. N., & Armstrong, C. (2005). The chilling effect and family secrets: Examining the role of self-protection, other protection, and communication efficacy. Human Communication Research, 31(4), 564-598.

Altman, I., Vinsel, A., & Brown, B. B. (1981). Dialectical conceptions in social psychology: An application to social penetration and privacy regulation. In Advances in experimental social psychology (Vol. 14). Academic Press, Inc.

American Academy of Pediatrics. (2013). Policy statement: Transitioning HIV-infected youth into adult health care. American Academy of Pediatrics, & Health, C. o. C. a. A. (1988). Age limits of pediatrics. Pediatrics, 81(5), 736.

Brackis-Cott, E., Mellins, C. A., Abrams, E., Reval, T., & Dolezal, C. (2003). Pediatric HIV medication adherence: The views of medical providers from two primary care programs. *Journal of Pediatric Health*, *17*, 252-260. https://doi.org/10.1067/mph.2003.13

Bute, J. J., Petronio, S., & Torke, A. M. (2015). Surrogate decision makers and proxy ownership: Challenges of privacy management in health care decision making. Health Communication, 30, 799-809. https://doi.org/10.1080/10410236.2014.900528

Butler, A. M., Williams, P. L., Howland, L. C., Storm, D., Hutton, N., & Seage, I., G.R. (2009). Impact of disclosure of HIV infections on health-related quality of life among children and adolescents with HIV infection. Pediatrics, 123, 935-943. https://doi.org/10.1542/peds.2008-1290

Calabrese, S. A., Martin, S., Wolters, P. L., Toledo-Tamula, M. A., Brennan, T. L., & Wood, L. V. (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. AIDS Care, 24(9), 1092- 1096.

Catona, D., Greene, K., & Magsamen-Conrad, K. (2015). Perceived benefits and drawbacks of disclosure practices: An analysis of PLWHAs' strategies for disclosing HIV status. Journal of Health Communication: International Perspectives.

Catona, D., Greene, K., Magsamen-Conrad, K., & Carpenter, A. (2016). Perceived and experienced stigma among people living with HIV: examining the role of prior stigmatization on reasons for and against disclosures. Journal of Applied Communication Research, 44(2), 136-155.

Chambers, L. A., Ruenda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., Rourke, S. B., & team, t. S. R. (2015). Stigma, HIV and health: a qualitative synthesis. BMC Public Health, 15(848), 1-17.

Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatizing identity. Psychological Bulletin, 136(2), 236-256.

Coffelt, T. A., & Olson, N. L. (2014). No more birds and bees: A process approach to parent-child communication. Annals of the International Communication Association, 38(1), 207-240. https://doi.org/10.1080/23808985.2014.11679163

Control, C. f. D. (2018). HIV among pregnant women, children and infants. Retrieved from http://www.cdc.gov/hiv

Control, C. f. D. (2019). HIV Treatment Fact Sheet. Retrieved October 14, 2019 from http://www.cdc.gov

Damm, L., Leiss, U., Habeler, U., & Ehrich, J. (2015). Improving care through better communication: Continuing the debate. The Journal of Pediatrics, 167(2), 501-502.e502. https://doi.org/http://dx.doi/101016/jpeds.2015.05.040

Darlington, C. K., & Hutson, S. P. (2017). Understanding HIV-related stigma among women in the Southern United States:A literature review. AIDS Behavior, 21, 12-26.

Derlenga, V., Winstead, B., Greene, K., Serovich, J., & Elwood, W. N. (2004). Reasons for HIV disclosure/nondisclosure in close relationships: Testing a model of HIV-disclosure decision making. Journal of Clinical and Social Psychology, 23(6), 747-767.

Derlenga, V. J. (1987). Self-disclosure: Inside or outside the mainstream of social psychological research. Journal of Social Behavior and Personality, 3, 27-34. (2007 ProQuest)

Duggan, A., & Petronio, S. (2009). When your child is in crisis: Navigating medical needs with issues of privacy management. In T. J. Socha & G. H. Stamp (Eds.), Parents and children communicating with society: Managing relationships outside the home. Routledge.

Ebersole, D., & Hernandez, R. (2016). "Taking good care of our health": Parent-adolescent perceptions of boundary management about health information. Communication Quarterly, 64(5), 573-595.

Garvie, P. A. (2017). Transitioning youth with HIV to adult HIV care: Bridging the gap with adult care clinics for the life span. Society for Adolescent Health and Medicine, 61, 407-408. https://doi.org/http://dx.doi.org/10.1016/j.jadohealth.2017.07.13

Gerson, A. C., Joyner, M., Fosarelli, P., Butz. A., Wissow, L., Lee, S., Marks, P., & Hutton, N. (2001). Disclosure of HIV diagnosis to children: When, where, why and how. Journal of Pediatric Health Care, 15, 161-167. https://doi.org/10.1067/mph.2001.114835

Greene, K., Carpenter, A., Catona, D., & Magsamen-Conrad, K. (2013). The brief disclosure intervention (BDI): facilitating African-Americans disclosure of HIV. Journal of Communication, 63, 138-158.

Greene, K., Derlega, V. J., Yep, G. A., & Petronio, S. (2003). Privacy and disclosure of HIV in interpersonal relationships: A source book for researchers and practitioners. Lawrence Erlbaum Associates.

Greene, K., & Faulkner, S. L. (2002). Expected versus actual responses to disclosure in relationships of HIV positive African American adolescent females. Communication Studies, 53(4), 297-317.

Grover, G. (2014). Talking with parents. In C. D. Berkowitz (Ed.), Berkowitz's pediatrics: A primary care approach (5th ed., pp. 19-23). American Academy of Pediatrics.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). Applied thematic analysis. Sage Publications, Inc.

Haskell, H., Mannix, M. E., James, J. T., & Mayer, D. (2012). Parents and families as partners in the care of pediatric cardiology patients. Progress in Pediatric Cardiology, 33, 67-72. https://doi.org/10.1016/j.ppedcard.2011.12.011

Hatfield-Timajchy, K., Brown, J. L., Haddad, L. B., Chakraborty, R., & Kourtis, A. P. (2016). Parenting among adolescents and young adults with Human Immunodeficiency Virus infection in the United States: Challenges, unmet needs and opportunity. AIDS Patient Care and STDs, 30(7), 315-323.

Hawk, S. T., Keisjers, L., Hale, W. W., & Meeus, W. (2009). Mind your own business! Longitudinal realtions between perceived privacy invasion and adolescent-parent conflict. Journal of Family Psychology, 23(4), 511-520.

Helms, C. B., Turan, J. M., Atkins, G., Kempf, M.-C., Clay, O. J., Raper, J. L., Mugavero, M. J., & Turan, B. (2017). Interpersonal mechanisms contributing to the association between HIV-related internalized stigma and medication adherence. Aids Behavior, 21, 238-247. https://doi.org/10.1007/s10461-016-1320-2

Herrman, A. R., & Tenzek, K. E. (2017). Communication Privacy Management: A Thematic Analysis of Revealing and Concealing Eating Disorders in an Online Community. Qualitative Research Reports in Communication, 18(1), 54-63. https://doi.org/10.1080/17459435.2017.1294617

Hong, S. J. (2018). Gendered cultural identities: The influences of family and privacy boundaries, subjective norms, and stigma beliefs on family health history communication. *Health Communication*, *33*(8), 927-938. https://doi.org/10.1080/10410236.2017.1322480

Kalichman, S., Katner, H., Banas, E., & Kalichman, M. (2017). Population density and AIDS related stigma in large-urban, small-urban, and rural communities of the Southeastern USA. Prevention Science, 1-9.

Kamberelis, G., Dimitriadis, G., & Welker, A. (2018). Focus group research and/in figured worlds. In N. K. Denzin & Y. S. Lincoln (Eds.), The SAGE handbook of qualitative research (5th ed., pp. 692-716). Sage Publications, Inc.

Keating, D. M., Russell, J. C., Cornacchione, J., & Smith, S. W. (2013). Family communication patterns and difficult family conversations. Journal of Applied Communication Research, 41(2), 160-180.

Kelly, A. E., & McKillop, K. J. (1996). Consequences of revealing personal secrets. Psychological Bulletin, 120(3), 450-465. Kennedy-Lightsey, C. D., & Frisby, B. N. (2016). Parental privacy invasion, family communication patterns, and perceived ownership of private information. Communication Reports, 29(2), 75-86.

Koerner, A. F., & Fitzpatrick, M. A. (2002). Toward a theory of family communication. Communication Theory, 12(1), 70-91. Levetown, M. (2008). Communicating with children and families: From everyday interactions to skill in conveying distressing information. Pediatrics, 121(5), e1441- e1460. https://doi.org/10.1542/peds.2008-0565

Lewis, C. C., Matheson, D. H., & Brimacombe, C. A. E. (2011). Factors influencing patient disclosure to physicians in birth control clinics: An application of the Communication Privacy Management Theory. Health Communication, 26, 502-511. https://doi.org/10.1080/10410236.2011.556081

Li, J. Y., Qiao, S., Harrison, S., & Li, X. (2017). Utilizing an interpersonal communication framework to understand information behaviors involved in HIV discourse. International Journal of Information Management (37), 250-256. https://doi.org/http://dx.doi.org/10.1016/j.ijinfomgt.2016.12.001

Lichtenstein, B., Sturdevant, M. S., & Mujumdar, A. A. (2010). Psychosocial stressors of families affected by HIV/AIDS: Implications for social work practice. Journal of HIV/AIDS & Soical Services, 9(2), 130-152. https://doi.org/10.1080/15381501003795717

Marshall, C., & Rossman, G. B. (1999). Designing qualitative research (3rd ed.). SAGE Publications.

Mazur, M. A., & Hubbard, A. S. E. (2004). "Is there something I should know?":Topic avoidant responses in parent-adolescent communication. Communication Reports, 17(1), 27-37. https://doi.org/10.1080/08934210409389371

Mellins, C. A., Brackis-Cott, E., Dolezal, C., Richards, A., Nicolas, S. W., & Abrams, E. (2002). Patterns of HIV status disclosure to perinatally HIV-infected children and subsequent mental health outcomes. Clinical Child Psychology and Psychiatry, 7(1), 101-114. https://doi.org/1359-1045 (200201)

Miles, M. B., Huberman, A. M., & Saldana, J. (2020). Qualitative data analysis: A methods sourcebook. (4th ed.). Sage Publications, Inc.

Morgan, D. L. (2012). Focus groups and social interaction. In J. F. Gubruim, J. A. Holstein, A. B. Marvasti, & K. D. McKinney (Eds.), The SAGE handbook of interview research: The complexity of the craft (pp. 161-176). SAGE Publications. https://doi.org/http://dx.doi.org/10.4135/781452218403.n11

Nesheim, S., Taylor, A., Lampe, M. A., Kilmarx, P. H., Harris, L. F., Whitmore, S., Griffith, J., Thomas-Proctor, M., Fenton, K., & Mermin, J. (2012). A framework for elimination of perinatal transmission of HIV in the United States. Pediatrics, 130(4), 738-744. https://doi.org/10.1542/peds.2012-0194

Ngula, K., & Miller, A. N. (2010). Self-disclosure of HIV seropositivity in Kenya by HIVpositive Kamba men and their families. Southern Communication Journal, 75(4), 328-348. https://doi.org/10.1080/1041794x.2010.504443

Noble, J. E. (2014). Primary Care:Introduction. In C. D. Berkowitz (Ed.), Berkowitz's pediatrics: A primary care approach (pp. 3-6). http;//ebookcentral.proquest.com.

Nowell, L., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods, 16, 1- 13. https://doi.org/10.1177/1609406917733847

Olson, A. L. (2005). Communication with families and specialists. In L. M. Osborn, T. G. Dewitt, L. R. First, & S. A. Zenel (Eds.), Pediatrics. Mosby. https://doi.org/https://doi.org/10.1016/13978-0-323-01199-0.X5001-4

Omarzu, J. (2000). A disclosure decision model: Determining how and when individuals will self-disclose. Personality and Social Psychology Review, 4(2), 174-185.

Patton, M. (2002). Qualitative Research & Evaluation Methods (3rd ed.). SAGE Publications, Inc.

Petronio, S. (2002). Boundaries of privacy: Dialectics of disclosure. State University of New York Press.

Petronio, S. (2010). Communication privacy management theory: What do we know about family privacy regulation? Journal of Family Theory & Review, 2, 175-196.

Petronio, S., & Gaff, C. l. (2010). Managing privacy ownership and disclosure. In C. L. Gaff & C. L. Bylund (Eds.), Family communication about genetics: Theory and practice (pp. 121-135). Oxford University Press.

Petronio, S., & Reierson, J. (2009). Regulating the privacy of confidentiality. In T. D. Afifi & W. A. Afifi (Eds.), Uncertainty, information management, and disclosure decisions. Routledge.

Petronio, S., & Sargent, J. (2011). Disclosure predicaments arising during the course of patient care: Nurses' privacy management. Health Communication, 26, 255-266. https://doi.org/10.1080/10410236.2010.549812

Petronio, S., Sargent, J., Andea, L., Reganis, P., & Cichocki, D. (2004). Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. Journal of Social and Personal Relationships, 21(1), 33-52. https://doi.org/10.1177/0265407504039838

Petronio, S., & Sweeney-Lewis, S. (2011). Medical disclosures in oncology among families, patients and providers: A communication privacy management perspective. In M. Miller-Day (Ed.), Family communication, connections, and health transitions: Going through this together. Peter lang.

Petronio, S., & Reierson, J. (2009). Regulating the privacy of confidentiality. In T. D. Afifi & W. A. Afifi (Eds.), Uncertainty, information management, and disclosure decisions: Theories and applications. Routledge.

Piazza, J., & Bering, J. M. (2010). The coevolution of secrecy and stigmatization: Evidence from the content of distressing secrets. Human Nature, 21, 290-308. https://doi.org/10.1007/s12110-010-9090-4

Rafferty, K. A., Hutton, K., & Heller, S. (2019). "I will communicate with you, but let me be in control": Understanding how parents manage private information about their chronically ill children. Health Communication, 34(1), 100-109. https://doi.org/https://doi.org/10.1080/10410236.2017.1384432

Saldana, J. (2016). The coding manual for qualitative researchers. SAGE Publications. Scandlyn, J. (2000). When AIDS became a chronic disease. Western Journal of Medicine, 172(February), 130-133.

Schensul, J. J. (2008). Documents. In L. M. Given (Ed.), The SAGE encyclopedia of qualitative research methods (pp. 232-233). Thousand Oaks, CA: SAGE Publications, Inc.

Serewicz, M. C. M., Dickson, F. C., Morrison, H. T. A., & Poole, L. L. (2007). Family privacy orientation, relational maintenance and family satisfaction in young adult's family relationships. Journal of Family Communication, 7(2), 123-142. https://doi.org/10.1080/15267430701221578

Sia, C., Tonniges, T. F., Osterhus, E., & Taba, S. (2004). History of the medical home concept. Pediatrics, 113, 1473-1478. https://doi.org/http://pediatrics.aappublications.org/content/113/Supplement_4/1473

Siegel, K., & Lekas, H. M. (2002). AIDS as a chronic illness: psychosocial implications. AIDS, 16(Supplement 4), S69-S76.

Simonda, L. M., Camic, P. M., & Causey, A. (2012). Using focused ethnography in psychological research. In H. Cooper (Ed.), APA Handbook of Research Methods in Psychology: Research Designs (Vol. 2, pp. 157-170). American Psychological Association. https://doi.org/10.1037/13260-010

Styron, J. F., & Evans, P. J. (2016). The evolution of office notes and the electronic medical record: The CAPS note. Cleveland Clinic Journal Of Medicine, 83(7), 542-544. https://doi.org/10.3949/ccjm.83a.14191

Tenzek, K. E., Herrman, A. R., May, A. R., Feiner, B., & Allen, M. (2013). Examining the impact of parental disclosure of HIV on children: A meta-analysis. Western Journal of Communication 77(3), 323-339.

Tracy, S. J. (2013). Qualitative research methods: Collecting evidence, crafting analysis communicating impact. In. Wiley-Blackwell.

Uninsurance., I. o. M. U. C. o. t. C. o. (2002). Health insurance is a family matter. National Academies Press. https://doi.org/https://www.ncbi.nim.nih.gov/books/NBK221009.

Vangelisti, A., Caughlin, J., & Timmerman, L. (2001). Criteria for revealing family secrets. Communication Monographs, 68(1), 1-27. https://doi.org/10.1080/03637720128052

Vangelisti, A. L. (1994). Family secrets: Forms, functions and correlates. Journal of Social and Personal Relationships, 11, 113-135.

Vangelisti, A. l., & Caughlin, J. P. (1997). Revealing family secrets: The influence of topic, function, and relationships. Journal of Social and Personal Relationships, 14(5), 679- 705.

Wager, K. A. (Ed.). (2013). Health care information systems a practical approach for health care management (3rd ed. ed.). Jossey-Bass.

Weiner, L. S., Kohrt, B. A., Battles, H. B., & Pao, M. (2009). The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. Journal of Pediatric Psychology, 36(2), 141-154. https://doi.org/10.1093/jpepsy/jsp129

White, P. H., Cooley, W. C., Transitions Clinical Report Committee, American Academy of pediatrics, American Academy of Family Physicians &, & Physicians., A. C. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics, 142, 2587-2607. https://doi.org/10.1542/peds.20182587

Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV diagnosis to children: History, current research and future directions. Journal of Developmental and Behavioral Pediatrics, 28(2), 155-166.

Wyatt, G. E., Williams, J. K., Gupta, A., & Malebranche, D. (2012). Are cultural values and beliefs included in U.S. based interventions? Preventive Medicine, 55, 362-370.

Xu, W., & Zammit, K. (2020). Applying thematic analysis to education: A hybrid approach to interpreting data in practitioner research. International Journal of Qualitative Methods, 19, 1-9. https://doi.org/10.1177/1609406920918810

APPENDIX A

USE OF TERMINOLOGY

Use of Terminology

The codes developed for creating the themes, provided below, are based on a priori categories derived from the academic literature defining families and the concepts important to Communication Privacy Boundary theory (Petronio, 2002). The following definitions are for family as they apply to this study.

A. The Family Group, Relationships and Life Circumstances

Family Group: Family Group is a group of adults and children who are related by the ties of marriage, blood or adoption and who have established long-term emotional and relational commitments to one another based on the ties of blood, marriage or adoption (Olson et al., 2012; Segrin & Flora, 2005).

Family Relationships: A system of complex interpersonal relationships between members of a family group (O'Mara & Schrodt, 2017).

Family Readiness: The circumstances in which a family lives its daily life. The presence or absence of these factors may facilitate or complicate the disclosure of HIV status: housing security, food security, transportation, parental chronic illness, employment status, substance abuse, parental or juvenile incarceration, and domestic violence (David, 2018; Lichtenstein, Sturdevant & Mujumbar, 2010).

B: Perceptions of a Family's Privacy Orientation:

The following codes were developed from the literature to describe the provider's perceptions of how open the family was to discussing HIV issues and other health matters among themselves. These codes are derived from Communication Privacy Boundary Management theory (Petronio, 2002).

Open*:* A family who is willing to discuss HIV issues and other health concerns with the immediate and extended family.

Closed*:* A family that is not willing to discuss HIV issues among themselves and is perceived by providers as very private.

C. Other Codes Derived from the Literature

Concepts around trust in the relationship between the providers and the parents of the patients in this study were used to create the codes for trust and secrets (Horn et al., 2012; Peek et al., 2013; Petronio, 2002; Vangelisti, 1994). The codes about the child's need to know their HIV status were derived from the communication literature around an adult person living with HIV/AIDS who needs to disclose HIV status to other people (Greene et al., 2003).

Trust: Trust is a key element of an effective professional relationship as it allows for shared decision making by the provider and patient (Peek, et al., 2013). Trust also encompasses a patient-centered communication style by the provider (Horn, et al. 2012).

Secrets: Providers and parents keep the HIV status a 'secret' until the time is appropriate for complete and full disclosure. This code represents the providers' perceptions of parents need to keep HIV status hidden (Petronio, 2002).

Child Needs to Know: A parent believes that the child needs to know and be educated about their own HIV status (Greene et al., 2003).

D: Codes Derived directly from the Data

The following codes arose directly from the data.

Adolescent Reaction: Providers' perspectives on their adolescent patient's reactions to finding out that they have HIV.

Adolescent Readiness: Combination of age, cognitive issues, and emotional maturity that allow the patient to comprehend the ramifications of living as a person with HIV.

Adolescent Dating: Adolescent is interested in dating, and this behavior is noticed by providers and/or parents prior to disclosure.

Adolescent Question Asking: Adolescent asks parent and/or provider about the rationale for medication and frequent provider visits (Focus group Question 2).

Age: Chronological age of patient appropriate for disclosure (Focus group Question 1).

Cognitive Issues: Patient's inability to understand emotional, medical, social, and relational issues related to persons living with HIV/AIDS (Focus Group Question 2).

Disclosure Event: Critical Incident (Non-Typical)   Disclosure occurs due to a critical incident that has occurred (Focus Group Question 7).

Disclosure Event- Non-Critical (Typical): Disclosure occurred and is not driven by a critical incident; parent has agreed without resistance (Focus Group Question 6).

Medication Adherence: Patient is not complying with the prescribed medication regimen.

Non-Family Relationships: Interpersonal relationships a family group and/or individual members of the family have with other people who are not related by blood, adoption, or marriage to the family group. Examples of these relationships are a child’s teachers, family, friends, sports coaches, church members, employers, neighbors, and childcare providers and relationships with any other members of the community in which the patient and his or her family reside. The relationship with the health care team at the Lewin Clinic is excluded from this definition.

Parent Decision to Disclose: The factors that parents use to determine whether the disclosure occurs and that effect their decision to disclose HIV status.

Agree: Parent agrees to disclosure after being approached by provider.

Disagree: Parent disagrees to disclosure after being approached by the provider.

Who else should know: Parents thoughts on the other people who should know the child's HIV status once the child has been given full disclosure or has been fully informed.

Parent Initiates Disclosure: Parent initiates disclosure of HIV status to child.

Parent Reaction: The emotional reaction of the parent to the idea of disclosure.

Patient education: Information given to patient by provider in response to questions or concerns raised by adolescent after disclosure.

Provider Approach: The approach taken by the provider with the parent when the decision to disclose needs to be made.

Ultimatum: Provider's comments that indicate disclosure will occur because the child needs to know his or her health condition.

Sexual behavior: Adolescent is engaging in sexual activity.

Stigma: Negative attitudes within the family and/or community towards PLWHA

Transition: The process of concluding a patient's treatment within the pediatric practice and transitioning the patient to the adult health care system.

APPENDIX B

TABLE OF DATA SOURCES

Time frame: September 1, 2018 through April 30, 2019

Item	**Description**	**Time Frame**	**Amount of Time**	**Number of Pages/Entries**
Field Notebook	Handwritten notes and phrases I kept throughout the data collections process. These notes were snippets of information I used to create a field notes diary. This notebook and the diary contains personal contact information for the parents I contacted for an interview.	09/12/2018 to 04/28//2019	1 to 2 hours per day; 1 to 2 times per week	72 pages in a spiral bound notebook
Field Notes Diary	During the time in which the data were collected, I kept a diary in which I wrote about my experiences with the Lewin Clinic staff and Wellington Hospital system, the theoretical connections I saw as the data were being collected, and my frustrations with the people I encountered and the situations throughout my experience at the site.	8/26/2018 to 04/28/2019	1 to 2 hours per week	48 double spaced pages

Patient Medical Charts	I reviewed portions of 42 patient charts. I collected demographic information, data regarding the family and the data about HIV status disclosure.	9/18/18 to 10/31/2018	Approximately 6 weeks	801 entries[2] (M= 19.07, SD = 5.67)
Anecdotal Notes	In addition, I reviewed the records to record anecdotal information the provider recorded about the disclosure process.	9/18/18 to 10/31/2018	Approximately 6 weeks	133 entries for 37 patient records
Advisory Board Transcript	The meeting at which a semi-structured interview guide was used to elicit the provider perspectives for this study and ideas for recruiting patients and parents for the interview phase.	09/12/2018	77 minutes	36 pages
Patient Interview	The equipment failed for this interview. I captured my recollection of the patient's remarks as best I could from my notes.	4/3/2019	45 minutes	4 single spaced pages
Parent Interview (Chuck)	Semi-structured interview with parent.	4/9/2018	45 minutes	18 pages

---

[2] For each record, I counted the number of progress notes, social work notes and Disclosure forms I reviewed for each individual patient.

Parent Interview (Cora)	Semi-structured interview with parent.	4/18/2019	60 minutes	29 pages

APPENDIX C

WELLINGTON HOSPITAL ORIGINAL APROVAL 2018

(REDACTED VERSION)

August 9, 2018

Cady Berkel, PhD
Phoenix, AZ 85016

RE: IRB # (redacted): Parent-Child Disclosure About Chronic Conditions.

Dear Dr. Berkel:

- I have reviewed your request for expedited approval of the new study listed above. Your study is eligible for expedited review under 21 CFR 56.110 and 45 CFR 46.110, category 7, Research on individual or group characteristics or behavior, or research employing survey, interview oral history focus groups, program evaluation, or quality assurance methodologies. You are granted permission to start your study as described effective immediately.
- The approval includes the following documents:
- IRB Paperwork (4/16/2018)
- Informed Consent (5/3/2018)
- Assent for Children Ages 12-17 Years of Age and Older (5/31/2018)
- Authorization to use or Disclose Protected Health Information (5/31/2018)
- Protocol V3 (7/27/2018)

The study is next subject to continuing review on or before 8/8/2019, unless closed before that date. You may not continue the study beyond the expiration date noted above. You must apply for reapproval 45 days in advance of expiration to allow adequate time for IRB review.

As Principal Investigator, you are responsible for assuring that:

- The approved protocol is followed, and prior IRB approval is obtained for any changes (including changes in recruitment procedures, subject, population, location, protocol); and
- Any problems are reported promptly to the IRB (including adverse events and deviations from the approved protocol).
- Approval period: 8/9/2018 - 8/8/2019

If you have any questions, please contact (redacted for privacy reasons).

Sincerely,
SIGNED
(redacted), MD
Chair, Institutional Review Board #1

cc: Anna Maria Campbell

APPENDIX D

ARIZONA STATE UNIVERSITY IRB APPROVAL

(REDACTED)

On August 22, 2018, the ASU IRB reviewed the following protocol:

Type of Review:	Contextual review
Title:	Disclosure Study
Investigator:	Paul Mongeau
IRB ID:	STUDY 0000 (redacted)

The above-referenced protocol has been given a contextual review and the IRB acknowledges that oversight is deferred to the Wellington IRB. The ASU IRB understands that the Wellington IRB will provide review, approval, and continuing oversight as required by 45 CFR Part46, 21 CFR Parts 50,56, and 812 and in accordance with applicable Federal and State Laws as authorized by the Affiliation Agreement. The Wellington IRB number is (redacted).

APPENDIX E

DATA COLLECTION SHEET-PATIENT MEDICAL CHART

Medical Record Coding Sheet

Participant No:___________

I. Demographic Information:

a. Sex of patient M F Transgender M-> F Transgender F-> M

b. Ethnic Origin: Asian African American Non-Latino White Latino Native American/American Indian Native Hawaiian/Pacific Islander Other

d. SES: Public Ins. Pvt. Ins. Both Pub & Pvt. Ins. No Ins. Military Ins

e. Current Age: (write in the age of the patient)

f. Language: English Spanish Other: (specify)

g. Status: Non-immigrant Immigrant Country of origin:

II. Family and Parents Information

a. # of people in family/household infected w/HIV:

b. Patient lives with parent(s): Biological Foster Adoptive

People other than parents: Yes Relationship: Kinship Yes No

c. Parent 1 Sex: M F Trans

Parent 2 Sex: M F Trans

d. Parent 1 age: (Write in parent's age if available) Parent 2 age:

e. Parent 1 ethnic background: Asian African American Non-Latino White Latino Native American/American Indian Native Hawaiian/Pacific Islander Other

Parent 2 ethnic background: Asian African American Non-Latino White Latino Native American/American Indian Native Hawaiian/Pacific Islander Other

f. HIV status of Parent 1: Positive Negative Unknown

HIV Status of Parent 2: Positive Negative Unknown

III. HIV Disclosure Information

a. Patient has been told by that he or she has been infected with HIV/AIDS: Yes No

b. Age at which full disclosure occurred (if applicable):

c. Disclosure Event: Patient was informed by Parent only Physician and Parent together Physician only Other Unknown

---

IV. Open-ended notes regarding disclosure process (See reverse if necessary)

Reverse side of medical record coding form

APPENDIX F

RECRUITMENT FLYER

Research Study
Opportunity
(REDACTED

Wellington Hospital’s Lewin Clinic is working on a study what parents and children say to each other about a child’s chronic health condition.

Parents/caregivers must:

- Be over the age of 18

Patients must:

- Be age 12 or older
- Know all about their chronic health condition
- Speak English

Parents/caregivers and patients are being asked to participate in separate, private interviews with a memberof the research team.

Parents/caregivers may participate in the study without the patient participating as well.

Parents/caregivers and patients will each receive a $25.00 gift card for their participation.

The interview will be conducted individually in private by a member of the research team. The interview may last from 30 to 90 minutes in length. This study has been approved

By the IRB at Wellington Hospital.

Help us continue to give patients access to the best and most up-to-date care.To enroll, contact Anna Marie Campbell, (phone number redacted).

APPENDIX G

PATIENT WORKBOOK

My Workbook

Name:

Who am I?

Date:____________________

What are my strengths?

What do I like to do for fun?

Support People andFriends

Describe friends, family, and others who provide
Support in your life.

Name: Relationship:

Why I trust them:

Ways they help me:

Ways I help them:

Name: Relationship:

Why I trust them:

Ways they help me:

Ways I help them:

Name: Relationship:

Why I trust them:

Ways they help me:

Ways I help them:

How is my health? Date:

How healthy am I?

What do I do to stay healthy? Do I exercise, eat healthy,and get enough sleep?

How do I feel about my body? Do I feel over or underweight?

Am I having difficulty in school or getting along with other people?

Do I do things that put my health at risk? (i.e., drugs,alcohol, unprotected sex)

Do I ever take substances, such as drugs and alcohol, to help deal with my life situation?

When do I feel sad? Do I have thoughts of low self esteem or hopelessness?

Do I ever have thoughts of harming myself?

What do I do to make myself feel better?

Finding Health Information

List and describe the names and places where you get health information.

Name: Relationship:
Why I trust
How is their information helpful?

Name:

Relationship:

How is their information helpful?
Why I trust him/her/it:

Name:
Relationship

Why I trust him/her/it:

How is their information helpful?

Name:
Relationship

Why I trust him/her/it:

How is their information helpful?

Name:
Relationship:

Why I trust him/her/it:

How is their information helpful?

What do I know about HIV?

What is HIV?

How can someone get it?

What can people do to prevent spreading HIV?

What does a high CD4 count mean? A low CD4count?

What does a low viral load mean? A high viral load?

Medications

List all of the medications that you are currently taking.

Date:________________

Name of Medication

Why do I take
this medication?
e.g. pain, nausea

Do I have any side effects?
E.g., Nausea or dizziness

How do I take it?
(0rally,injection)

How well do I take my medications?

Disclosure

Who knows about my HIVstatus?

How do I tell someone about my HIV status?

Have I ever told someone about my HIV status?
What was the experience like?

My Sexual Health

What do I know about sex?

What are my feelings about sex?

Do I have any questions and concerns about my sexuality?

If I plan to have sex, do I know how to use and negotiate condoms?

What are my feelings about having babies?

How can I prevent pregnancy until I am ready?

How does HIV affect pregnancy?

My Legal Rights

Are you aware of your legal rights and entitlements?

Legal Right**:** A privilege granted to you by local,state, or federal law

Entitlement: Your legal right to a benefit or program if you meet certain eligibility criteria (e.g., a certain income, aspecific age)

Is my medical care "confidential?" What does that mean? (e.g., who gets to knowabout my medical status, and who can they tell?)

Are there limits to medical care confidentiality? If so, what are they?

What measures are being taken to avoid accidental disclosure (giving out information which might commonly be kept secret) of my HIV status? (for example, phone calls, mail, insurance company forms)

Besides me, who else has a say in my medical treatment? Why and for how long?

Does my medical condition affect me going to school? How?

My Legal Rights Continued...

- What does my school do to help me?

- Do I need special arrangements to participate in any event(s) because of my medical condition? What are they?

- If something happens to me, and I cannot talk with my doctors, who do I want to make decisions for me?

- Are there certain types of medical care I definitely do not want if I am unable to communicate? What kinds of things (e.g., life support)?

- What can I do to try to make sure my medical wishes are followed?

My Goals

Identify your goals (health-related and personal) and make an action plan to achieve them with guidance from a mentor. Check the box when you accomplish your goal!

Goal:

Today's Date: ________

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Today's Date: ________

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Goal:

Today's Date: ________

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Accomplishments

Identify how to take care of yourself as you become increasingly independent.

(Chart removed for publication purposes).

Free Write

Use this space to write about whatever you are thinking orfeeling. For example, write about how you envision your future, your goals, or what having HIV means to you.

:

AIDS EDUCATION &TRAINING CENTERS

This tool was developed by the Life Skills subset (Chair: Patricia Robinson, PhD, ARNP-C, FAETC) of the AIDS Education and Training Centers (AETC) National Resource Center, Adolescent HIV/AIDS Workgroup (Chair: Marion Donohoe, RN, MSN, CPNP, St. Jude Children's Research Hospital, ANAC and Ronald Wilcox, MD, FAAP, Delta Region AETC). Collaborating members include Yolanda Cavalier, MPH (HRSA), CarolDavison, RN, MSN, FNP-C (FXB Center), Marion Donohoe, Margery Donovan, RN, ND, ARNP (NE AETC), Durrell Fox (NE AETC), and Michelle Lyle, MPH (NY/NJ AETC). The workgroup efforts were coordinated by the AETC National Resource Center (Managing Editor: Megan Vanneman, MPH).