

BARRIERS TO ETHICAL DECISION-MAKING FOR HIV/AIDS TREATMENT  
PROVIDERS AROUND THE GLOBE

by

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(Under the Direction of Larry Nackerud)

ABSTRACT

The purpose of this study was to analyze how international HIV/AIDS treatment providers in Australia, Kenya, and Lebanon navigate systematic social and political barriers to ethically meet the needs of their clients living with HIV through grounded theory methodology. Data collection methods include the use of interviews, field notes, observations, historical media publications, and scholarly literature on barriers to ethical decision-making for treatment providers. Data collection took place with key informants, agency care workers, and community respondents from July 15, 2015 to August 4, 2015 in Melbourne, Australia, Beirut, Lebanon, and Nairobi, Kenya. After data collection, three clear opportunities for meaningful analysis emerged to inform international HIV social work practice, including: 1) a case study from Lebanon evaluating the utility of the four quadrants model to ethical decision-making; 2) an evaluation of the core challenges to consensual HIV disclosure and ethical-decision making for treatment providers and their clients; and 3) an examination of the new challenges from diminishing funding to ethical decision-making by HIV treatment providers. These three research papers are presented in a potentially publishable format and bookended between introduction and conclusion chapters. Implications for international social work practice and policy

recommendations are discussed at length.

INDEX WORDS: HIV/ AIDS; Ethical decision-making; International social work;  
Treatment providers; Grounded theory

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AROUND THE GLOBE

by

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## DEDICATION

Those who have contributed to the completion of this dissertation and my PhD are too many to name without unintentionally leaving someone out, so I'll just dedicate this to the continued growth and high regard of the profession of social work and those who dedicate their lives to uphold those values.

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## **CHAPTER 1**

### **INTRODUCTION**

The following dissertation is an analysis of barriers to providing and accessing HIV/AIDS treatment and prevention services in three countries: Australia, Lebanon, and Kenya. This first chapter describes the current state of the global HIV/AIDS pandemic, explores the multitude of challenges associated with an HIV diagnosis and ethical decision-making, and explicates the purpose of this dissertation research. In addition, this chapter describes the sample selection, data collection, and methodology of data analysis. Lastly, the three separate studies that make up a large portion of this dissertation will be introduced with a brief description of their content. Please note, common terminology and acronyms used in international HIV treatment implementation and research and throughout this dissertation are defined and contextualized for readers is located at the beginning of the dissertation for easy referencing. This first chapter sets the stage for three separate studies through grounded theory analysis and the investigation of an actual case study encountered in Lebanon.

#### **Current State of the Global HIV/AIDS Epidemic**

When Nelson Mandela spoke at the International AIDS Conference in Durban, South Africa in July 2000, he spoke of a tragedy of unprecedented proportion. He observed that AIDS was “claiming more lives than the sum total of all wars, famines, and floods” (as cited in Boseley, 2000, para. 5). At the time, people feared it would be impossible to reverse the course of the epidemic. However, the number of deaths resulting from HIV/AIDS complications has fallen each year since peaking in 2004. The rapid increase in access to antiretroviral therapy (ART) has been a tremendous contributing factor to the many successes in the global battle

against HIV/AIDS. An estimated 36.9 million people around the world are currently living with HIV, and as of March of 2015, 15 million of those people (or about 40%) are accessing ART medications (UNAIDS, 2015). There were approximately 2 million new cases of HIV in 2014, which is down from 3.2 million (35%) new infections in the year 2000. According to UNAIDS (2015), 1.2 million people died of AIDS-related illnesses in 2014, compared to 2 million (42% decrease in deaths) from the peak in 2004.

### **HIV/AIDS & Stigma**

Several decades into the HIV pandemic, HIV-related stigma continues to fuel the HIV transmission and impede prevention and treatment efforts worldwide (Mahajan et al., 2008; Monteiro, Villela, & Soares, 2013; Tsai et al., 2013). Since the first cases of AIDS were documented in 1981, people living with this obstinate virus have been stigmatized (Monteiro, Villela, & Soares, 2013; Turan & Nyblade, 2013). The swift and fatal nature of the disease (Vanable, Carey, Blair, & Littlewood, 2006) combined with ignorance surrounding transmission of the virus, led to severe panic and alienation of those living with the virus. This stigma compounded challenges related to disclosure, testing, and treatment throughout the world in varying degrees (Gohain & Halliday, 2014). Furthermore, typical challenges from economic strain, social ostracism, internalized stigma, discriminatory national policies and laws, and insufficient access to health services are both analogous and unique from country to country. For example, within these systemic confines people living with HIV/AIDS regularly need to make decisions about their health and the health of their loved ones (e.g., partners, children, other family members), often while their own wellbeing is compromised.

In low- and middle-income countries, HIV-related stigma has been connected to reduced voluntary testing and counseling (Hutchison & Mahlalela, 2006) and increased sexual

risk-taking in the general population (Pitpitan et al., 2012). Among people living with HIV, stigma is linked with emotional distress (Tsai et al., 2012), decreased adherence to ART (Boyer et al., 2011; Katz et al., 2013) and reduced likelihood of HIV status disclosure (Tsai et al., 2013; Turan & Nyblade, 2013). People living with the virus may accept negative beliefs and feelings associated with HIV/AIDS about themselves through the course of their lives due to strong negative social stigma (Mak, Poon, Pun, & Cheung, 2007). Internal stigma, described as felt, imagined, or expected self-stigma, is the product of the internalization of shame, blame, hopelessness, and fear of discrimination connected with being HIV-positive (Brouard & Wills, 2006). Internal stigma is innately connected with external stigma, as anticipated judgment or discrimination from others can impact the way people see themselves, cope with their status, and guide daily decision-making. Internalized stigma can make individuals more sensitive to actual, perceived, and anticipated rejection by others, which detrimentally impacts self-disclosure and candid conversations (Chesney & Smith, 1999). Some people living with HIV/AIDS are also members of marginalized groups termed 'key populations' (i.e., sex workers, transgender persons, people who use drugs, and men who have sex with men). In many of these cases, people living with HIV may choose not to receive services or disclose their status to loved ones due to fear of discrimination or legal repercussions (Venable et al., 2006).

Additionally, an HIV/AIDS diagnosis can bring severe and lasting consequences of financial strain and poverty. Accessing essential healthcare comes at a cost, including transportation, substantial treatment costs, and opportunity costs of clinic visits. Research suggests that financial stress related to adult HIV infection, such as loss of earnings, healthcare expenses, disruption of savings, and premature sale of assets (e.g., cars, houses, retirement savings) to meet healthcare costs can be debilitating and have long-term repercussions

(Bachmann & Booyesen, 2006; Collins & Leibrandt, 2007). Economic strain for people living with HIV and their families create challenging environments where options are limited and healthy decision-making is more challenging.

Women, particularly when pregnant, are vulnerable to the adverse effects of HIV-related stigma. A pregnant woman is often the first family member to be tested for HIV due to her contact with ANC clinic, she is vulnerable to blame for bringing the virus into the family (Turan, Miller, Bukusi, Sande, & Cohen, 2008). Pregnant women have become especially vulnerable to risks of unwanted disclosure and stigma, as the Antenatal Care (ANC) and maternity services that they utilize have now become prime locations for HIV testing and provision of PMTCT interventions, especially in sub-Saharan African countries with the highest HIV prevalence (Turan & Nyblade, 2013). These factors are compounded by gender norms that penalize women for promiscuity, often assumed of persons living with HIV, and place women in positions of socio-economic vulnerability (Turan & Nyblade, 2013). In addition, women living with HIV often struggle with the challenges of multiple or “layered stigmas” if they experience stigma not only for having HIV but also for being members of other marginalized groups, including key populations. Pregnant or parenting women living with HIV often also suffer from another layer of stigma and negative judgment for getting pregnant and putting a child at risk of HIV infection (Kendall, 2009).

An HIV/AIDS diagnosis frequently signifies profound challenges to mental health and decision-making (Whetten, Reif, Whetten, & Murphy-McMillan, 2008), and can have long-term intergenerational impacts as well. Numerous studies suggest that compromised parental mental health, as a result of learning HIV status, has immediate effects on the quality and quantity of attention a parent is able to devote to their young child (Atkinson et al., 2000; Kingston &

Touch, 2014; Martins & Gaffan, 2000). Diagnosed parents need to manage their HIV treatment, consider disclosure, and accommodate relationship changes, all while after experiencing clinical levels of stress, depression (Sherr, Clucas, Harding, Sibley, & Catalan, 2011), anxiety (Clucas et al., 2011), and even suicide ideations (Catalan et al., 2011), which can impact a person's decision-making capabilities. These difficulties may continue for some time, as unlike other conditions such as diabetes, HIV/AIDS diagnoses are often not shared and may remain a troublesome secret. Two recent systematic reviews identified 54 (Sherr, Mueller, & Varrall, 2009) and 21 (Sherr, Croome, Parra-Castaneda, Bradshaw, & Romero, 2015) studies, respectively, with the majority showing a form of cognitive delay in children both infected and affected by HIV (Sherr et al., 2015). All domains of development are implicated, including expressive and receptive language (Rice et al., 2013), memory, information processing, visual-spatial tasks, executive functioning (Llorente et al., 2014), and decision-making (Laughton, Cornell, Boivin, & Van Rie, 2013). HIV/AIDS infected women are disproportionately subjected to various forms of verbal, physical, and sexual abuse. In addition, children in HIV/AIDS affected families have been shown to endure a threefold higher levels of abuse (Cluver, Orkin, Boyes, Gardner, & Meinich, 2011).

In conclusion, evidence suggests HIV/AIDS increases risks of mental health issues and overall economic wellbeing for people living with HIV, their families, and greater communities. The presence of adult HIV infection severely challenges the family system and child rearing through pathways linked to poverty, stigma, ill health, and adjustment difficulties. These challenges are not isolated but weave a complex web with cumulative effects on both the adults with HIV and their loved ones. The buildup of these challenges can have exacerbating

negative outcomes for people living with HIV, their ability to make decisions, and the long-term trajectory of the disease.

### **The Significance of the Study**

A nation's laws, systems, and institutions can compound ethical dilemmas for HIV treatment providers while assisting clients to navigate healthcare systems. Care workers can face occupational dilemmas when their cultural values, national policies, or professional codes of ethics seem to conflict. Without support and guidelines on how to manage such complex situations, care workers may unknowingly or unintentionally act in ways that increase the alienation of, stigma to, or discrimination toward these populations. To address these barriers to family-centered services an international working group, including the Coalition for Children Affected by AIDS and The Global Network of People Living with HIV, advocated for an ethical decision-making tool entitled *Difficult Decisions: A Tool for Care Workers*, essentially similar to the "four quadrants" model designed by Jonsen, Siegler, Winslade in 1982, and updated in 2010, to be used internationally by HIV treatment providers. This model will be examined through the lens of an actual case study from Lebanon in Chapter 2. This ethical decision-making model is currently being used in Australia, Lebanon, and Kenya to assist highly trained and relatively untrained HIV care workers to manage ethical dilemmas while supporting their clients. However, little research has been done about the utility and efficacy of this tool among HIV care workers with various skill levels and in countries with diverse laws and values.

### **Purpose of the Research**

For clarity, the original purpose when this dissertation research began was targeted to measuring the efficacy of the decision-making tool. However, due to the nature of grounded theory methodology of this dissertation, meaningful themes began to emerge during interviews and focus groups that influenced future discussions and direction of the overall goal of the final



dissertation. Therefore, the purpose of this dissertation research is to better understand how treatment providers and people living with HIV in a variety of settings and circumstances navigate their country's social, cultural, and political systems to meet their needs and by making use of the decision-making tool. The findings of this dissertation are intended to inform international social work and health services practice in order to provide more inclusive HIV/AIDS treatment and supportive services.

### **Methods**

The study employs grounded theory methodology as the researchers used observation, participant interviewing, and the collection of artifacts and texts used by stakeholders in their daily lives (Glaser & Strass, 1967). This method of constantly comparing data with new data throughout the process of coding allowed meaningful themes to emerge surrounding international barriers to ethical decision-making.

### **Sample**

The analysis of this dissertation draws on interviews conducted in July and August of 2015 with stakeholders (N=79) of community-based HIV treatment providers in three countries: Australia, Lebanon, and Kenya. See *Table 1* for a breakdown of the number of key informant, community respondents, and care worker participants from each country. These countries were selected for comparison due to their diverse cultures, dissimilar primary populations infected with HIV, various stages of overall HIV epidemic, and the large percentage of English speakers in those countries. Treatment providers in Australia, Lebanon, and Kenya were selected due to their relationship with the previously mentioned international working group and their willingness to implement the *Difficult Decisions: A Tool for Care Workers* with their employees.

	<i>n</i>	Date
<b><i>Australia</i></b>		
<i>Key informants</i>	6	July 15, 2015
<i>Community respondent focus group</i>	12	July 15, 2015
<i>Care worker focus group</i>	11	July 15, 2015
<b><i>Lebanon</i></b>		
<i>Key informants</i>	5	July 30, 2015
<i>Community respondent focus group</i>	3	July 30, 2015
<i>Care worker focus group</i>	3	July 31, 2015
<b><i>Kenya</i></b>		
<i>Key informants</i>	4	Aug 4, 2015
<i>Community respondent focus group</i>	9	Aug 5, 2015
<i>Care worker focus group(s)</i>	39	Aug 4, 2015
	<i>Group 1</i>	23
	<i>Group 2</i>	9
	<i>Group 3</i>	4

Table 1. Key Informant, Community Respondent, and Care Worker Participant Breakdown

**Australia.** The Victorian AIDS Council (VAC) located in Melbourne, Australia connected the researchers to participants (n=29). Formed in 1983 as an immediate response to the newly identified HIV epidemic, the agency provides a broad range of health services for the prevention and treatment of HIV/AIDS in their local community.

**Lebanon.** In Lebanon, researchers partnered with Soins Infirmiers et Developpement Communautaire (SIDC) to identify participants (n=11). SIDC is a community-based health

organization located in Beirut, Lebanon which coordinates HIV prevention efforts and treatment for people living with HIV. Participants from L'Escale is a sister agency to SIDC that provides treatment and support for intravenous drug users.

**Kenya.** Participants from Kenya (n=39) were identified through partnering with the National Empowerment Network of People living with HIV/AIDS in Kenya (NEPHAK). See Table 1. NEPHAK is the coordinating agency in Nairobi, Kenya responsible for directing efforts of local clinics and CHWs to ensure prevention and treatment of people living with HIV/AIDS.

All participants were given a consent form detailing the dissertation research project with the option to opt out. *See Appendix A* for the informed consent form and proposed question outline for community respondents. Upon receiving signed consent, researchers conducted interviews and focus groups with care workers and community respondents. *See Appendix B* for the consent form and interview outline for care workers. Key informants were also included as “information-rich cases for study” through in-depth interviews in order for the researchers to learn about the issues of central importance (Patton, 2002, p. 230). The two researchers took turns being the primary facilitator for all interviews and focus groups. However, both support each other during the groups and asked follow-up questions. In addition, both simultaneously took notes and sent typed notes to the other after each interview.

Detailed notes were typed or handwritten while interviewing and facilitating focus groups simultaneously. Participants' exacting wording was typed whenever possible, and quotation marks were placed around these words or phrases. *See Appendix D* for an example of the structured typed notes. Participants were encouraged to look at the notes to check consistence. However, only five participants from all of those interviewed checked the researcher's notes, and no participant gave indication that he or she disagreed with what was written. Focus groups

lasted approximately one hour. A semi-structured approach was adopted for interviews and focus groups, using themes identified through analysis of the preceding focus groups. Sections of the interview were dropped if questions were not relevant to the interviewee. For example, if the care worker had not used the ethical decision-making tool, the researchers would skip questions about positive and negative differences the worker noticed from using the tool. This method provided consistency across participants from various standpoints while remaining flexible enough to respect the time and interest of those being interviewed. All notes were transcribed and shared between researchers.

### **Qualitative Analysis**

In qualitative research, trustworthiness is established by using well-grounded methods (Guba & Lincoln, 2005), including developing a familiarity with the participating organization and stakeholders, triangulation through frequent debriefing among researchers, participants, and the literature, peer scrutiny, thick description in the findings (Shenton, 2003), and maintaining a detailed audit trail (Guba & Lincoln, 2005). The dominance of in-depth interviews in this research study is acceptable as in-depth interviews facilitate access into participants' cultures and perspectives and shift authority away from the researcher to the participant (Goodman, 2001).

Several of findings were immediately evident (e.g., shifting financial trends) due to the rich thick description provided by participants and frequent discussions immediately after interviews between researchers. Ryan and Bernard's (2003) techniques for identifying themes from basic expressions in the notes were used. Open coding in this dissertation was done independently by the author. Following intensive open coding, the coded categories were then grouped and summarized. For an example of coding occurrences and grouping themes *see*

*Appendix E.* The resulting coding structure is reflected in the studies described in third and fourth chapters of this dissertation.

To address limitations to qualitative research, this dissertation relied on multiple strategies. First, data was collected using a method of triangulation (i.e., interviews, observations, and artifacts). Second, participants were given an opportunity to provide feedback regarding data accuracy during and after the focus groups to employ member checks. This strategy is described by Lincoln and Guba (1985) as “the most critical technique for establishing credibility” (as cited in Creswell, 2007, p. 208). Finally, this proposed dissertation will strive to achieve analytic generalization through a constant process of comparing data with established theory and literature and considering rival explanations as discussed in Yin (2009), Chapter 1.

### **An Introduction to the Three Studies**

After data collection, three clear opportunities for meaningful analysis to inform international HIV treatment have emerged: 1) A case study from Lebanon assessing the utility of the four quadrants model to ethical decision-making, 2) an evaluation of the thematic sociopolitical systemic barriers people living with HIV encounter when deciding to disclose their HIV status, and 3) an examination of the many challenges, largely due to diminishing funding, to ethical decision-making by HIV treatment providers. The findings gathered for this dissertation research were based on feedback from key informants, agency care workers, and community respondents. These three research papers are presented in a potentially publishable format.

### **A Case Study to Evaluate the Four Quadrants Model**

In Chapter 2, this scholarly paper assesses the utility of the four quadrants model through the lens of an actual case study encountered during data collection regarding a trained social worker who was unsure of whether or not to disclose a client’s HIV status. The four quadrants model for ethical decision-making first appeared in medical ethics literature over 30 years ago

(Jonsen, Siegler, & Winslade, 1982), and it is widely implemented in the United States and United Kingdom. However, only a handful of studies across disciplines have evaluated its utility through the use of a case study. Notably, relatively little scholarly literature has examined ethical decision-making models for health professionals from the professional lens of social work, regarding non-consensual HIV disclosure, or from the framework of practicing in the Middle East. The case study highlights the contextual features of living in a social and political climate where non-consensual HIV disclosure is expected or encouraged in some instances. The paper is largely conversational, while framing the discussion squarely within established philosophical schools of thought, such as universalism and relativism.

### **Barriers to Disclosure for People living with HIV around the World**

Persistent rates of nondisclosure of HIV status by those who test positive pose difficult legal and ethical challenges for policy makers, health workers, and people living with HIV. The third chapter focuses findings derived from the meaningful discussions with community respondents, care workers, and key informants regarding the multitude of consequences of disclosing one's HIV status in their home countries, particularly while making health-related decisions for themselves and their loved ones. Substantial research from around the globe has examined the significant consequences, both positive and negative, of HIV disclosure, which is integrated in the findings from this study. From the interviews, it was clear that there were severe consequences of disclosure, including socioeconomic consequences, challenges to parenting, and difficulties navigating legal issues around non-disclosure. Based on the findings, there are implications for practice for health care workers, including programmatic strategies to improve increased access to and utilization of services to improve health outcomes. Based on discussions with HIV treatment providers and key informants, health workers regularly report heavy

workloads and high levels of stress and burnout (Mkhabela, Mavundla, & Sukati, 2008; Turan, Miller, Bukusi, Sande, & Cohen, 2008) and in some countries HIV treatment providers are shifting more and more responsibilities to lower level workers to address these serious resource constraints.

### **Obstacles for International HIV Providers**

HIV has long-term financial implications for treatment costs because it is a chronic condition that requires medical attention throughout the life of the patient. The fourth chapter of this dissertation focuses on the increased constraints to HIV treatment providers due to international donor funding for HIV programs diminishing in recent years, which may damage the availability of HIV programs worldwide to achieve universal access and sustain current progress. The literature largely focuses on those HIV providers who are in low- and middle-income countries and strategies to begin matching more international funding. Findings include the perception of shifting global trends, combined public health efforts, distrust of government access to HIV records, and the ways health workers need additional support. Particularly interesting are the challenges faced by Community Health Workers in Kenya, as they appear to have been immediately and severely impacted by diminishing international funds. Implications are discussed for countries attempting to allocate additional funding to their own HIV relief and for health workers in rural settings.

### **Conclusion**

This first chapter highlights the various parts of this dissertation, calling attention to the statement of the problem, purpose of the dissertation research, methodology, and introduces the final scholarly papers in Chapters 2, 3, & 4. This introductory chapter will be bookended with a closing chapter, Chapter 5, addressing the challenges and limitations of the research and implications from the findings of the three studies will be interwoven and discussed at length.

Particularly noteworthy is a call to action for the international profession of social work and social work educators to coalesce and have a voice in these important global conversations.



**CHAPTER 2**  
**USING THE FOUR QUADRANT APPROACH TO ETHICAL DECISION-MAKING**  
**FOR INTERNATIONAL SOCIAL WORK: A CASE STUDY**

Social work values and ethics have been acknowledged as unifying features of the international profession, but from a multicultural perspective these values and ethics may be more divisive than unifying. Navigating ethical dilemmas where cultural context impacts decision-making can be particularly challenging for social workers. In 1982, Siegler and Winslade published *Clinical Ethics*, in which they describe the then-new four quadrants approach to, a method of analyzing clinical ethics cases. Although the book is now in its 6<sup>th</sup> edition, a literature search has revealed only two academic papers demonstrating the method at work. However, the four quadrant approach to ethical decision-making is now being recommended by an independent international working group for use in numerous countries to guide difficult decisions around HIV patient care. This approach has been implemented in other healthcare professions in the United States and in parts of the United Kingdom and has been popularized through its use in the ethics fellowship-training program at the University of Chicago's MacLean Center for Clinical Medical Ethics (Sokol, 2008). However, very little published research examines the appropriate uses of this model in multicultural international use in cases for non-consensual HIV disclosure? There may be specific policies or cultural factors to consider that may or may not be addressed by the approach. Therefore, an actual case study of an ethical dilemma presented to the author by a trained social worker in Lebanon is examined

through the four quadrant approach to further explore these concerns. Please note, some information has been changed to protect the identity of those involved.

*Case Study:* Hassan is a 19 year-old man being treated for HIV in Beirut, Lebanon. He believes he was infected with HIV due to past intravenous drug use. Hassan has been taking antiviral medication for the past three months and is six months sober from drugs. However, he has recently found out he is also positive for Hepatitis C and has not yet started treatment. He told his social worker that he has not yet disclosed his HIV or Hepatitis C status to his girlfriend, Fatima, and that she is currently two months pregnant with their child. Fatima is 18 years-old and an active intravenous drug user. She is not a client, nor does Hassan know Fatima's HIV or Hepatitis C status. Hassan has reported Fatima is trying to stop using drugs due to her pregnancy. While both adults still live at home with their families, they have hidden the pregnancy from their parents as pre-marital sex goes against the families' faith. Hassan told his social worker that she is the only other person who knows about the pregnancy. Since disclosing this information, the social worker has tried to convince him to bring Fatima in to get tested in order to get the treatment needed if she is infected, but the social worker believes that Hassan is stalling and is not being cooperative. However, rapid response is needed due to the risks of transmitting HIV or Hepatitis C to Fatima and the unborn child. What should the social worker do?

If or when to disclose a client's HIV status is a common and challenging ethical and human rights concern social workers and other health professionals regularly face all over the world. These concerns are particularly challenging to Western-trained social workers who may

be working in countries that do not have the legal and social frameworks to support non-disclosure ideals in relation to HIV transmission. In these instances how can social workers balance the medical confidentiality, safety, and wellbeing of people living with HIV and the cultural norms of the rights of families? When faced with these difficult ethical dilemmas, a systematic approach would be used to ensure success in reaching an ethical decision or recommendation for a client. Therefore, the purpose of the paper is to understand the goodness-of-fit between the four quadrants approach to ethical decision-making for non-consensual HIV disclosure within the international social work profession.

### **The Four Quadrants Approach**

The four quadrants approach consists of four broad topics: medical indications, patient preferences, quality of life, and contextual features. Each topic represents one of the four quadrants, within which lie more specific questions. *See Table 2.* Take specific note of the suggested hierarchy of the quadrants going from top down and left to right. The medical indications portion appears first, followed by the patients' preferences, and quality of life. Visually, the contextual features quadrant appears to be given the least priority. However, these contextual features are of specific interests for social workers wanting to be culturally competent when practicing internationally. The creators of this model stressed each quadrant is essential in the decision-making process (Jonsen, Siegler, & Winslade, 2010).

<b>Medical Indications</b>	<b>Patient Preferences</b>
<p data-bbox="183 268 630 300"><i>Beneficence and Nonmaleficence</i></p> <ul data-bbox="240 344 792 751" style="list-style-type: none"> <li>• What is the patient’s medical problem? History? Diagnosis? Prognosis?</li> <li>• Is the problem acute? Chronic? Critical? Emergent? Reversible?</li> <li>• What are the goals of treatment?</li> <li>• What are the probabilities of success?</li> <li>• What are the plans in case of therapeutic failure?</li> <li>• In sum, how can this patient be benefited by medical care, and how can harm be avoided?</li> </ul>	<p data-bbox="820 268 1219 300"><i>Respect for Patient Autonomy</i></p> <ul data-bbox="868 344 1435 821" style="list-style-type: none"> <li>• Is the patient mentally capable and legally competent? Is there evidence of capacity?</li> <li>• If competent, what is the patient stating about preferences for treatment?</li> <li>• Has the patient been informed of benefits and risks, understood this information, and given consent?</li> <li>• Has the patient expressed prior preferences (e.g., advance directives)?</li> <li>• In sum, is the patient’s right to choose being respected to the extent possible in ethics and law?</li> </ul>
<b>Quality of Life</b>	<b>Contextual Features</b>
<p data-bbox="183 945 760 1010"><i>Beneficence, Nonmaleficence, and Respect for Patient Autonomy</i></p> <ul data-bbox="240 1054 792 1423" style="list-style-type: none"> <li>• What are the prospects, with or without treatment, for a return to normal life?</li> <li>• What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?</li> <li>• Is the patient’s present or future condition such that his or her continued life might be judged as undesirable?</li> <li>• Are there plans for comfort and palliative care?</li> </ul>	<p data-bbox="820 945 1101 976"><i>Loyalty and Fairness</i></p> <ul data-bbox="868 1020 1414 1423" style="list-style-type: none"> <li>• Are there family issues that might influence treatment decisions?</li> <li>• Are there provider (physician, nurse) issues that might influence treatment decisions?</li> <li>• Are there financial and economic factors? Religious or cultural factors? Are there problems of allocation of resources?</li> <li>• Is there any conflict of interest on the part of the providers or the institution?</li> </ul>

Table 2. The Four Quadrants Model from Jonsen, Siegler, & Winslade (2010)

### Medical Indications

The medical indications quadrant is the suggested starting point of any ethical case analysis (Jonsen, Siegler, & Winslade, 2010). It requires the social worker to review the critical issues surrounding a client’s health, identify treatment options, and determine how the client can be benefited, if at all, by treatment. According to Hassan’s social worker, his health would

greatly benefit from Hepatitis C treatment, and his treatment would lessen the risk of transmission to others, including Fatima and the unborn child. Additionally, Fatima needs to be tested for HIV and Hepatitis C to better identify her current health needs and neonatal care. Without treatment, mother to child HIV transmission rates from range from 15-45% (WHO, 2015). This rate can be reduced to levels below 5% with effective interventions (WHO, 2015). Hepatitis C has a mother to child neonatal transmission rate of about 5% with or without treatment (Mok, Pembrey, Tovo, & Newell, 2005; WHO, 2015). However, there may be slight smaller risk (about 3% neonatal transmission) for those mothers who are also being treated for HIV through antiretroviral therapy (ART) (Snijdewind et al., 2015). Therefore, it would be medically ideal if the social worker could provide HIV treatment and counseling to Fatima in order to better understand her risk factors, current HIV/Hepatitis C status, and health needs. Unfortunately, there is much unknown about Fatima's condition as the social worker only knows what Hassan has told her.

### **Patient Preferences**

The patient preferences quadrant focuses on the wishes of the client. Hassan appears competent and is not under the influence of substances. Three months ago when he first told his social worker about Fatima, he agreed to bring her in for testing, but he has delayed this process and refused to share her contact information with the social worker. Since that disclosure, Hassan shuts down when asked follow-up questions about Fatima or her neonatal care. It appears as though he does not want Fatima to know about his HIV or Hepatitis C status, and he has not shared why he is reluctant to disclose this clarifying information with the social worker. Based on recent behavior, the social worker is concerned Hassan may stop meeting with her all together

if she continues to press the issue, which may influence his sobriety status, treatment consistency, and long-term health.

Additionally, Hassan is financially dependent on his parents and they have been very active, both financially and emotionally, in his treatment for HIV and substance abuse. Hassan's parents call the social worker regularly and expect the social worker to talk candidly about Hassan's case so they can ensure he is properly cared for at home. Hassan told the social worker his parents would not let him see Fatima if they knew about her pregnancy. The social worker is concerned that if Hassan's parents find out she knows about Fatima and does not tell them, they may terminate Hassan's treatment with her agency. She ultimately fears disruption in his treatment may jeopardize his long-term health. Fatima's preferences are not known in this situation.

### **Quality of Life**

All treatment interventions should aim to maintain or improve a client's quality of life. When evaluating the suitability of a treatment decision, it is important to consider how it will impact the client's quality of life and how likely it is to achieve the overall goals of treatment. In the case study, Hassan reported being happy about the pregnancy and wanting the responsibility of fatherhood. However, the social worker thinks she may be putting Fatima and the unborn child at risk of contracting life-complicating viruses by supporting Hassan's decision to stay quiet. If Fatima is positive for either HIV or Hepatitis C, it could strain Fatima's relationship with Hassan and make co-parenting challenging.

In addition, Hassan is currently looking for a job. His parents are hesitant for him to become employed because they are afraid if he has his own money, he will start using drugs again. With or without a job, the social worker has concerns that Hassan will be able to take full

reasonability to ensure the financial stability and medical care of himself, his girlfriend, and their soon-to-be child.

### **Contextual Features**

As the authors (Johnse, Siegler, & Winslade, 2010) of this model acknowledged, every interaction with a client occurs within a larger social and political context. This final quadrant invites workers to consider contextual features and their relevance to the ethical analysis of the case. These may include political, economic, religious, and cultural factors, confidentiality issues, and the impact of the decision on the patient's family, community, or progression through treatment. The quadrant also encourages workers to reflect internally on any biases that might influence treatment decisions. As this final quadrant is less defined than the others, relevant issues may need to be parsed out into broader themes to create additional quadrants. In Hassan's case, the laws and procedures around HIV disclosure, HIV stigma, and the expectations of shared health information with his family complicate the analysis and are broken down into their own mini-quadrants.

**HIV Disclosure Policy.** While HIV status is considered protected in Lebanon, unless there is a serious risk of transmission to other people, health professionals or employers do not always respect confidentiality protocols with few (if any) consequences due to extreme stigma and cultural norms. In other countries in the Middle East, the majority of HIV testing is mandatory (e.g., part of the job hiring process) with little guidance on disclosure (Hermez, Petrak, Karkouri, & Riedner, 2010). Here, it is important to note that the legal context has an impact on institutional support for disclosure at health facilities in the form of guidelines, protocols, programs, and other resources that enable social workers and other health professionals to support their clients around disclosure.

For those countries with guidelines, laws, and policies that may authorize but not require health professionals to inform sexual partners about their clients' HIV-positive status, such as in Lebanon, the UN High Commissioner for Human Rights and UNAIDS (2006), suggests consider the following questions: 1) Has the HIV-positive person has been thoroughly counseled? 2) Has counseling failed to achieve appropriate behavioral changes? 3) Has the HIV-positive person refused to notify or consent to notification of partner(s); and 4) Does a real risk of HIV transmission to the partner(s) exists? In Hassan's case, the answer is 'yes' for all of these questions. Based on the guidance from the UN, the social worker has the option to inform Fatima of Hassan's HIV status due to her risks without his consent.

**HIV Stigma.** As stated previously, intense institutionalized stigma and discrimination around HIV has been a major challenge to prevention efforts in the Middle East (Abboud, Nouredine, Juijer, DeJong, & Mokhabat, 2010; Mumtaz; Riedner, & Abu-Raddad, 2014). In this region, there has been relatively little published research on ways to address HIV-related stigma and attitudes as discussing sexuality remains taboo and societal views continue to be very conservative and largely hostile towards intravenous drug use, premarital sex, and same-sex sexual behavior, which perpetuates silence around HIV transmission and makes estimating prevalence rates difficult.

**Roles of Families and Communities.** In locations where access to health and social services is deficient and kinship care continues to be strong, families may be perceived as being accountable for people who are unwell and therefore have a right to be knowledgeable about the HIV positive status of their family member (Li et al., 2007; Yoshioka & Schustack, 2001; Satyanarayana, Chandra, Vaddiparti, Benegal, & Cottler, 2009). If, as in India, close involvement of the family is thought to be in the best interest of the patient, than a social



worker's breach of confidentiality can be seen as choosing to conform to local social norms rather than to national standards (Datye et al., 2006).

**Roles of Professionals.** In studies throughout the Middle East and parts of Africa, workers describe stress and uncertainty about how to respond when patients' refuse to disclose their status to partners or put children at risk (Evans & Ndirangu, 2009). For example, in Uganda, HIV counselors described wanting more guidance about what to do when members of discordant couples refused to disclose their HIV status to one another (Medley & Kennedy, 2010). Angotti et al. (2012) discussed the strain between social and ethical norms of rural African communities and the testing and disclosure standards based on Western concepts that emphasize individual rights. Such evidence suggests that policy debates about confidentiality and facilitated disclosures of HIV status are pertinent to difficult challenges that care workers face in their daily work, and that if common ground can be found between the values of patient privacy and protection of public health, then this should be converted into better guidance to health workers (Angotti et al., 2012).

Physicians are given final authority to decide on disclosure in some countries, as detailed in a comparative study in Asian and Middle Eastern countries where 80% of Saudi physicians stated they would reveal a patient's HIV status to his or her family without consent (Mobeirrek et al., 2008). Practitioners may think they know better than low-income or uneducated clients, particularly women, and they involve family members as a way of identifying hierarchies within families in order to make health decisions on behalf of patients (Chandra, Deepthivarma, & Manjula, 2003). A qualitative study from Lesotho (2008) found that when health professionals kept patients' HIV status strictly confidential, some family caregivers lacked crucial information needed to secure appropriate medical care for their loved ones (Makoae & Jubber, 2008).

### **Recommendation Based on the Four Quadrant Model**

Completing the ethical decision-making model allows the social worker to think through these important considerations and documenting factors before making a decision. Based on the findings from working through the model with the case study, the social worker has the option and legal backing to inform Fatima of her risks. However, the social worker fears the severe consequences to Hassan and his long-term treatment. While all of these factors are well documented through the use of the model, there is not a clear recommendation for the social worker from completing the model. It appears that disclosure is dependent on opposing sets of values: Those designed to respect clients' confidentiality and those meant to assist and protect those around the client. Social workers may be caught between these conflicting values and may feel that they should provide information to family members, either to rally support for an HIV-positive person or because they feel responsibility to those around that person if patients refuse to disclose themselves (Seidel, 1996).

### **Discussion**

An enduring question for social workers, highlighted by this case study, is whether there are any universal "truths" in social work ethics. Are social work values and ethical standards always dependent on local views and customs or are some standards applicable across all cultures? To what extent is it appropriate to say that social workers everywhere, without exception, should promote social and economic equality, uphold the dignity and worth of people, and strengthen the recognition of the importance of human relationships? To what degree are these vitally important social work values culture bound? As an international profession can we commit to supporting, influencing, and enabling structures and systems that positively address the root causes of oppression and inequality? At the very least, social workers should be mindful of the provocation in the NASW Code of Ethics (2008) concerning practitioners' duty to learn

about, and be sensitive to, clients' cultures: "Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups" (1.05[b]).

Since the arrival of HIPAA and other strict confidentiality statutes and regulations, social workers trained in the United States are extremely concerned with protecting client confidentiality (Reamer, 2013). With rare exceptions (e.g., emergencies involving imminent risk), social workers cannot share confidential information about clients with their family members without client consent. However, in other cultures, the family unit is considered primary, so much so that social workers are expected to share information about the client with the family, even in the absence of the client's informed consent individual clients' privacy interests are secondary (Reamer, 2013). Indeed, in some cultures the concept of informed consent is not widely recognized (Nijhawan et al., 2013) Furthermore, in other cultures family members are inclined to share confidential information about the client with the social worker, fully expecting that the social worker will not share this information with the client (e.g., concerning the client's poor health prognosis or the family's plan to place the client in a nursing home) (Mobeirrek et al., 2008).

The relevance of the universalism/relativism debate in social work has grown with the increased globalization of the profession and expanding practice contexts (Healy & Link, 2012). This discussion is pertinent not only to cross-national practice and cross-national efforts to define professional values, but increasingly to social work within countries, as more and more countries become multicultural. The conversation is also germane through social work's growing involvement in the global human rights struggle (Mapp, 2014). Universalism and relativism are

hotly contested in the field of human rights, especially regarding the rights of oppressed and excluded groups (Healy & Link, 2012).

### **Universalism and Relativism**

Competing schools of thought in ethics differ in the extent to which ethical rules are viewed as fixed or contextual. These points of view are at the heart of debates in the arena of human rights, where they are often labeled the *universalist* and *cultural relativist* positions (Dolgoff et al., 2005). The deontological school of ethics “stresses the overriding importance of fixed moral rules,” arguing that “an action is inherently right or wrong” and therefore those ethical rules are universal (Dolgoff et al., 2005, p. 43). The universalist’s view is that “all members of the human family share the same inalienable rights” (Mayer, 1995, p. 176) and that “culture is irrelevant to the validity of moral rights and rules” (Donnelly, 1984, p.400).

The teleological school holds that ethical principles are contingent on context; ethical decisions may vary “on the basis of the context in which they are made or on the basis of the consequences that result” (Dolgoff et al., 2005, 42). As explained by Donnelly (1984), an extreme cultural relativist argument is that “culture is the sole source of the validity of a moral right or rule” and that there are no common standards, only culturally specific ones (p. 400). Between these extremes are mixed positions, ranging from moderately universalists to moderately relativist. Individual social workers may find their positions on the continuum are not static but move along the mid-ranges depending upon the particular situation.

Many stakeholders in the international human rights area struggle with the extent to which individual human rights supersede claims of cultural or national sovereignty. For example, the rights of racial groups, women, and children were encouraged internationally in the Convention on the Elimination of All Forms of Discrimination (CEDAW) of 1979 (Cobbah,

1987). The strongest voices of opposition to CEDAW have come from the Middle East and Africa. The African scholar Cobbah (1987) objects to what he labels the individualistic bias of human rights treaties. He states that universal declarations are “a product of Western liberal ideology” and cites similarities between this cultural standardization and colonial rule (Cobbah, 1987, p. 316). Fearing the type of cultural change that CEDAW promotes, Cobbah posits the international promotion of human rights may be a Trojan horse sent in to change African cultures. Similarly, Mutua (2000) argues for the specific African Charter on Human Rights to “eliminate every discrimination against women” (p. 10) but also highlights the duty to “preserve the harmonious development of the family” and to uphold traditional values (as cited in Murrey, 2001, p. 9). Mutua (2001) suggests international treaties should incorporate values of communalism, such as hierarchy, respect, restraint, responsibility, and reciprocity, and “groupness, sameness and compatibility” rather than individual freedoms (as cited in Murrey, 2001, p. 9). Some of these values may be more likely to be accepted by social work (such as responsibility and reciprocity) than others (like hierarchy and restraint) in aim of social justice.

Individual social workers may find both the universalist and relativist positions attractive for different reasons. Social work codes of ethics from diverse countries show considerable agreement about fundamental social work values (DuBois & Miley, 2013), suggesting a modest level of universalism. Noteworthy, it must be recognized that existing social work codes of ethics and ethical decision-making models fail to explicate the communalist perspective and are fairly heavily biased towards the individualistic cultural perspective. Individualism, especially in its rugged and competitive forms, diminishes the importance of caring, reciprocity, community building, generosity, and cooperation. Conversely, the communalist perspective holds important

values that can be captured in social work ethics and future ethical decision-making models in diverse international communities.

### **Implications for International Social Work Practice**

Social workers who are trained in the West or who are inclined to adopt Western-oriented interventions must reconcile their beliefs in clients' fundamental right to self-determination with their beliefs about what interventions are in their clients' best interest as reflected in the evidence-based professional literature. The complex challenge for all social workers, it seems, is to recognize that while some ethical issues are truly international and cross-cultural, others may be unique to diverse nations and cultures. The concepts of confidentiality, privacy, boundaries, and self-determination are relevant for social workers everywhere, but their particular meaning and application vary considerably. Social workers who firmly embrace ethical standards and concepts in their own nation, language, and cultural context must be careful to avoid assuming these standards and concepts translate well in other nations, languages, and cultural contexts. Therefore, it is worth introspection for potential ethical hubris, where social workers may assume their personal view of ethical issues fits squarely anywhere in the world.

In this respect, social workers can learn much from widely accepted principles in cultural anthropology. For decades, cultural anthropologists have reminded us how important it is to enter another culture sensitively and empathetically (La Brack & Bathurst, 2012). Skilled ethnographers rely on participant observation and efforts to learn from key informants in a way that is deeply respectful of the informants' worldview. Social workers who seek to understand and appreciate the ways in which different nations and cultures interpret and apply key ethical concepts would do well to draw on these time-honored principles and methods.

## **Application of the Four Quadrants Approach in International Social Work**

How appropriate, then, is this tool for international social work use? It appears as though the tool is beneficial for social workers who want to systematically think through and document the various ethical aspects of a case, which can be helpful when justifying decisions. However, the vague and non-directive nature of the four quadrants model does not often end with a *clear answer* for practitioners, as indicated in our case study, which social workers should be aware of before spending valuable time completing the quadrants. For international application, on the other hand, being vague and non-directive about a case's contextual features could be framed as a strength of the tool. Notably, someone who understands the local customs, values, and ethics may employ the tool more successfully than an outsider. For example, a social worker raised and educated in Lebanon would more likely to prioritize the contextual features more accurately when working with Hassan than a British-trained social worker.

If international social work associations want to enhance the application of the four quadrants approach to social workers all over the world, they may wish to consider developing an accompanying piece prioritizing a hierarchy of values or concerns for specific countries and/or regions in more culturally relevant ways. However, without a clear understanding of the most important values and concerns of a specific nation, geographic region, or in a family, the four quadrant ethical decision-making model is not recommended for international use for non-consensual HIV disclosure. Even with a pristine understanding of local values, non-consensual HIV disclosure has irreparable consequences to clients, as explored throughout the rest of this dissertation. Instead, social workers should seek guidance from skilled clinical supervisors and peers to support their client with the difficult decisions of how and when to disclose their HIV status.

## **Conclusion**

Hopefully, this beginning effort to assess the goodness-of-fit of the four quadrant model demonstrated that ethical decision-making is highly complex in multicultural contexts.

Consideration of the extent to which social worker values should be applied universally is particularly challenging. The four quadrant approach for case analysis and decision-making has both strengths and limitations, and overall, is recommended for instances with social workers who want to document their systematic analysis of ethical dilemmas. In addition, more research and analysis is needed on international ethical principles to explore ways in which positive communalistic values can be accommodated into social work practice and decision-making.



### CHAPTER 3

#### **BARRIERS TO DISCLOSURE FOR PEOPLE LIVING WITH HIV: COMPARING CASE EXAMPLES FROM AUSTRALIA, KENYA, AND LEBANON**

HIV is a global pandemic, and people living with this disease experience challenges, compounded by stigma, throughout the world in varying degrees (Gohain & Halliday, 2014). Researchers and activists have argued that HIV related stigma is a persistent force reducing the effectiveness of preventative measures, discouraging those at risk of infection from HIV testing, and creating barriers to HIV related treatment (Dlamini et al., 2009; Link & Phelan, 2001; WHO, 2010). Stigma exists at multiple levels, from within individuals, interpersonal relationships, and broader political and cultural structures (Mahajan et al., 2008). This stigma can create barriers to disclosure and negatively impact multiple domains of an individual, including one's home life, employment, and health care decision-making (Deacon, 2006; Holzemer et al., 2007). This study attempts to identify thematic barriers to disclosure for people living with HIV/AIDS in Australia, Kenya, and Lebanon in order to inform service delivery and social justice advocacy for these highly stigmatized and vulnerable groups of people around the world.

Frameworks on stigma differentiate between experiences of discriminatory behavior ("interpersonal discrimination") and internalized feelings of low self-worth ("felt or internalized" stigma) (Link & Phelan, 2001). Of course, both types of stigma can negatively influence people with HIV. Living with strong negative social stigma and challenges to their health, people living with HIV may endorse negative beliefs and feelings associated with HIV about themselves (Mak, Poon, Pun, & Cheung, 2007). Internal stigma, described as felt, imagined, or self-stigma is

the product of the internalization of shame, blame, hopelessness, guilt, or fear of discrimination associated with being HIV-positive (Brouard & Wills, 2006). Internal stigma is intrinsically linked with external stigma, as the fear of judgment or discrimination from others can profoundly influence the way in which people living with HIV view themselves, cope with their HIV status, and make daily decisions (Brouard & Wills, 2006). Internalized stigma can make individuals more sensitive to actual, perceived, or anticipated rejection by others, which detrimentally complicates self-disclosure and candid conversations (Chesney & Smith, 1999).

Additionally, an HIV/AIDS diagnosis can bring financial challenges to already vulnerable populations. Healthcare access comes at a cost, including transportation and opportunity costs to clinic visits and substantial treatment costs. Studies show co-occurring economic stressors of adult HIV infection, such as loss of earnings, healthcare expenditures, disruption of savings, and premature sale of hard-to-replace assets (e.g., cars, houses, retirement savings) to meet healthcare costs (Bachmann & Booyesen, 2006; Collins & Leibrandt, 2007) can be debilitating. Financial strain on individuals and their families can create challenging environments where options are limited and healthy decision-making is more challenging.

### **Importance of HIV Disclosure**

Despite increasing numbers of people being tested all over the world, research indicates that substantial proportions of individuals diagnosed with HIV do not reveal their serostatus to those around them, including sexual partners and family members (Obermeyer, Baijal, & Pegurri, 2011). Low rates of HIV disclosure raise difficult ethical and human rights concerns about how to balance medical confidentiality, safety, and wellbeing of people living with HIV and the rights of partners and children to be protected from HIV transmission. Around the globe a spate of recent laws, policies, and programs have tried to encourage, or in some cases, mandate

HIV disclosure. These policies have generated ethical and policy debates within legal and public health circles (UNAIDS, 2015). Meanwhile, international public health agencies have launched initiatives to encourage voluntary HIV disclosure and to include partner testing as part of antenatal care (Obermeyer et al., 2011).

Reported disclosure rates can be difficult to compare across studies when researchers use different categories of people to whom individuals disclose (e.g., to anyone, family, friends, partners, etc.). In addition, disclosure rates are usually based on self-reports, which may not always be reliable. For example, a study from Kenya found that a substantial percentage (27%) of men who said they had disclosed to their partners were contradicted by their female partners who said they did not know their partner's status (Katz, Kiarie, John-Stewart, Richardson, John, & Farquhar, 2009). Smaller but still substantial levels of conflicting reports were found in Malawi (Anglewicz & Chintsanya, 2011).

Research suggests that HIV disclosure is not a one-time event, but a process that occurs over time as HIV-positive individuals disclose to different people in their network (Obermeyer et al., 2011). For example, a study from South Africa found that while nearly all (92%) respondents disclosed to at least one person, a substantial percentage (15%) waited more than a year to tell their partners (Skogmar et al., 2006). In Tanzania, only 22% of pregnant women interviewed disclosed to partners within 2 months of diagnosis, and 40% had done so after 4 years (Antelman et al., 2001). Disclosure varies by HIV status, and those who test negative generally report higher disclosure rates than those who test positive (Brou et al., 2007; Medley & Kennedy 2010) with some exceptions (Kiene, Bateganya, Wanyenze, Lule, Nantaba, & Stein, 2010).

### **Balancing Disclosure, Confidentiality, and Partner Notification**

Lack of HIV disclosure to partners pose serious ethical challenges, particularly given that considerable proportions of those living with HIV are members of serodiscordant couples

(Desgrees-du-Lou & Orne-Gliemann, 2008; Eyawo et al., 2010). A recent review (Obermeyer, Bajjal, & Pegurri, 2011) found that disclosure rates around the world varied widely, with lower rates typically reported for partner disclosure compared to disclosure to other family members. While men and women may fear negative consequences of disclosure, secrecy carries its own burdens, including isolation, lack of support in the face of a potentially life threatening disease, and concerns about transmitting the infection to partners or children (Cames et al., 2010). Health care providers in these countries may struggle to balance a duty to notify partners at risk with a competing ethical obligation to protect the medical confidentiality, safety, and wellbeing of those living with HIV (Evans & Ndirangu, 2009).

Policy makers are also grappling with the dilemma of confidentiality and its limits. There is consensus within the international public health and human rights community that criminalizing nondisclosure undermines human rights and serves no useful public health benefit (UNAIDS, 2008). However, there is less consensus about the ethics of partner notification. In the face of nondisclosure to sexual partners, some argue that partner notification, even without the patient's consent, may be the "lesser of two evils" (Masiye & Ssekubugu, 2008). Guidelines issued by the UN High Commissioner for Human Rights and UNAIDS, and policies in Kenya suggest that health workers may disclose patients' HIV status without their consent if a risk of HIV transmission exists, as long as they meet certain conditions, including concealing the identity of the patient (if possible) and providing follow-up support (UNAIDS, 2008). In Kenya, such conditions are difficult to fulfill and little is known about how to protect HIV-positive clients who might be placed at risk through involuntary third party disclosure (WHO, 2015).

Despite official commitments from all countries to overcome disparities in testing, most-at-risk key populations (but particularly MSM) continue to face barriers to access in parts of the

world, including the Middle East and Africa. Regional reviews in Africa note that HIV policies and programs historically focus almost exclusively on heterosexual transmission, with a corresponding neglect of research, surveillance, prevention, treatment, and care for MSM (Smith, Tapsoba, Peshu, Sanders, & Jaffe, 2009). Smith and colleagues (2009) argue that this neglect stems from a context of extreme political, cultural, and religious hostility towards such men in Africa, where (as of this writing) male-to-male sex is illegal in 35 out of 56 countries (including Kenya) and punishable by the death penalty in three countries (Ferreira, 2015). This context of hostility has serious negative consequences for access to HIV treatment and prevention services.

There have also been international debates about how to balance HIV-positive individuals' right to medical confidentiality with the need to prevent transmission to others and to diagnose partners living with HIV (Masiye & Ssekubuguu, 2008; Obermeyer et al., 2011). Additionally, there are concerns about how to ensure equitable access to testing and treatment for those who face barriers to testing and care around the globe, particularly the most at-risk populations (Mitchell, Cockcroft, Lamothe, & Andersson, 2010).

### **National Context for HIV-Related Policies and Practices**

Governments around the world have laws or policies that inform HIV disclosure, medical confidentiality, and criminalize HIV transmission. Navigating these complex social, cultural, and political challenges are both analogous and unique from country to country and from person to person. Within these related confines, people living with HIV/AIDS around the world need to make decisions about their health and the health of their loved ones (e.g., partners, children, etc.), often while their own wellbeing is compromised. However, where these people are located in the world, will impact the “how” and the “when” these decisions of disclosure or treatment are made.

## **Living with HIV in Australia**

Australia had a strong and swift response to the growing HIV epidemic in the early 1990s (Cameron & Godwin, 2014), so much so that Australia's approach to HIV became an international model (UNSW, 2014). The introduction of antiretroviral therapy (ART) in the mid-90s facilitated a shift in focus to medical interventions in Australia (Cameron & Godwin, 2014). These early treatment successes triggered a reconceptualization of HIV as a chronic but manageable condition. These medical advances signaled that HIV was no longer considered a community crisis requiring radical legal and policy interventions, and recently Australia has focused on the importance of increasing HIV testing, early diagnosis, and early treatment initiation (Cameron & Godwin, 2014).

HIV in Australia has been closely aligned with the gay community and continues to disproportionately affect its members (Brener, Wilson, Slavin, & de Wit, 2013); therefore, prevention, treatment, and supportive services have largely targeted gay men. People living with HIV in Australia have benefitted from the capacity of the publically funded health system which provides access to free or affordable medical services for all citizens (Scamell & Ward, 2009). The system uses a Pharmaceutical Benefits Scheme that heavily subsidizes the cost of medication, and there is also a social security safety net that further reduces the price of medication for those on limited incomes. Due to these effective safeguards, Australians consider the HIV crisis in their country to be largely under control (Scamell & Ward, 2009).

In addition, state and federal law make it unlawful to discriminate against any person living with HIV or any person thought to be HIV positive (Scamell & Ward, 2009). Under state law, it is also unlawful to discriminate against people on the grounds of sexual orientation, gender identity, or intersex status (Scamell & Ward, 2009). In Australia there are laws that

criminalize injected drugs use, but needle and syringe exchange programs have proven extremely effective, with an estimated 32,00 HIV infections averted and a net financial cost savings exceeding a billion dollars between 2000 and 2009 (Wilson et al., 2009). However, peer distribution of clean injecting equipment remains illegal (Wilson et al., 2009). Australian states also vary on policies around legalization of sex work, and there are states that criminalize it altogether (Donovan et al., 2012). Australia's rich economy, bountiful healthcare system, innovative policy reform, and rapid response to HIV are in direct contrast to the experiences of other countries around the world.

### **Living with HIV in Lebanon**

In contrast to Australia, intense institutionalized stigma and discrimination around HIV (and key populations) has been a major challenge to prevention efforts in Lebanon and the Middle East (Abboud, Noureddine, Huijer, DeJong, & Mokhabat, 2010; Mobeireek et al., 2008). In this region, there has been relatively little published research on HIV related stigma, and attitudes about discussing sexuality remain taboo and societal views continue to be very conservative and largely hostile towards homosexuality. These cultural norms perpetuate silence around HIV transmission and make estimating prevalence rates difficult (Mobeireek et al., 2008). Despite these challenges, the Lebanese government provides HIV-specific health treatment to those living with the virus, but there are reports of inconsistent delivery of medication (UNAIDS, 2014), which has harmful consequences to long-term HIV management.

In terms of the epidemiology of HIV in Lebanon, over the 20-year period from 1989 until December 2013 there have been a cumulative number of 1,617 HIV cases reported to the Ministry of Public Health (National AIDS Program). The number of people estimated to be living with HIV in Lebanon in 2009 was 3,760, approximately .09% of the total population

(UNAIDS, 2014). The number of reported cases has risen in recent years, with a growing rate of infection between MSM in particular. While new cases of HIV/AIDS are decreasing worldwide, it is increasing in the Middle East (UNAIDS, 2014). In 2008 a first HIV bio-behavioral survey with key populations reported risky behaviors to be relatively high but prevalence to be low, except for among MSM, where the population prevalence was found to be 2.6% (Mahfoud et al., 2010). In 2013, 119 reported cases were new, and out of these cases, 90% were among MSM (UNAIDS, 2014).

As in other parts of the world, gay online social networking sites are widely used as forums for men to connect (Abu-Raddad et al., 2010). However, Lebanon, and specifically Beirut, is seen as more socially progressive than other countries in the region (Healy & Link, 2012). While societal attitudes in Beirut have grown more tolerant over the past decade and there is increasing coverage and support in the media, stigma remains high nonetheless, and public discretion is still very much a priority in the lives of MSM in Beirut. It is worth noting that the growing acceptance of gay culture in central Beirut is not reflective as the rest of Lebanon, which continues to be predominantly intolerant of homosexuality and where “unlawful sexual acts,” including between men, remain illegal (Healy & Link, 2012).

### **Living with HIV in Kenya**

Kenya has the fourth-largest HIV epidemic in the world but is largely considered a success story in the fight against HIV. In the mid-1990s HIV was one of the major causes of mortality in the country putting huge demands on the healthcare system as well as the economy (UNAIDS, 2014). Kenya’s HIV epidemic is referred to as generalized, meaning it affects all sections of society including children, adults, men, and women. HIV prevalence peaked at 10.5% in 1996, but by 2012, this number had fallen to 6.1% (1.6 million Kenyans) due mainly to the



rapidly scaling up of ART. The same year roughly 57,000 Kenyans died from HIV-related complications (UNAIDS, 2014).

Although HIV prevalence among the general population has fallen in Kenya over the last two decades, women and key populations continue to be disproportionately impacted by the epidemic (UNGASS, 2014). Sex workers have one of the highest reported HIV prevalence of any group in Kenya. In 2011, an estimated 29.3% of sex workers were living with HIV (UNGASS, 2014). Also in 2011, an estimated 18.3% of people who inject drugs in Kenya were living with HIV (IBBS, 2012). However, the majority of HIV cases are concentrated in specific geographical areas, such as Nairobi and Mombasa (UNAIDS, 2014).

Prevalence of HIV in MSM in Kenya is more than two times the general population (UNAIDS, 2014). Sexual acts between men are illegal under Kenyan statutes and carry a maximum penalty of 14 years of imprisonment. Homosexuality is “largely considered to be taboo and repugnant to [Kenya’s] cultural values and morality” (United Nations, 2011, p. 5). While there is international pressure to change anti-gay policies, some Kenyan leaders contend that these outside interests conflict with their traditions and customs. However, as MSM continue to be stigmatized in healthcare facilities and Kenyan society, they face substantial barriers to accessing healthcare services (Onyango-Ouma, Birungi, & Geibel, 2009; Clark, 2014) causing their mental and physical healthcare treatment to be regularly postponed (Kennedy et al., 2013). MSM in Kenya who disclose their sexual orientation through choice or necessity have reported family rejection, public humiliation, harassment by authorities, and ridicule by healthcare workers (Beyrer et al., 2009; Geibel et al., 2012). This political and cultural hostility towards MSM presents a main barrier for implementing effective HIV research, policy, and health programs for MSM in Kenya.

## **Purpose**

The purpose of this paper is to better understand the political, cultural, and socioeconomic barriers in Australia, Lebanon, and Kenya that limit disclosure and treatment availability to people living with HIV to better inform service delivery and social justice advocacy for these highly stigmatized and vulnerable groups of people around the world.

## **Methods**

### **Sample**

The analysis in this paper draws on interviews conducted with stakeholders (N=79) of community-based HIV treatment providers in three countries: 1) the Victorian AIDS Council located in Melbourne, Australia (n=29); 2) SICD located in Beirut, Lebanon (n=11); and 3) NEPHAK, located in Nairobi, Kenya (n=39) in July and August of 2015. All participants were given a consent form detailing the research project with the option to opt out. *See Appendix A.* Upon receiving signed consent, the researchers conducted the interviews and focus groups with care workers and community respondents with an outline of agreed upon questions. *See Appendices B & C.* Key informants were also interviewed using the outlines for the same purpose. *See Appendix D.* Two researchers conducted all interviews and focus groups. Detailed notes were simultaneously typed or handwritten while interviewing key informants and facilitating the focus groups. Participant wording was typed whenever possible, and quotation marks placed around participants' exact wording. Participants were encouraged to examine the researchers' notes to check consistence; however, only five participants from all of those interviewed checked the notes, and no participant gave indication that he or she disagreed with what was written. Focus group interviews lasted approximately one hour. A semi-structured approach was adopted for interviews and focus groups, using themes identified through analysis of the preceding focus groups. Sections of the interview were dropped if questions were not

relevant to the interviewee. This provided consistency across participants whilst remaining flexible enough to respect the time and interest of those being interviewed. All notes were transcribed and shared between researchers.

### **Qualitative Analysis**

In qualitative research, trustworthiness is established by using well-grounded methods (Guba & Lincoln, 2005), including developing an familiarity with the participating organization and stakeholders, triangulation, frequent debriefing among researchers and participants, peer scrutiny, thick description in the findings (Shenton, 2003), and maintaining a detailed audit trail (Guba & Lincoln, 2005). Several of these findings were immediately evident (e.g., shifting financial trends) due to the rich thick description provided by participants and frequent discussions immediately after interviews between researchers. Ryan and Bernard's (2003) techniques for identifying themes from basic expressions in the notes were used. All coding in this dissertation was done independently by the author. Following intensive open coding, the coded categories were then grouped and summarized. The resulting coding structure is reflected in the themes identified in this study.

The Institutional Review Board at the University of Georgia approved this project. All identifying information was removed from findings to further protect anonymity of participants. Direct quotes and wording from participants are weaved into the findings to evoke meaning for readers. Quotations from participants are *italicized* to designate the exact words (and sometimes deeper meanings) used by participants.

### **Findings**

Research participants discussed multiple challenges when deciding to disclose their HIV status, often weaving stories of their own experiences as a way to bring clarity and meaning to the systematic barriers they face. Much of the rich, descriptive qualitative data collected in

Kenya came from residents (CHW and community respondents) of the Kibera neighborhood. Kibera, literally translated from Nubian as “jungle”, is a neighborhood 3.1 miles from the city center of Nairobi and is the largest urban slum in Africa (APHRC, 2014). Kibera residents live in extreme poverty, earning less than \$1.00 USD per day, and are exposed to many health risks as a result of confined living conditions, a lack of clean water, and limited access to health services (APHRC, 2014).

### **Socioeconomic Consequences of Disclosure**

The social and economic findings are presented together due to the frequently simultaneous consequences in one’s meaningful relationships and finances upon HIV disclosure. In both Kenya and Lebanon, participants reported fear of being dismissed from work if they disclosed their HIV status. In Lebanon one participant stated, *“They will fire me as soon as I tell them [my HIV status],”* and *“most of the people who know that you are HIV-positive won’t hire you. You could lose your friends, your family.”* Another Lebanese man told the story of a woman who was raped and contracted HIV from her attacker, but added *“if [she] disclose[s] [her] HIV status, [she] could lose [her] job the next day.”*

In Kenya, one participant stated, *“If I disclose [my HIV status], I’ll never see my partner again. Where will I stay? Where will I get food? Who will take care of my children?”* Another participant in Kenya told the story of a husband and wife who had five children together. The wife found out her HIV status, but when she told her husband, he denied any wrongdoing and left her alone with the children. It’s been three years since her husband left, and the wife has learned to support her family through an income generating activity. With such major consequences to disclosing one’s HIV status and no assurances of a financial safety net, people living with HIV must make measured decisions to ensure their safety and wellbeing.

Community health volunteers in Kenya reported they attempt to fight the continued HIV discrimination and stigma, but there are natural socioeconomic consequences if someone's HIV status is disclosed. For example, people who are known to be HIV may receive social pressures to stop accessing certain facilities (e.g., "*shared watering points*"). However, workers in Kenya reported they also thought of HIV as a "*common disease*," and people with it are now healthier, stronger than they ever were before. One participant reported that HIV has been accepted. In fact, she stated that being pregnant in Kenya has bigger health risk than being HIV-positive.

A community respondent living in the urban slum Kibera reported that she hasn't told her male partner that she's living with HIV. When asked about her decision to not tell her partner, she discussed the struggles of being a single mother in Nairobi. The ability to secure a financially stable partner is a very precious resource to her. She reported that if she does disclose her HIV status to him, he might already know he has HIV or he may blame her for infecting him, when in fact, he may have infected her. She added that being HIV-positive is not the death sentence it once was and there are other health issues to be concerned about (e.g., tuberculosis, malaria, etc.). For this mother, her priority is to provide a safe and financially stable environment for her children.

These negative socioeconomic consequences are key barriers to HIV testing and treatment. One community respondent from Kenya added, "*Some people don't want to be tested unless you give them something. They don't know if you will actually help them.*" For these individuals it appears as though the benefits of knowing one's HIV status do not outweigh the potential socioeconomic fallouts of disclosure.

## Parenting an HIV-Positive Child

Participants also commented on the challenges of parenting an HIV-positive child. Children who are HIV-positive must have consistent medical treatment (i.e., routine visits with healthcare professionals, reliable access to and consistency with HIV medications) or complications such as drug resistance can occur. According to a few participants in Kenya their children are “*on medications but don’t know why.*” Another participant mentioned that these children are told they “*have asthma or a cold*” in order for them to remain consistent with their medications. One parent spoke of the difficulties of disclosing to her daughter that she, her daughter, was HIV-positive. She told a story of a mother instructing her daughter to take her HIV medications. The mother tells her daughter, “*This [is] medication you have to take every day, otherwise you will die. After some time passes, the girl confronts her mother and says, ‘You are a liar, mother. I stopped taking [the medication] and I didn’t die.’ And the mom was forced to disclose [her HIV status].*” This story highlights the challenges that parents face as their HIV-positive children mature. One participant asked, “*When is the right time to tell your child they are HIV-positive, and they got it from you?*” She added, “*HIV is still stigmatized, and it’s not something you want to tell your children.*” Another participant highlighted the challenges specifically to parenting adolescents. This mother added, on the “*world wide web, there’s nothing they cannot find. [HIV] disclosure [to] children is very, very difficult because the parent doesn’t want to be blamed.*” These complex feelings of parents appear particularly challenging when parenting an HIV positive child. Parents want to ensure their children are emotionally mature enough to deal with the stigma of the disease while simultaneously not wanting “*to be blamed*” for these consequences.

The challenges around HIV disclosure to children impact treatment providers as well. A worker in Kenya commented on struggling to support HIV-positive parents and their positive children. He said, *“We are not in the business of disclosing people’s status, but what do you do if you see a HIV-positive mother breast-feeding?”* Of course not all parents have access to HIV treatment. One parent commented, *“When I was expecting my son, there was not enough [HIV medication], but luckily my child was not HIV positive. Now whenever I see a positive pregnant woman, I feel like I should do something to support her, and I thank God all of those children are HIV negative. The people I’ve worked with continue to call me and update me about their lives. I feel good because of those children. We need to have a generation free of HIV.”*

### **Policies Perpetuate HIV Stigma and HIV Transmission**

HIV treatment providers in Australia, Lebanon, and Kenya mentioned a reluctance to involve police or authority figures, even when clients intentionally do not disclose their HIV status to sexual partners due to the severe potential consequences to the client’s treatment and backlash from the community due to continued HIV stigma. Workers in all three countries mentioned ways of navigating their systems in order to inform potentially infected people rather than trying to incriminate their client despite nondisclosure of one’s HIV status to sexual partners being criminalized in all three countries. An overwhelming majority of workers believed that reporting non-disclosure of HIV is going to cause more damage (e.g., loss of job, isolation from family, potential death, etc.) than good.

*Australia.* All Australian states and territories have criminal laws that can be applied to cases of HIV transmission or exposure through sex. Such cases have been reserved for instances where the accused is alleged to have failed to disclose their HIV status before sex, effectively criminalizing sex without disclosure. Australia’s HIV criminalization statutes are inconsistent

with public health models because they discourage people at greatest risk for HIV from getting tested (Deblonde, et al., 2010). By limiting criminal liability only to those knowledgeable about their HIV infection, it disincentives people to get tested so they will not be liable for any criminal charges, which may increase the transmission of other Sexually Transmitted Infections (STIs) (Deblonde, et al., 2010).

While there are policies in place to protect people living with HIV in Australia there is still the threat of prison from non-disclosure. Incarcerating people who know their HIV status further stigmatizes testing and those people who are HIV-positive. While criminalizing non-disclosure goes against public health models, some workers think criminalization may have some benefit. For example, a key informant from Australia reported that confidentiality *“can be double edged, though. If you don’t have awareness and publicity, you can also be forgotten – things can be kept out of the view of the general public.”*

In addition, in parts of Australia sex work is legal and sex workers are required to get frequent STI tests in order to continue working. Australian research suggests that mandatory testing for sex workers is expensive, invasive, and without benefit to the individual or society. According to Australian researchers, mandatory tests fail to reach the intended target group, drawing testing resources away from high-risk populations and do not reduce HIV infection rates (Jeffreys, Fawkes, & Stardust, 2012; Sataranayake et al., 2009; Wilson et al., 2009).

**Lebanon.** As previously stated, Lebanon is largely intolerant of homosexuality and where ‘unlawful sexual acts’, including between men, remain illegal under ‘Article 534 - Law Against Nature’ (UNAIDS, 2014). Despite same-sex sexual activity being illegal, community respondents in Lebanon discussed a culture clash, of sorts, in Beirut between traditional customs and Western ideals frequently seen through television, cinema, and social media. Participants



discussed multiple Lebanese celebrities publicly advocating for equal rights for same-sex couples. In addition, people are starting to come out to their families as LGBT and/or HIV-positive. Participants also mentioned that the government is taking notice of these shifting cultural tides and pushing back against them. According to one participant, government officials are targeting LGBT activists and arresting them. He stated that the government is using intimidation measures, such as arresting 27 men in a Turkish bath in 2014 (Stewart, 2014), two of whom were his friends. These men were not arrested for engaging in same-sex activity, but because of their assumed sexual orientation (Stewart, 2014). Two community respondents discussed a telephone hotline for LGBT persons who are arrested due to their assumed sexual orientation that links them with an attorney who is experienced in combatting this particular policy. Despite the recent pushback from the Lebanese government as they strangely enforce these anti-gay policies, the participants believe the stigma surrounding HIV and homosexuality is declining in Beirut over the last decade.

For intravenous drug users who are arrested in Lebanon, there are also major hurdles to recovery and HIV treatment. One participant stated that *“instead of going to rehab, they go to jail to get more drugs.”* She also mentioned that the judicial system had *“a lot of corruption when it comes to drug users. The rich are able to leave sometimes - get out of it, and the poor will always get it in the head. They will be sent to jail instead of going to rehab, they go to jail to get more drugs.”* She continued, if they go to jail *“they learn how to do worse things. At least they may get help [in rehab, but] in jail, it’s God forsaken.”*

The same worker told the story of a person living with HIV and Hepatitis C who went to jail for drug possession. This client was prescribed medication that required the use of a syringe. In jail the client would not take his full dose and would attempt to sell the rest to other inmates.

The worker instructed her client that he must stop selling his medication due to the high risk of transmitting HIV or Hepatitis C. She spoke with the attending physician and got his dosage significantly lowered without disclosing the risk of transmitting HIV or Hepatitis C to other inmates. Two weeks later she discovered he was still selling his medication. After consulting with her treatment team, she told the doctor to change his medication due to his HIV status. Neither the social workers nor the doctor involved the authority. However, the client was very upset with the worker and did not return to treatment once leaving jail. The worker has not been able to connect with the client since he was released. The consequences of HIV disclosure make it challenging to ensure consistent treatment adherence.

**Kenya.** As previously discussed above, non-disclosure of HIV status with partners and sex acts between men are illegal in Kenya. Participants stated that these non-disclosure policies make it challenging for HIV treatment providers. One worker stated that the unintended consequences of involving authority when a client does not disclose their HIV status to partners “*make it difficult to go to the police.*” The same worker suggested, “[*W*]e need to amend our policies so we can work freely without fear.” While sex acts between men are illegal, no one in our sample openly identified as MSM, and therefore we did not have the opportunity to discuss the intricacies of this barrier for openly gay and bisexual men.

Workplace discrimination based on HIV status is also illegal in Kenya. However, there are ways for employers to get around this policy. One Kenyan participant spoke about HIV discrimination in the workplace and stated that HIV discrimination “*won’t be done directly.*” She stated that if an employer wants to fire you for being HIV-positive, an employer will just cite another reason.

## Discussion

### Socioeconomic Consequences of Disclosure

Substantial research from around the globe has examined the substantial consequences, both positive and negative, of HIV disclosure (Deribe et al., 2008; Gari, Habte, & Markos, 2010; Obi & Ifebunandu, 2006; Paintsil et al., 2015). From these studies, and reinforced in this study, it is clear that fears about negative reactions from partners, family members, employers, and communities are a major barrier to both testing and disclosure throughout the world (Beyrer et al., 2009; Geibel et al., 2012). Similar to this study, other researchers have documented a myriad of negative reactions from HIV disclosure, such as isolation, criticism, ostracism by family members (Obi & Ifebunandu, 2006), divorce, separation, violence from partners, and rejection by friends (Deribe et al., 2008; Gari, Habte, & Markos, 2010; Iliyasu, Abubakar, Babashani, & Galadanci, 2011).

Variations in disclosure rates, particularly to partners, reflect multiple factors. For example, in South Africa studies have found higher disclosure rates in urban cities with more institutional services available compared with rural areas (Norman, Chopra, & Kadiyala, 2007), and among individuals with higher socio-economic status (Wong et al., 2009). Similarly, in Nigeria, researchers found that respondents with higher levels of education disclosed more often than less educated counterparts (Akani & Erhabor, 2006). The association between disclosure and socioeconomic status is not simple, however, and may be influenced by gender and power imbalances as illustrated by the community respondent who had not disclosed her status to her partner. In Ethiopia, Deribe and colleagues (2010) found men were less likely to disclose their HIV status to their partner(s) because they did not want to reveal infidelity or cause their partner concern about contracting HIV, while women were more likely to cite fear of physical violence

or abandonment for their lack of disclosure. These findings suggests that due to women's subordinate social and economic status relative to men, fear of stigma, abandonment, and violence are particularly important barriers to both testing and disclosure for women (Maman & Medly, 2004).

Other studies in Africa have documented high levels of supportive reactions from families and friends, (Kouanda et al., 2012), and evidence suggests that HIV disclosure may positively influence behaviors that protect the health of people living with HIV, their partners, and their children (Betancourt et al., 2013). For example, research from Cameroon (Loubiere et al., 2009), South Africa (Wong et al., 2009) and Uganda (King et al., 2008) found that people who disclosed their HIV status to sexual partners were significantly more likely to report safer sex behaviors, including using condoms, reducing the number of sexual partners, and/or becoming monogamous (Wong et al., 2009). In addition, HIV-positive women diagnosed during antenatal care who disclosed their status to partners were more likely to convince their partner to test than women who did not disclose (Brou et al., 2007). Finally, HIV disclosure has been linked to better adherence to treatment and to replacement feeding as a means of preventing HIV transmission to infants (Betancourt et al., 2013). A key finding from this study is that health care providers in various settings need more training and guidance about how to counsel and advise people living with HIV as they balance the competing consequences and wellbeing of those around them.

### **Positive Parenting**

As previously discussed, an HIV/AIDS diagnosis can have profound challenges to mental health and decision-making when it comes to parenting (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Numerous studies suggest that compromised parental mental health, as a result

of learning one's HIV status, has immediate effects on the quality and quantity of attention a parent is able to devote to their young child (Kingston & Touch, 2014; Martins & Gaffan, 2000). Diagnosed parents need to maintain treatment adherence, consider disclosure to loved ones, and accommodate developmental changes in their children, all while experiencing high levels of stress, depression (Sherr, Clucas, Harding, Sibley, & Catalan, 2011), anxiety (Clucas et al., 2011), and even suicidal ideations (Catalan et al., 2011), which can impact a person's decision-making capabilities. These difficulties may continue for some time, as evidenced by conversations with participants, because HIV/AIDS diagnoses are often not shared and may remain a troublesome secret. In a study with 298 caregivers of children living with HIV, Paintsil et al. (2015) found that a majority of these children in sub-Saharan Africa were not informed of their HIV status. Caregivers reported being reluctant to disclose the HIV status to their children due to concern about the child's ability to understand, parental sense of guilt, and a fear of social rejection and isolation (Paintsil et al., 2015).

Children affected by or who are infected with HIV regularly face numerous challenges. Two recent systematic reviews identified 54 (Sherr, Mueller, & Varrall, 2009) and 21 (Sherr, Croome, Parra-Castaneda, Bradshaw, & Romero, 2015) studies, respectively, with the majority showing a form of cognitive delay in children both infected and affected by HIV (Sherr et al., 2015). All domains of development are implicated, including expressive and receptive language (Rice et al., 2013), memory, information processing, visual-spatial tasks, executive functioning (Llorente et al., 2014) and decision-making (Laughton, Cornell, Boivin, & Van Rie, 2013). HIV-positive women are disproportionately subjected to various forms of verbal, physical, and sexual abuse, and children in HIV/AIDS affected families have a three times higher risk of abuse (Cluver, Orkin, Boyes, Gardner, & Meinck, 2011).

Participants in this study articulated the challenges of raising children and adolescents, as these children start to assume self-responsibility of their medical treatment and care as well as their sexual and reproductive needs change (Giacomet et al., 2003). These findings are informed by a South African study (Watermeyer, 2013) which found that information sharing between adults and children is complicated by cultural expectations that limit what parents can share with their children, especially information regarding sexuality, finances, and illness. In this context, disclosing the diagnosis to HIV to a child is complex and brings confusion, hesitancy, and ethical dilemmas, continuing strong feelings of self-blame and related secrecy around HIV infection hamper and necessary openness for disclosure (Watermeyer, 2013). HIV-related stigma adds an additional layer to the burden of parenting as articulated by several Kenyan participants, requiring mothers and fathers to deal with the pressure between the secrecy surrounding the disease and the openness required to provide and receive consistent treatment and support (Battles & Wiener, 2002; Qiao, Li, & Stanton, 2013). As parents live in fear of disclosure as indicated in this report, they develop concealment strategies around their children's treatment and the nature of the disease such as saying they have diabetes or a cold. A study in Zimbabwe (Kidia et al., 2014), found that that HIV disclosure to perinatally-infected adolescents was positively related to social support, self-competence, and decreased problem behavior (Kidia et al., 2014), as well as adherence to antiretroviral combination therapy (Mutwa, 2013). Kidia and colleagues (2014) recommend tailored, age-appropriate guidelines around disclosure and open communication about the diagnosis. More education and support is needed for parents, particularly when their children are at an age at which decisions about relationships, sexual activity, and plans for the future are the focus of adolescent development and individualization (Kidia et al., 2014).

## **HIV Criminalization**

Australia, Lebanon, and Kenya have criminal laws that can be applied to cases of HIV transmission or exposure through sexual activity. HIV criminalization and subsequent prosecutions undermine and negate public health messages of mutual responsibility for safer sex practice. These policies can create a false expectation that HIV-positive people will disclose (Dodds et al., 2009) and suggest people can rely on disclosure as a fundamental safer sex practice. However, there is no evidence that HIV-related prosecutions facilitate disclosure of HIV status prior to sex or decrease risk-taking. To the contrary, in a study out of Australia almost half (45%) of people living with HIV surveyed said they were concerned about disclosing their HIV status prior to sex because of the law (Grierson, Pitts, & Koelmeyer, 2013).

Additionally, laws criminalizing injected drugs use around the world exacerbate the risk of harm as drug source and quality is frequently unknown and injecting regularly occurs in covert environments where injecting is hurried and clean equipment is not available (Cameron & Godwin, 2014). When key population behavior is criminalized (e.g., same-sex sexual activity, sex work, intravenous drug use, etc.), it ostensibly drives the most at-risk people away from mainstream treatment and preventive services (Cameron & Godwin, 2014).

Australia, Lebanon, and Kenya are not the only countries that have enacted laws that criminalize HIV transmission by positive individuals, mandate disclosure to partners, or authorize third party, involuntary partner notification by health workers. After analyzing evidence, the UNAIDS Reference Group on HIV and Human Rights concluded that, “in the overwhelming majority of cases, applying criminal law to HIV transmission or exposure does more harm than good” (UNAIDS, 2008, p. 1). Instead, the group suggests, “promoting a social and legal environment that is supportive of and safe for voluntary disclosure of HIV status” as

well as for expanding evidence-based programs that prevent HIV transmission while, “protecting the human rights both of those living with HIV and those who are not infected” (UNAIDS, 2008, p. 2). These arguments have persuaded parliamentarians in parts of the world to reject criminalization, but these policy mandates remain on the books in both developed and developing countries (USAIDS, 2015).

### **Implications for Practice**

As highlighted throughout this paper, personal relationships and finance issues are intimately linked with the challenges related to HIV disclosure. In general, women are more likely than men to be HIV-positive, to know their status, and to cite fear of abandonment or violence as the reason for nondisclosure (Deribe et al., 2008; Obermeyer et al., 2011). While protecting people from HIV transmission is often cited as the rationale for policies mandating disclosure or criminalizing transmission around the world, such laws and policies do not address the underlying fear of stigma and discrimination that contributes to low testing and disclosure rates (UNAIDS, 2008).

These laws, policies, and programs have tried to encourage, or in some cases, mandate HIV disclosure, both globally and in the countries highlighted in this paper, often generating heated debates within legal, human rights, and public health circles (UNAIDS, 2008). There is a broad consensus that laws criminalizing transmission, mandating HIV disclosure by people living with HIV, or requiring premarital HIV testing are difficult to enforce, undermine rights, and offer no real public health benefits (UNAIDS, 2008). There is less clarity about the ethics of involuntary, third party partner notification, especially in low resource settings. Some argue that routine partner notification may undermine patient privacy and confidentiality, but is the lesser of two evils or is entirely outweighed by partners’ right to be informed of the risks they face (Kiene et al., 2010). Others highlight the need for a cautious approach in which third party



disclosure is accompanied by counseling and consideration for the risk for HIV-positive individuals (Maman & Medley, 2004).

Based on the identified barriers in this study there is a critical need to develop and implement appropriate HIV interventions for MSM in the Middle East and Africa, as rates of HIV transmission are increasing in this key population (UNAIDS, 2014). Successful behavioral and biomedical interventions for MSM in other parts of the world should be adapted and evaluated in these cultural contexts. For example, van der Elst and colleagues (2013) studied the effects of an educational intervention for Kenyan health community workers' knowledge of and attitudes about MSM HIV transmission. Results from this study showed a significant better understanding of MSM sexual health issues and reduced homophobic attitudes three months after the training (van der Elst et al., 2013). Interestingly, qualitative data from the same study revealed that CHWs who underwent the MSM sensitivity training experienced secondary stigma from colleagues who had not been trained (van der Elst et al., 2013). Successful delivery of evidence-based interventions with MSM or health workers are tempered with the recognition that many, if not most MSM conceal their behavior for fear of repercussion and remain beyond the reach of developed interventions (Smith et al., 2009).

Overall, there is clearly a need for more investment in health sector initiatives to encourage voluntary HIV disclosure and partner testing in parts of Africa, including those that provide guidance and training to HIV counselors and those that support individuals diagnosed with HIV. More evidence is needed about the effectiveness of interventions to promote voluntary discussion, including couples counseling, specifically about the extent to which they reduce adverse events, encourage male participation, increase utilization of services, and improve health outcomes. It is clear, however, that increasing disclosure and mitigating negative consequences

for women will require attention to gender norms and power differentials. Taken as a whole, the findings presented in this study suggest a need for more attention to the challenges and dilemmas faced by both clients and providers in relation to HIV disclosure and for continued efforts to consider the perspectives and rights of all those affected.

Other programmatic efforts to facilitate disclosure, encourage partner testing, and providing parental support are promising. Efforts to increase partner participation in routine testing of women within ANC seem to have potential for positive outcomes, despite challenges, as do community support initiatives for people living with HIV (Obermeyer et al., 2013). Despite these increased efforts, HIV counselors will continue to face challenging ethical dilemmas about how to balance confidentiality with a duty to prevent transmission to others and to ensure that HIV-positive patients receive the social and economic support they need.

### **Limitations & Future Research**

As with all qualitative research, there are noteworthy limitations to this exploratory examination of case studies. First of all, readers must be discerning when attempting to generalize these findings, particularly given the very small sample size from each location. A potential weakness of grounded theory methodology is that the researchers' own expectations, perceptions, and beliefs can influence the analysis of the data. To assuage this threat, the researchers worked as a team to analyze data and presented quotes to support how themes were interpreted. While agency workers read and spoke English at a very high level in Lebanon and Kenya, it was typically not their first language learned in the home. There could have easily been miscommunications due to language barriers. In addition, a small percentage of quotations used are from an interpreter, and therefore, identified themes are an interpretation of the interpreters understanding of the conversation. Crosschecks were in place to mitigate these potential

miscommunications, but it is unknown if there are misrepresentations of participants opinions scattered within the notes. Furthermore, these themes are limited by the cultural and linguistic differences between the researchers and the participants and are likely missing valuable information that could inform better practice.

Continued research is needed to further explore the findings in this study. While substantial scholarship has explored the international HIV treatment, and a fair number of studies have examined rates of disclosure, less empirical research has investigated how changing anti-gay policies in traditionally heteronormative countries may change risky behavior between MSM. Another question is how informed treatment availability will influence disclosure over time. Ideally, as Norman and colleagues (2007) describe, there would be a “virtuous circle” whereby increased access to treatment would lower fear and stigma associated with testing positive, thereby increasing disclosure and further destigmatizing HIV, but some evidence suggests that levels of HIV stigma may change slowly (Gilbert & Walker, 2009).

While substantial theoretical scholarship has explored the ethics of policies and laws, and a fair number of studies have examined response for and rates of disclosure, less empirical research has investigated how policies in the region include behavior in practice, although it is clear that laws and policies are not always enforced or implemented (Obermeyer et al., 2014). Another question is how increased treatment availability will influence disclosure over time. Ideally, as Norman and colleagues (2007) describe, there would be a “virtuous circle” whereby increased access to treatment would lower fear and stigma associated with testing positive, thereby increasing disclosure and further destigmatizing HIV, but some evidence suggests that levels of HIV stigma may change slowly (Gilbert & Walker, 2009).

## Conclusion

Increasingly, researchers, policy makers, and program planners have recognized the implications of HIV disclosure for prevention, treatment, and stigma reduction. When people who test positive for HIV disclose their status they may encourage partners to be tested, obtain emotional support and caregiving from family and friends, and gain partners' cooperation in preventative behaviors such as safer sex, replacement feeding for infants, and adherence to treatment. In contrast, nondisclosure may have negative consequences for preventing HIV transmission to partners and children, for continuity of care, and for persistent levels of HIV stigma (Loubiere et al., 2009). Nondisclosure to partners is particularly concerning in light of evidence that large proportions of new HIV infections occur within HIV-serodiscordant couples (Eyawo et al., 2010).

Persistent rates of nondisclosure of HIV status by those who test positive pose difficult legal and ethical challenges for policy makers, health workers, and people living with HIV. There is a need for more consideration of the perspectives and rights of all those affected, particularly key populations. Specifically, this paper is intended to offer support to HIV treatment providers and care workers as they advocate for the rights of people living with HIV who must make difficult decisions within complex systems. There is clearly a need for more investment in health sector initiatives to encourage voluntary HIV disclosure and partner testing around the globe, including those that provide guidance and training to HIV counselors and those that support individuals diagnosed with HIV. More evidence is needed about the effectiveness of interventions to promote voluntary discussion, including couples counseling, specifically about the extent to which they reduce adverse events, eliminate discriminatory and ineffective policies, and increase utilization of services to improve health outcomes.

## **CHAPTER 4**

### **CHALLENGES FACED BY HIV TREATMENT PROVIDERS FROM DIMINISHED INTERNATIONAL HIV FUNDING**

International donor funding for HIV programs has flattened out in recent years (Katz, Routh, Bitran, Hulme, Avila, 2014; Resch, Ryckman, & Hecht, 2015; UNAIDS, 2015), which limits the availability of HIV treatment providers worldwide to achieve universal access and sustain current improvements. In parts of the world, HIV services are currently delivered in a context of severe resource and financial constraints, such as staff shortages, a lack of private counseling spaces, and insufficient referral services (Evans & Ndirangu, 2009). Such trends of diminishing dollars are exacerbating challenges in these presently weathered systems. Health workers regularly reported heavy workloads and high levels of stress and burnout (Mkhabela, Mavundla, & Sukati, 2008; Turan, Miller, Bukusi, Sande, & Cohen), and in some countries HIV treatment providers are shifting more and more responsibilities to lower level health workers to address these serious resource constraints (Zachariah et al., 2009). In addition, HIV has long-term implications for treatment costs due to it being a chronic condition requiring medical attention throughout the life of the patient. In addition, as an infectious disease epidemic, HIV requires continuous financial resources for treatment and prevention.

#### **International HIV Funding**

The United States remained the largest donor in 2014 (USD \$5.6 billion) accounting for approximately two-thirds (64.5%) of donor government disbursements for HIV (UNAIDS, 2015). The United Kingdom was the second largest donor (12.9%) followed by France (3.7%), Germany (3.2%), and the Netherlands (2.5%). In addition, contributions from The Global Fund

to Fight AIDS, Tuberculosis, and Malaria (referred to colloquially as ‘The Global Fund’), went up worldwide, while bilateral funding directly from governments went down. While international HIV funding has risen sharply in the prior decade, it then stabilized and declined after the global economic crisis. However, increases in funding over the past 10 year period were significantly less in constant dollars than in current dollar spending. Bilateral assistance (73% of all assistance) for HIV declined. Funding from 9 of 14 governments either declined (Australia, Canada, Denmark, France, Ireland, Sweden, and the European Commission) or was essentially flat (Germany and the United States) after accounting for exchange rate fluctuations (UNAIDS, 2015).

After rapidly expanding in the early 2000s, HIV funding from donor countries has flattened out between 2008 and 2015 (UNAIDS, 2015). To address these challenges, in 2007 President Georgia W. Bush and the 108<sup>th</sup> US Congress created the President’s Emergency Plan for AIDS Relief, commonly referred to as PEPFAR (National Research Council, 2007). The objective of PEPFAR was to begin providing approximately \$5.4 billion per year specifically to high-need countries such as Kenya (National Research Council, 2007). According to the investment framework led by the global HIV strategy helmed by UNAIDS, estimated budgets between USD \$16 billion and USD \$22 billion are required annually between 2011 and 2020 to effectively fight the AIDS epidemic (Schwartlandre et al., 2011). However, the recent global recession, coupled with increasing competing demands for causes such as new non-communicable diseases and environmental causes, may further jeopardize international donor funding for HIV (Katz et al., 2014).

### **More Stringent Requirements for Recipient Countries**

Azuine et al. (2014) discovered increasing donor assistance in developing countries led to an overall reduction of HIV infection rates (Azuine et al., 2014); however, UNAIDS, the Global Fund, PEPFAR, and other donors have already begun to consolidate and focus their funding on specific public health priorities (UNAIDS, 2015). Many of these funding shifts are related to public and private international donors demanding greater and greater counterpart participation and evidence of effectiveness (UNAIDS, 2015). The key goal of the five-year PEPFAR reauthorization in 2008 has been to transition from emergency response to country-led sustainable HIV programs (PEPFAR, 2008). In order to boost country contributions by recipient governments, the Global Fund issued eligibility and counterpart financing guidelines in 2011, which requires countries to match the grant funds with a contribution based on their income level (Global Fund, 2013). For example, low-income countries are required to match only 5% of their Global Fund financing, while upper middle-income countries are required to match 60% (Katz et al., 2014). In parallel, a number of countries receiving donor assistance for their HIV programs have graduated in recent years to upper or lower middle-income groups as a result of the economic growth, enabling them to increase their share in funding of their HIV response (Katz et al., 2014). As of this writing, 17 countries have grown ineligible for Global Fund financing based on their level of economic development (Katz et al., 2014).

The Global Fund's new stringent requirements were developed in an international climate of constrained funding which requires more scrutiny of cost effectiveness and spending oversight (Global Fund, 2015). Countries impacted by reduced funding are worried about protecting the gains made and further scaling up programs to contain and reverse the devastating impact of the disease. In response to these concerns the Global Fund reports that implementing countries will

take the lead in determining where and how to best fight these diseases, as it has the desire to “reach beyond the mindset of paternalistic aid that sometimes created obstacles in the past (The Global Fund, 2015, p. 5).” However, donor dependence is particularly concerning for HIV programs in low- and middle-income countries where HIV prevalence is high. In a vast majority of these low- and middle-income countries, national health systems are beginning to face major financial sustainability challenges as donor funding declines (Resch, Ryckman, & Hecht, 2015). Programs specifically planned to address HIV tend to rely more on international donor funding than does the wider health sector. For example, in the Ukraine, classified as a lower middle-income country, donor funding as a percentage of total health expenditure was only 0.3%, whereas it accounted for 46% of the funding for the national HIV program in 2009 (Tarantino, Chankova, Rosenfeld, Routh, & Preble, 2011). In upper middle-income Jamaica in 2008, donor assistance to the health sector overall amounted to 1.5%, as opposed to 51% for the country’s HIV program (PAHO, 2011). In countries with fewer resources, politicians may not want to prioritize national funds be given to a disease that continues to be stigmatized.

### **Reliance on Lower Skilled Health Workers to Minimize Costs**

In some countries HIV treatment providers have shifted responsibilities to lower level health workers to address their resource limitations (Zachariah et al., 2009). Indeed, community health workers (CHWs) represent a widespread strategy in the majority of the world to address shortages of health workers and the lack of a ubiquitous national health system, particularly in rural areas. Although CHWs operate under a variety of names, there is evidence that the role has long existed in one form or another for more than 50 years (Lehmann & Sanders, 2007). Recently, reliance on these workers to accomplish the health-related Millennium Development Goals has grown combined with the lack of resources available for public health in the majority



of the world. Community engagement in health systems has been seen as both a practical response to these challenging conditions of health provision in low-income settings (Adam et al., 2014; Reidpath, Ling, Yasin, Rajagobal, & Allotey, 2012) and a key principle for strengthening health systems more generally (Kamuzora, Maluka, Ndawi, Byskov, & Hurtig, 2013).

**HIV & Confidentially.** Under strained financial conditions, various cultural norms, and low-skilled health workers, concerns around lack of confidentiality and involuntary HIV disclosure represent barriers to health care (Otieno et al., 2010). However, there is relatively little published information on breaches of HIV medical confidentiality within such health facilities in low-income countries (Bott & Obermeyer, 2013). Involuntary disclosure of patients' HIV status by health workers has been observed in diverse settings and may occur for various reasons, some having to do with the physical environment (e.g., no dividing walls, ease of overhearing private communications, etc.), others related to social and cultural factors (Obermeyer et al., 2011). The lack of privacy in health facilities is a serious challenge to medical confidentiality in parts of the world. Patients are regularly accompanied by family members to overcrowded facilities that lack separate spaces for counseling (Gruskin, Ahmed, & Ferguson, 2008).

Cultural views about the need to involve spouses and other family members in medical decision-making, as well as concerns about ensuring continuity of care for patients may also influence provider behavior. Turan et al. (2008) found maternity care providers in Kenya found it inconceivable that a husband would not be informed of his wife's HIV status. Similarly in parts of Western Africa a majority (57%) of health workers believed that relatives and sexual partners of patients with HIV should be notified of their status even if the patient did not consent (Reis et al., 2005).

In addition, health workers may feel pressure to disclose a patient's status without his or her consent in order to prevent transmission to a child or partner. In studies across the globe, health workers regularly describe anxiety and doubt about how to respond when patients refuse to disclose their status when they put their partners or children at risk (Evans & Ndirangu, 2009). For example, in Uganda, HIV counselors described wanting more guidance about what to do when members of serodiscordant couples refused to reveal their HIV status to each other (Medley & Kennedy, 2010). Angotti et al. (2014) described tension between the social and ethical norms of rural communities in Malawi and the testing norms based on Western concepts of individual rights.

Such evidence suggests that policy debates about confidentiality and how health workers can facilitate disclosure of a patient's serostatus are highly relevant to difficult constraints that HIV counselors face in their daily work, and that if common ground can be found between the values of patient privacy and protection of public health, than this should be translated into better guidance to health workers. In addition to legislation, governments around the world continue to develop policies, strategic plans, and guidelines to influence health-care providers' behavior with regard to confidentiality, disclosure, and partner notification (Bott & Obermeyer, 2013).

### **Purpose**

The above financial reality and challenges to ethical treatment require policymakers of national health sectors to expand their fiscal space to address the financial sustainability and ethical considerations of national HIV programs as their donor funding is expected to decline. In addition, a substantive account of low level health workers views of their own practice under these constraints has been lacking up until now, hindering the integration of CHWs experiences in the policy needs from the shifting financial climate. It has been argued, for example, "that CHWs have privileged insights into the social determinants of health in communities . . . there is

a need for these insights to inform policy (Theobald, MacPherson, McCollum, & Tolhurst, 2014, p. 9).” Therefore, the purpose of this paper is to better understand the views and opinions of community respondents, key informants, and health workers in Australia, Lebanon, and Kenya who are working under financial strain to better inform policy and service delivery practices.

## **Methods**

### **Sample**

The analysis in this paper draws on interviews conducted with stakeholders (N=79) of community-based HIV treatment providers in three countries: 1) the Victorian AIDS Council located in Melbourne, Australia (n=29); 2) SICD located in Beirut, Lebanon (n=11); and 3) NEPHAK, located in Nairobi, Kenya (n=39) in July and August of 2015. All participants were given a consent form detailing the research project with the option to opt out. *See Appendix A.* Upon receiving signed consent, researchers conducted interviews and focus groups with care workers and community respondents. *See Appendices B.* Key informants were also interviewed using the outlines for the same purpose. *See Appendix C.* Two researchers conducted the interviews and focus. Detailed notes were typed or handwritten while interviewing and facilitating focus groups simultaneously. Participant wording was typed whenever possible, and quotation marks placed around participants’ exact words. Participants were encouraged to look at the notes to check consistence. However, only five participants from all of those interviewed checked the researcher’s notes, and no participant gave indication that he or she disagreed with what was written. Focus groups lasted approximately one hour. A semi-structured approach was adopted for interviews and focus groups, using themes identified through analysis of the preceding focus groups to instigate meaningful discussions. Sections of the interviews were dropped if questions were not relevant to the interviewee. This provided consistency across

participants while remaining flexible enough to respect the time and interest of those being interviewed. All notes were transcribed and shared between researchers.

### **Qualitative Analysis**

In qualitative research, trustworthiness is established by using well-grounded methods (Guba & Lincoln, 2005), including developing a familiarity with the participating organization and stakeholders, triangulation, frequent debriefing among researchers and participants, peer scrutiny, thick description in the findings (Shenton, 2003), and maintaining a detailed audit trail (Guba & Lincoln, 2005). Several of these findings were immediately evident (e.g., shifting financial trends) due to the rich thick description provided by participants and frequent discussions immediately after interviews between researchers. Ryan and Bernard's (2003) techniques for identifying themes from basic expressions in the notes were used. Open coding in this dissertation was done independently by the author. Following intensive open coding, the coded categories were then grouped and summarized. The resulting coding structure is reflected in the themes identified in the findings of this dissertation chapter.

The Institutional Review Board at the University of Georgia approved this project. All identifying information was removed from the findings to further protect anonymity of participants. Direct quotes from participants are weaved into the findings for readers. Quotations from participants are *italicized* to designate the exact words (and sometimes deeper meanings) used by participants.

### **Findings**

Participants talked about the direct consequences of “*externally driven*” (i.e., international) funding diminishing and their ability to provide effective HIV/AIDS prevention and treatment for their communities under such constraints. Workers in Australia, Lebanon, and Kenya perceive that international funding for HIV treatment and prevention has gone down and

other issues are given more of a priority. Providers in Lebanon and Kenya commented that they believe HIV funding is changing due to shifting “*trends*” to new causes (e.g., “*global warming*”). In Lebanon, a key informant commented that international funders may think “*HIV is no longer a disaster, but . . . people are still getting infected.*” Kenyan workers mentioned that money for HIV support groups, which used to be prevalent, is now drying up. One worker mentioned that support groups “*[do not] happen anymore unless a group meets by their own initiative.*” Other workers included funding focusing on increasing better “*nutrition*” or support to “*orphans*” is way down. Several workers in Kenya mentioned that funding is now targeting “*maternal and child health*” and “*family planning.*” In Kenya, one worker reiterated that the United States provides a large portion of their HIV prevention and treatment funding, and the rest is delivered through the global fund (“*about 15%-20%*”), with very little HIV prevention and treatment funding coming directly from Kenya, so their services are extremely impacted by these global trends.

### **Combined Public Health Efforts**

A key informant in Kenya noticed the increased involvement of The Global Fund, which requires integrated public health efforts. He reported that these new regulations require HIV treatment providers also address TB and Malaria to receive any funding. In addition, the worker stated that The Global Fund only targets areas with high prevalence of diseases and where key populations live. This year funding only covered 26 out of the 47 counties in Kenya; counties without funding are in largely rural where access to general healthcare, in addition to HIV treatment and services, is limited. The Global Fund also requires recipients to match part of the funding from local government money. As stated in the introduction and reiterated by the key informant, these changes have a profound impact on Kenya, whose economic status in improving

for a small percentage of the population. These economic changes require Kenya to increase their own national funding for HIV treatment and prevention. Most importantly, there appears to be profound negative impacts to rural communities where access to health services is already diminished.

A key informant in Kenya noted that he belonged to a number of international HIV forums, and he can see money slipping at both at the national and global levels. He stated, “*we lost the momentum*” in the financial fight in the global pandemic of HIV. This informant commented on the relationship of the growing economy in Kenya. He posited that the rise of a middle class and increased number of wealthy persons (a very small percentage of families) created a counter development of more impoverished people. For example, rural populations flood the urban slums in Nairobi in attempt to find work, which exacerbates the existing public health conditions from overcrowding and diminished already strained resources in these communities. He believes the new financial constraints will move funders away from broad-based funding for HIV. He stated, “*Kenya might not be eligible because [international] dollars are for countries with poor people.*” He mockingly jested, “*Goal 6, it is done,*” referring to the combatting HIV, TB, and Malaria in the Millennium Goals of the UN. He also believes addressing HIV through combined public health issues is a mistake. He believes taking HIV out of isolation has complications because it is still extremely stigmatized and therefore it can be difficult to secure funding.

### **Pressure to Identify People Living with HIV & Distrust from Stakeholders**

Due to economic constraints and questionable prevalence data of people living with HIV in the Middle East and parts of Africa, more and more governments are becoming aggressive about identifying people living with HIV to ensure efficient spending of international money. A

worker in Kenya stated some international funders may believe the government's estimate of people living with HIV is exaggerated. He gave the example that there is an "estimate" of 1.6 million people in Kenya who are HIV+, but the current number of enrolled Kenyans in treatment is approximately 700,000. He reported the challenges of getting accurate prevalence data. He continued, "*People are tricky, they enroll in two or three community-based programs and get the medications more than once, and then they can sell them.*" The people who buy these secondhand medications may be concerned about the stigma of being HIV positive or be unwilling to let HIV treatment providers or the government know private information about them. However, these people are not "*educated [about] these medications,*" and could experience negative consequences from not consulting with healthcare professionals about their specific medical needs.

Despite external pressures to create a database for people living with HIV, there appears to be significant pushback from stakeholders. For example, in both Kenya and Lebanon workers and clients cited distrust about how the government and health workers (e.g., national health systems, hospitals, doctors, nurses) may use their HIV status to discriminate against them. In addition, ethical concerns around privacy and confidentiality may be created by a desire for efficiency and accuracy. In addition, new financial pressures are created as HIV-positive persons living longer and longer, as noted by participants in Australia, Lebanon, and Kenya. Until a cure is developed, people living with HIV will require costly medications to treat the chronic condition, which as previously discussed has significant financial consequences to international HIV donors.

## Financial Strain on Health Workers

By in large, care workers in low- and middle-income countries need additional financial support. In Kenya, workers on the front line of the HIV epidemic are made up of CHWs who typically have very little formal education but have abundant knowledge about their communities. Care workers are charged with providing prevalence data and are given little support or finances to do is emotionally challenging and often hazardous work; as of the data collection, workers were not receiving any consistent compensation for their work. Despite not being regularly paid, CHW are expected to continue to support their communities and turn in reports about their work every month. One worker cited she had 66 people living with HIV on her caseload. No one else commented on the accuracy of her estimated caseload or how it compared to their own caseload.

Participants discussed the challenges of not being paid “*We are jobless, but we have families*” and “*We don’t have much food at home.*” CHW mentioned when visiting clients, they expect something from them (e.g., food, shelter, soap) that go beyond basic HIV treatments. A worker reported that their clients assumed “*we are getting paid but the opposite is true. It’s a big challenge.*” Workers also expressed frustration about the government’s handling of CHWs, largely aggravated by the lack of compensation for their work. One participant noted “*[politicians], they come and go. They all have different idea[s],*” but their ideas “*place [significant] demand[s] on CHWs.*” Other similar sentiments included: “*fighting for our rights,*” the “*work we are doing is not recognized,*” “*wake up the government,*” we have “*the right to be safe, the right to be paid,*” and the “*dollars [are] for the big fish, not for the small fish. We are minnows.*”



When asked about specific supports needed to improve the efficacy of their work, CHWs asked for compensation for their work, official identification (a photo ID) recognizing their health worker status, working tools (e.g., gloves, bags, flashlights, uniforms, air masks), ability to dispense some medications (in lieu of providing referral to a medical clinic), and the ability to provide social service funds for their clients (e.g., transportation to health centers, nutritional support, phone credit, etc.). It appears as though CHW are given little resources while they are expected to endure hazardous conditions for no compensation.

### **Additional Training and Support Needed for Health Workers**

Several participants commented on the emotional toll of working with vulnerable clients with chronic diseases. One participant stated she was “*sick*” (emotionally upset) for a month after her client “*died of TB.*” She attributed his death to her inability to convince the client to take his medications. “*I felt really bad when we buried him.*” Another CHW reported it was common for people to decline treatment, and attributed this to “*the drugs are mean.*” In one focus group with care workers, there was a long discussion of the challenges when “*youth*” refuse ART. Apparently, two young people died recently when they succumbed to “*peer pressure*” to stop their treatment. These adolescents were described as having started taking the medications when they were children. Workers also mentioned the complexity and treatment of combined HIV and TB treatments. The condition is made worse if a client drinks “*changaa,*” a ubiquitous and inexpensively home-brewed alcohol with high levels of Methanol (APHRC, 2014). One worker added if a client does not have any food (or enough food) it can intensify side effects from the TB medications and people become weak.

Since most of the CHWs who participated in the focus group live in Kibera, the same community as many of their clients, it can make it difficult for confidentiality around one’s HIV

status to be maintained. When workers have ethical dilemmas, they consult with other CHWs or their superiors called “extension workers.” The extension workers are regularly consulted by CHWs as they provide oversight for the communities and allocate resources. For example, extension workers are contacted by CHWs if a new case of polio, diarrhea, or cholera is identified.

### **Harm Reduction and Treatment as Prevention Methods are Undervalued and Not Supported via Policy**

Despite strong support of harm reduction and treatment as prevention models by public health and social work academics, there is slow political movement around these ideals even in countries considered to have strong and responsive health care systems (e.g., United States, Australia). As previously discussed in this paper, participants are skeptical about their government’s ability to enable programs to best support people living with HIV. When asked about policies or laws Kenyan participants would like to see change to make the lives of people living with HIV better, one participant stated, “*The government cannot change.*” They referenced preferring other countries’ health systems (i.e., United States) that they believed provide stable HIV prevention and treatment.

**Harm Reduction Methods.** Despite an established international consensus about best practices these methods are rarely supported by governmental policy some decisions about harm reduction interventions continue to be driven by moral concerns rather than empirical evidence (Strathedee, Shoptaw, Dyer, Quan, & Aramrattena, 2012). For example, the outreach program in Beirut distributes clean syringes to intravenous drug users, but the method of delivery is challenging because policies in Lebanon do not support needle exchange programs if needles aren’t being dispensed to clients by physicians or pharmacists. However, the worker stated that

intravenous drug users are generally welcoming of harm reduction methods and needle exchange programs. According to the participant, clients “*trust in the team that goes to the streets.*”

Another participant criticized Lebanon’s policy against drug users as it goes against the medical model. In Lebanon, illegal drug users are jailed, but a participant believes drug users should be treated with dignity and be sent to a rehab center. She argued that when drug users are sent to jail they continue to use drugs, syringes, and transmit diseases to other people incarcerated and they find networks to exacerbate criminal behavior once released. If Lebanon’s laws cannot be changed, she believes that harm reduction strategies should be used in prisons. As of now, jail officers are skeptical of any supportive services (e.g., methadone treatment, social work involvement to prevent relapse and recidivism, etc.). The same participant stated that social media campaigns sponsored by the International Drug Policy Consortium, such as “*Support. Don’t punish.*,” are starting this important dialogue in her country.

**Treatment as Prevention.** While HIV treatment providers promote the utilization of PrEP for key populations, there are challenges for consumers in accessing medication. For example, in Australia the Therapeutic Goods Administration (TGA) has not yet licensed PrEP for use, and therefore, it is not yet available at a subsidized price through Australia’s Pharmaceutical Benefits Scheme (PBS). Conversely, there is a strong international push for the use of PrEP in high-prevalence areas, such as in parts of Kenya, where they are targeting younger women. For example, a worker in Kenya mentioned that young girls being selected for new prevention efforts through the DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe) Initiative where at-risk young women will be provided with PrEP, and she has concerns that there will be little attempt to get “*buy-in*” from local women and the roll out of the drugs will not include an educational component.

Additionally, there is general concern in Australia, Lebanon, and Kenya of governmental strategies including PrEP as mode of prevention. For example, some workers interviewed had concerns about PrEP. Notable concerns include doubt of absolute efficacy and possibility of the increased prevalence of other STIs. As one participant in Australia stated, *“Yes, there is want, matches the need, but what is the risk?”*

### **Discussion and Implications**

The perceived drop mentioned by participants in HIV funding is primarily due to decreasing annual donor commitments by the United States government, the largest donor to HIV treatment and prevention in the world (UNAIDS, 2015). The United States bilateral HIV commitments have declined in recent years, and are currently below 2008 levels, and there is a consistent trend of diminishing funding compared to prior-years (UNAIDS, 2015). Overall funding for HIV from international donors grew by less than 2 %, totaling USD \$8.64 billion in 2014. After adjusting for inflation and exchange rate changes, the increase was marginal (1%). Most of the increase in HIV funding in 2014 can be attributed to the United Kingdom, without which overall disbursements would have dropped, rather than remain flat (UNAIDS, 2015).

As mentioned by a participant, the increase in combined public health efforts is largely due to the growing role of the Global Fund as a primary international fund for HIV treatment and prevention. In addition, recently there have been criticisms of HIV global spending and calls for more donor coordination due to the global economic downturn of the last few years (OECD, 2014). More donor countries and organizations are demanding for empirical evidence that their donations are impacting the epidemic and are making the desired influence in the lives of average people in developing countries. During the beginning of the global economic downturn, McCoy Chand, and Sridhar (2009) critiqued that the fragmented, complicated, and inadequate tracking of the state of global health finance required immediate attention. However, these recent

shifts towards more international accountability may have real consequences to rural communities that already have little access to health providers.

However, the financial future of HIV funding in Kenya is not bleak. Kenya anticipated the possibility of reduced aid from international funders after the global recession and in 2012 approved the Bill titled Additional Sustainable Financing for HIV/AIDS and Non-Communicable Diseases in Kenya (Katz et al., 2014). This policy established a Trust Fund through which the Kenyan government allocates 1% of all tax revenue to the fund, which covers 74% of the expected financial gap until 2020 (Katz et al., 2014). Kenya's foresight and political action is a standard developing countries concerned with reduced international aid should consider. Katz et al. (2014) recommends in their analysis of replacing international health funds involving the Ministry of Finance from the very beginning when attempting to mobilize additional financial resources, as Ministries of Finance are the stewards of the financial equilibrium of the country. The authors state that national strategies require the Ministry of Finance involvement and support, both technical and political. In addition, the lengthy and complex process of mobilizing non-donor funding suggests both countries and donors would benefit from formulating a financial sustainability plan before any donor funding for HIV programs and activities is committed, to ensure the funded activities also continue after the donor funding declines or ends (Fryatt & Mills, 2010; Ooms & Damme, 2008). In addition, the sustainability plan should include specific action as to how the recipient country or organization will gradually replace donor funds with domestic or internal financing over a specific timeframe. This timeframe might vary across countries by income level and by the burden of HIV (Fryatt & Mills, 2010).

### **More Support for Workers**

Research highlights the need for more support for HIV health workers in low- and middle-income countries (Medley & Kennedy, 2010; Mkhabela et al., 2008; Sarker, Papy, Traore, & Neuhann, 2009). Wide regional disparities in health services and shortages of human resources in the health sector make the availability and accessibility of health services in Lebanon and Kenya challenging. Various researchers have raised questions about CHW's training (Hill et al., 2014; Oliver, Geniets, Winters, Rega, & Mbae, 2015). The scarcity of resources shapes practices and informs programmatic priorities and giving CHWs appropriate compensation for their work, appropriate medical resources, and more training would all clearly be welcomed. Although resources are always likely to be limited in low-income settings, a more developed appreciation of current practices and potentially hazardous conditions allow for better informed decisions to be made around which resources to prioritize and how they should be distributed.

“[T]here is no longer any question of whether CHWs can be key agents in improving health: the question is how their potential can be realized (Kahssay, Taylor, & Berman, 1998, p. 2).” The importance of CHWs work to support the reach of the national healthcare systems is well evidenced, but concerns remain that CHWs' efforts are less effective than they can be. However, there is research that CHWs can accurately and reliably collect certain types of community health data, such as birth rates, which has cost-saving implications (Otieno-Odawa & Kaseje, 2014), especially for resource poor settings. Mumbo and colleagues (2013) proposed supervision, training, team-based approaches, and more support from community health committees (CHCs) as potential ways to improve CHWs' practice. Interestingly, these are primarily deficit-based interventions, assuming that CHWs themselves are the main issue,

although influences of local attitudes of health personnel or community members may also be problematic. Moreover, such interventions have not resolved matters; although training and supervision have been recognized as being important for nearly 30 years (Gilson et al., 1989), there remains considerable variation in what is available. So far, it appears the primary focus is on policy imperatives (what CHWs 'ought' to do) or special initiatives, which are not necessarily representative of regular, day-to-day- practice. These suggestions assume CHWs operate as an instrument of policy rather than as gatekeepers or negotiators who moderate and reinterpret initiatives to ensure their viability or relevance.

For example, some programs providing either no in-service training or only informal support, whereas others provide continuous training and/or refresher courses (Funes, Hausman, & Rastegar, 2012). Hill et al. (2014) identified that supervision only contributes to the quality of CHW's work when it is of high quality and supportive, whereas the quality of supervision can vary considerably (Hill et al., 2014). Additionally, their work involves referrals, monitoring, reporting, and educational interaction. While they face problems with resources and training, their accounts show they respond to this in creative ways, working within established systems of community power and formal authority in attempt to achieve ethical decision-making. Their work is widely appreciated as evidenced by the community respondents, although some households do resist interventions and figures of authority sometimes question their manner or expertise.

### **Programmatic Strategies to Increase HIV Disclosure and Testing**

There have been numerous efforts to increase provider-disclosure in multiple countries around the world by offering "facilitated disclosure" (whereby health workers help patients disclose) (Kairania et al., 2010), individual testing of male partners of women in ANC, couples

HIV testing and counseling (Conkling et al., 2010), “family focused” HIV care and treatment (Tonwe-Gold et al., 2009), and community support initiatives (Wouters, van Loon, van Rensburg, & Meulemans, 2009). These efforts have produced mixed results, and programs are working to determine the benefits, risks, and effectiveness of different strategies.

Much evidence suggests that nondisclosure poses a barrier to treatment initiation and adherence. In Tanzania, researchers found that while unwillingness to disclose HIV status was a barrier to entering programs that required a “treatment buddy”, they also found evidence that treatment availability had begun to change attitudes and reduce some barriers to disclosure in the community (Mshana et al., 2006). One study from South Africa noted that while clinicians had come to regard HIV as a chronic condition, HIV-positive respondents continued to report intense stigma from those around them with implications for both treatment adherence and disclosure (Gilbert & Walker, 2009). Therefore, while idyllically increasing access to treatment may eventually reduce stigma and thereby increase disclosure, these changes may not happen quickly or consistently across settings.

Increasingly, researchers, policy makers and program planners have recognized the implications of HIV disclosure for prevention, treatment, and stigma reduction. When people who test positive for HIV disclose their status they may encourage partners to be tested, obtain emotional support and caregiving from family and friends, and gain partners’ cooperation in preventative behaviors such as safer sex, replacement feeding for infants, and adherence to treatment (Betancourt et al., 2013). In contrast, nondisclosure may have negative consequences for preventing HIV transmission to partners and children, for continuity of care, and for persistent levels of HIV stigma (Loubiere et al., 2009). Nondisclosure to partners is particularly



concerning in light of evidence that large proportions of new HIV infections occur within HIV-serodiscordant couples (Eyawo, de Walque, Ford, Gakii, Lester, & Mills, 2010).

### **Treatment as Prevention**

An important article by Resch et al. (2011) argues that public investments in known HIV treatments result in net positive economic benefits. For example, the authors estimated the cost of maintaining ART during a 10-year period (2011-2020) for the 3.5 million patients in low- and middle-income countries worldwide. Next they estimated the economic savings resulting from such treatment. The authors concluded that the investment required for ART, equal in present value to USD \$14.2 billion, is expected to save 18.5 million life-years and return USD \$12-34 billion through increased labor productivity, averted orphan care, and deferred medical treatment for opportunistic infections and end-of-life care (Resch et al., 2011). In addition, WHO released a strong recommendation in 2014 for the inclusion of PrEP as a prevention choice in combination prevention packages oriented to MSM, making it clear that combination prevention includes not only a combination of individual-level biomedical and behavioral strategies, but also the conduct of interventions to remove structural barriers to prevention.

The concept of alternative HIV strategies, such as PrEP, is gaining increasing support and continues to be the focus of ongoing research. As noted in the findings, so far PrEP acceptance has been slower than might be expected from the magnitude of potential benefit. Moreover, it has been the focus of controversy among stakeholders, including many treatment providers. Some implementers and policy makers in various countries have raised concerns about potential low adherence leading to low effectiveness and drug resistance, “behavioral disinhibition” (people increasing risk taking because of perceived protection) leading to lower impact,

potentially drug toxicity, and high cost leading to low sustainability and competition with treatment (Caceres, O'Reilly, Mayer, & Baggaley, 2015).

Gradually there appears to be more acceptance of PrEP where there is urgent need for effective prevention, such is the case for young African women with annual HIV incidence rates of 5%-6% (UNAIDS, 2014) as mentioned by one participant. PERFAR's DREAM initiative for adolescent girls and young women is now evaluating accessible adherence strategies and delivery models to this key population (Celum et al., 2015). Advocates of prevention among sex workers and people who inject drugs have argued that authoritarian states could implement mandatory PrEP programs for key populations, resulting in human right violations or simply in the neglect of other effective prevention interventions, such as harm reduction strategies and condom requirements for sex workers. In any event, if PrEP is to be considered as an additional prevention option for inclusion within a comprehensive HIV program, than engaging with affected communities, and acknowledging that PrEP use is a choice that will only be appropriate for and desired by some people will be fundamental.

### **Limitations & Future Research**

As with all qualitative research, there are noteworthy limitations. First of all, readers must be discerning when attempting to generalize these findings. A potential weakness of qualitative research is that the researchers' own expectations, perceptions, and beliefs can influence the analysis of the data. To mitigate this threat, researchers worked as a team to analyze data and presented quotes to support how themes were interpreted. In addition, a few of the quotations used are from an interpreter, and therefore, identified themes are an interpretation of the interpreters understanding of the conversation. These themes are limited by the cultural and

linguistic differences between the researchers and the participants and are likely missing valuable information that could inform better practice.

Continued research is needed to further explore the findings in this study. While some scholarship has explored options for low- and middle-income countries concerned with diminishing international HIV funding, there is still much unknown about the consequences of pulling HIV funding out of vulnerable nations. In addition, Kenya is a particularly interesting country to research as its citizens have relatively quickly mobilized their resources and adapted to the HIV epidemic all while increasing their economy. Future research on Kenya's strategies to combat reduced international funds can inform other developing countries strategies who may want to replicate Kenya's model.

### **Conclusion**

International donor funding for HIV programs has flattened out in recent years, which limits the availability of HIV programs worldwide to achieve universal access and sustain current progress. In parts of the world HIV services are delivered in a context of severe resource constraints, including staff shortages, and inadequate referral service. These trends of diminishing dollars will exacerbate these already weathered constraints. More support is needed to support lower level health workers to address these serious resource constraints

## **CHAPTER 5**

### **CONCLUSION**

*“After climbing a great hill, one only finds out that there are many more hills to climb.”*

-Nelson Mandela

The fifth and closing chapter of the dissertation echoes the sentiments of the first chapter in several ways starting with a call to action to bolster the momentum gained during the three-decade battle against the international epidemic of AIDS. The first part of this chapter will weave together the findings and discussions from each of the three studies presented in Chapters 2, 3, and 4. In addition, the implications from findings will be addressed on a larger scale, specifically suggesting refocusing of professional role of social work in this epidemic and the responsibilities of international social work educators. Limitations of this dissertation research and potential future investigations will also be discussed.

#### **Interpretation of the Results**

In the case study in Chapter 2, readers worked through the four quadrants in the ethical decision-making model with a social worker as she struggled with the knowledge that her client could be transmitting HIV and Hepatitis C to his partner and their unborn child due to his refusal to disclose his status. The model outlined the importance of medical concerns, patient preferences, quality of life, and contextual considerations. Through this process it became clear that this model is best used by practitioners who clearly understand the values of their local communities and can accurately prioritize local contextual features. The ability to systematically and thoroughly document these ethical concerns is important when providing evidence to support difficult decision-making. However, this model is time consuming and does not provide clear

answers, which was reiterated in interviews with health care workers in Australia, Lebanon, and Kenya. These limitations to the decision-making model are important considerations for future use. As previously stated in the conclusion of Chapter 2, for international social work associations who want to enhance the application of the four quadrants approach to social workers all over the world, they may wish to consider developing an accompanying piece prioritizing a hierarchy of values or concerns for specific countries and/or regions in more culturally relevant ways. However, the author has concerns that social workers will take the lack of specificity when completing the model as license to disclose their clients' HIV status. Even with a firm understanding of local values, non-consensual HIV disclosure has irreparable consequences to clients and should be avoided at all cost. Instead, social workers should seek guidance from skilled clinical supervisors and peers to support their work. If a client asserts that it is unsafe to self-disclose their HIV status at the current, the client should be believed. It is the social worker's responsibility to make the client feel safe and have those difficult conversations. In addition, social workers should find appropriate and creative ways to address this challenge rather than taking it on themselves to disclose private information.

The professional role of social work can look and feel differently from country to country, as some ethical issues and their subsequent decisions may be unique to specific nations, customs, and cultures. The concepts of confidentiality, privacy, boundaries, and self-determination are relevant for social workers everywhere, but their particular meaning and application vary considerably. Social workers who firmly embrace ethical standards and concepts in their own nation, language, and cultural context must be careful to avoid assuming these standards translate well in other nations, languages, and cultural contexts. Social workers must keep their ethical hubris in-check and learn from their communities to ensure carefully

consideration of local best practice standards. These various roles were highlighted when an HIV-positive mother who was interviewed in Kenya stated that she did not need to disclose her HIV status to her partner, as the safety of her children was her priority. The mother was much more concerned about other, less-treatable illnesses than HIV. In that situation, a social worker's primary role may be to help the mother become financially independent and ensure the health and wellbeing of her children before focusing on her HIV disclosure.

In Chapter 3 specific barriers to HIV disclosure were identified which bring to life the tangible concerns (e.g., criminal and socioeconomic consequences, etc.) Hassan did not articulate illustrated in the case study in Chapter 2. Research participants interviewed in focus groups who identified as HIV-positive discussed fear of losing their jobs, family, and friendships if their status was disclosed. The continual support needed for these key populations who feel like they must hide from a hazardous system places enormous strain on social workers and low-level health workers as they must navigate systemic discrimination to ensure treatment adherence and make difficult decisions regarding ethical practices. However, achieving ethical best practices is easier said than done as values can change within systems, countries, and over time. While there is plenty of opposition to LGBT rights in Lebanon and Kenya, some cultural elements are beginning to shift as reported by participants. In Chapter 3, participants discussed changing cultural norms for young people in Lebanon, which were largely influenced by Western media. They reported that stigma against homosexuality and HIV is also losing ground. In Kenya, one worker commented that MSM are "*starting to have their say.*" In fact, groups like The Gay and Lesbian Coalition of Kenya (GALCK) are advocating for MSM decriminalization in Kenya. These growing rights in Lebanon and Kenya may be seen as culturally dissonant by many and openly rejected. However, more challenging implications may arise and overshadow these

conversations as Kenya's economy continues to accelerate and moves into a higher income categories. This international research experience solidified the need for social workers to collaborate internationally to better support our fellow social work brothers and sisters to address these ubiquitous challenges.

Chapter 4 discussed the consequences of diminishing international HIV funding and the constraints already put on worn services. In the face of likely ineligibility for certain donor funding, it is arguably critical that countries with growing economies, especially those with a high burden of HIV like Kenya, quickly take action to replace donor funds with domestic resources and other alternative funds over a relatively shorter timeframe (Fryatt & Mills, 2010). The diminished funding through consolation with other diseases will impact those the most who live in smaller communities and those being supported by treatment facilitates in rural areas. A long-term financial sustainability plan should include cost reduction, improved allocation of funding (both of tax money and within national health programs), and resource mobilization (Fryatt & Mills, 2010; Heller, 2006; Ooms & Damme, 2008). Financial stability in these countries is critical to maintain global gains as HIV is a chronic condition that requires medical attention throughout the life of the patient. In addition, as an infectious disease, it requires sustained resources for treatment and prevention. There should be more opportunities to link social workers from various countries to work together on these issues that have global implications.

### **Implications for the International Profession of Social Work and Social Work Education**

The increasing economically dependent world through globalization has necessitated the introduction of international concepts and global competence in social work education (Barner & Okech, 2013). As social problems resulting from global interactions and interdependence of countries around the world has increased, the need for additional attention from the profession of

social work is needed. While there are some international social organizations that are committed to supporting, influencing, and enabling international structures and systems to positively address the root causes of oppression and inequality, currently too little is taught in the United States at the university level about the needed response to international issues, including the barriers outlined in this dissertation. Fortunately, these conversations about international cooperation have been happening more and more frequently (Global Agenda, 2012; Mapp, 2014).

In 2012 the International Federation of Social Workers, the International Association of Schools of Social Work, and the International Council on Social Welfare created a list of priorities for the profession in the coming years called “The Global Agenda” to support unifying global issues and the Millennium Development Goals of the United Nations which addresses capacity building needs for HIV prevention and treatment among other issues (Global Agenda, 2012). In general, it appears as though there is very little encouragement from social work curriculum standards in the United States (CSWE, 2015) to familiarize social work students with critical global issues, despite student interests (Okech & Barner, 2014). This indicates a serious gap in terms of equipping social work manpower with necessary knowledge or skills for the realization of Millennium Development Goals. Therefore, current social work curriculum standards should more quickly adapt to these worldwide shifts from globalization and prepare graduates to address such important issues adequately.

In the context of social work education, at least in the United States, more must be done in order for these international social work goals to be realized. Current standards for social work curriculum (CSWE, 2015) do not require or even recommend coverage of the international commitments specified in the Global Agenda, such as working toward environmental



sustainability (Global Agenda, 2012) which is imperative for securing stable HIV treatment. For the Global Agenda to be actualized, existing curricula must be revised to provide students with extensive exposure to changing global realities. Implementing the international social work goals means social work education in the United States must increase globally relevant concepts and link them to local realities, such as labor standards in our globalized economy in the United States. As such, the profession ought to be a louder voice in the global debate about these changing conditions. In the absence of social work action, the status quo will be maintained with potentially disastrous effects for the most impoverished regions.

### **Limitations**

As stated multiple times throughout this dissertation, there are noteworthy limitations to this research as much of the data draws from an exploratory examination of case studies. First of all, readers must be discerning when attempting to generalize these findings, particularly given the very small sample size from each location. A potential weakness of grounded theory methodology is that the researchers' own expectations, perceptions, and beliefs can influence the analysis of the data. To assuage this threat, the researchers worked as a team to analyze data and presented quotes to support how themes were interpreted. While agency workers read and spoke English at a very high level in Lebanon and Kenya, it was typically not their first language learned in the home. There could have easily been miscommunications due to language barriers. Crosschecks were in place to mitigate these potential miscommunications, but it is unknown if there are misrepresentations of participants opinions scattered within the notes. In addition, these themes are limited by the cultural and linguistic differences between the researchers and the participants and are likely missing valuable information that could inform better practice.

## **Future Research**

Continued research is needed to further explore the findings in this dissertation. While substantial scholarship has explored these themes of ethical decision-making, supportive services needed by health workers, barriers to HIV disclosure, and international funding, continued research is needed on how low- and middle-income countries handle diminished external funding. For example, more research is needed to address ethical decision-making models that might be a better fit or more efficient when working with people living with HIV than the four quadrants model. In addition, more research is needed on programmatic elements that support HIV disclosure and investigations of changing anti-gay policies in traditionally heteronormative countries may change prevention, treatment, and health outcomes in MSM. Likewise, more research is needed on how the best way to support CHWs and other healthcare workers whose livelihoods are arguably the most impacted by these financial changes as there are likely long-term consequences to their reduced budgets. More research should follow the path of Wagman et al., (2015) who evaluated innovative training program with CHWs to increase consensual HIV disclosure.

In addition, more social work-trained evaluators should be called to examine the impact of these financial changes to low- and middle-income countries, as currently most research is originating from medical and financial journals. Social work researchers can more holistically contextualize the impacts of the noted treatment consolidation and diminished funding. In addition, it recommended that researchers intentionally select community-based participatory methodology for the most accurate depiction of how shifting funding has direct and long-lasting impacts to already marginalized populations. Community-based participatory research has been praised for helping HIV treatment providers find creative ways to better support prevention and

treatment efforts with unique populations (Young & McCloud, 2013). Giving voice to study participants and allowing for a holistic analysis of complex social problems may advance the development of useful knowledge and provide a richer understanding of the population served (Creswell, 2008). Another way to address CHWs requests for more training to support HIV disclosure with client is through the evaluation of online training modules, created through collaboration of international social work educators, focused on enhancing motivational interviewing skills.

### **Conclusion**

The next decade will prove interesting, as various national economies will need to adapt to less and less external funding. Particularly interesting will be the findings from Kenya's 1% tax for national health programs mentioned in Chapter 4, as these reports can benefit other countries who are similarly exploring new financing options. One day, hopefully, the world will look back and be thankful for all that it learns from this terrible AIDS epidemic, as it has required so many to be resourceful, innovative, and stretch our abilities. As countries continue to share knowledge and resources with each other, we lessen our collective burden. Ideally, as Norman and colleagues (2007) describe, our global interdependence will become a "virtuous circle" whereby increased access to treatment lowers fear and stigma associated with testing positive, thereby increasing disclosure, prevention efforts, and further destigmatizing living with HIV/AIDS.

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## APPENDIX A

### Informed Consent Form for Community Respondents Focus Group- Evaluation: Difficult Decisions

This informed consent form is for **community respondents** that are participating in an evaluation of a decision-making tool. The evaluation is called: Difficult Decisions.

**Name of Principal Investigator:**                    **Larry Nackerud, PhD**

#### **Introduction**

An international working group based in Canada is doing an evaluation. They would like to see how an ethical decision-making tool might help care workers who make difficult decisions with clients. They are interested in how care workers make decisions when working with clients, so the tool can be made better.

The way this will be done is by collecting information gathering from three different organizations, in three cities (Beirut, Nairobi and Melbourne). The evaluation will take place over 12 months.

I am going to give you information and invite you to participate in this focus group. If you have questions, and even during the focus group, please ask me to stop, and it will be explained. The purpose of this consent form is to ask you to participate in a focus group. The focus group will take no longer than 60 minutes.

#### **Participant selection**

You are being invited to take part in this focus group because your experience can help us understand if the decision-making tool helps care workers with clients when hard decisions have to be made. You can also help explain how care workers and clients deal with difficult decisions, and how these decisions might affect the services you receive. Only adults aged 18 and older can participate.

#### **Voluntary participation**

Your participation in this focus group is voluntary. This means it is your choice to participate or not. If you choose not to participate, all the services you receive from the place that told you about this group will continue and nothing will change. You may change your mind later and stop participating, even if you agreed earlier.

**Procedure**

If you decide to participate, you will be asked about your opinion about experiences with making decisions in this private room.

The information from the focus group is private, and your name will not be included in the notes taken. Your name and signature on this form will be kept in a separate place and will not be used or given to anyone. If you do not want to put your name down, you can make an X. The notes from the focus group will be put in a safe place and will only be used by the Evaluation team. All notes will be destroyed after the evaluation is finished. If there is a report or a publication made about the evaluation, it will never give your personal information and no one will be able to identify you.

If you are uncomfortable answering any of the questions during the focus group, remember that you do not have to answer. If you decide that you do not want to finish, that is fine. You are also welcome to leave at any time.

**Risks and discomforts**

There should not be any problems for you as a result of you doing this focus group. Your participation will not change the services you receive here or how the staff treats you, nothing will change.

Sometimes people may feel upset when they talk about decisions they have made. Remember that you are free not to answer any questions and to stop at any time. If you do have feelings that you would like to talk about with someone, the Evaluator has arranged that you can talk with a counselor from a different organization.

**Benefits**

There are no direct benefits for you in this evaluation. The evaluation will give valuable information to the center about the tool, and will be used to improve the tool. It is hoped that the information from the evaluation will be helpful to the center, its care workers and in the end, for clients like you.

**Incentives or compensation**

There are no incentives or compensation for participating in this focus group. By participating in this interview, you agree that your participation is voluntary. Some snacks and drinks are here if you want some as a small “thank you” for your participation.

**Confidentiality**

The research is being funded by an international working group in Canada. The project's research records may be reviewed by that international working group and departments at the University of Georgia responsible for regulatory and research oversight.

Any information that could identify you will not be shared with anyone outside of the Evaluation Team. Any sheets used for the focus group will have a number on it instead of your name. There will be no link between your name and that number. I will not talk about our focus group with your care worker or any of the staff here at this center.

By signing this form, we are also asking you not to share any information that your fellow participants say. Everything said in this group is confidential. However, when conducting a focus group the researcher cannot guarantee the confidentiality of participants in the focus group. The researcher cannot control what participants might say outside the research context. The data will be transported by the researcher to his office at the University of Georgia in two ways—stored on a laptop and a jump drive and carried personally by the researcher.

**Who to contact**

If you have any more questions about this evaluation, please contact the evaluator, Dr. Larry Nackerud, (706-542-5470; [Nackerud@uga.edu](mailto:Nackerud@uga.edu)). For any questions about the Evaluator or the purpose of this evaluation, please contact Mr. John Miller at [john.miller@ccaba.org](mailto:john.miller@ccaba.org)

Do you have any questions at this time?

### Certificate of Consent

I have read all the information in the information sheet, or it has been read to me. I have had the chance to ask questions about it. Any questions that I have asked have been answered, and I am satisfied. I have been informed that there is minimal risk for me participating in this evaluation. I consent voluntarily to participate in this evaluation. I understand that I have the right to not be part of the evaluation at anytime without my decision causing any change to services I received.

**Print Name of Participant** \_\_\_\_\_

**Signature of Participant** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

#### Statement by the person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what is being asked.

I confirm that the participant was given an opportunity to ask questions about the evaluation, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this form has been provided to the participant.

**Print Name of Researcher/person taking the consent** \_\_\_\_\_

**Signature of Researcher /person taking the consent** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

### **Focus Group Questions for Community Respondents End-Point Questions**

Instructions and Script: The Evaluator will read the informed consent instructions to the focus group. Each member of the group will have two copies of the consent form. After reading the form, the Evaluator will ask if there are any questions. After this, the Evaluator will ask the focus group participants, if they agree to consent, to sign both copies (with either their name or an X, both copies are identical) and inform that one copy is for their personal records and the other is for the Evaluator. The Evaluator reminds the participants that the copy retained by the Evaluator will be kept in a secure location with the Evaluator.

The Evaluator then tells the group: “We are now going to begin the focus group”, and proceeds with the questions. The Evaluator then says, “Some of you may know that I am here to talk with you about your ideas and opinions *on how clients and their care workers make decisions that affect clients lives*. We are asking this because an organization that I am a consultant for has made a tool (a guide) to help care workers to make good decisions with their clients that may help care workers to follow ethical and human rights. We are evaluating this tool at another civil society organization. We also want to know what it is like to be a client in this community. Some of you may have been in the first focus group last year, and some may not have. Either way, this is ok and we would like your views. I would now like, with your permission, to begin with the questions. For each question, I may ask some follow up questions.

Focus group questions:

1. Going to a certain example of a hard decision, if there are times when care workers contact the authorities (police or child protection services) about a client, what have you heard in the community about how these decisions are made since X date (will provide exact date which will correspond to the implementation of the tool)?
  - a. Are these decisions made jointly (care worker and client) or not jointly?
    - i. Can you describe this?
    - ii. In general, do you think clients are told in this community if the authorities are going to be contacted?
    - iii. Are the clients included in the discussion?
    - iv. Are there certain situations that care workers will definitely contact the authorities for?
    - v. How do you think this process could be done better?
  
2. Now I am going to ask you about care workers and how they manage your private information (client confidentiality). In this community, how do you think your personal information is managed?
  - a. Are client actions, opinions, etc. kept private?
  - b. If they are not kept private, why not?



- c. Who finds out?
  - d. Have there been any problems to clients in the past year, since date X in this community because information has not been kept private about a client?
    - i. Can you provide an example?
3. When care workers in this community make decisions that will affect their client's lives since date X, do you know how they decide what to do?
- a. Is it based on professional rules (e.g., guidance, standard operating procedures or codes of conduct)?
  - b. Is it sometimes based on personal opinion?
  - c. Other ways that they make decisions?
4. What may happen in this community if clients and their care workers do not agree about what should happen in the client's life (e.g., about seeking healthcare, disclosing health status, about a client's family situation, etc) since date X?
- a. Can you give an example (not from your own life and without giving any names or the name of the organization)?
5. This is the last question. Have any of you heard of the use of this decision making tool being used in the community among care workers?
- a. If yes, without giving any names or their personal information, have you heard it is helping or not helping in decision making?
  - b. Do you think decision making is the same or not the same as before the tool came to an organization in your community?
  - c. If yes, do you think that having a training tool on a process for making difficult decisions was helpful or unhelpful for clients? For care workers? At organizations in this community?
    - i. If yes, why?
    - ii. If no, why not?

Is there anything that we have not discussed today that you would like to comment on now?

Thank you for your time!

## APPENDIX B

### **Informed Consent Form for Care Workers Focus Group- Evaluation: Difficult Decisions**

This informed consent form is for **care workers** that are participating in an evaluation of a decision-making tool. The evaluation is called: Difficult Decisions.

**Name of Principal Investigator:**                      **Larry Nackerud, PhD**

#### **Introduction**

An international working group based in Canada is doing an evaluation. They would like to see how an ethical decision-making tool might help care workers who make difficult decisions with clients. They are interested in how care workers make decisions when working with clients, so the tool can be made better.

The way this will be done is by collecting information gathering from three different organizations, in three cities (Beirut, Nairobi and Melbourne). The evaluation will take place over 12 months.

I am going to give you information and invite you to participate in this focus group. If you have questions, and even during the focus group, please ask me to stop, and it will be explained. The purpose of this consent form is to ask you to participate in a focus group. The focus group will take no longer than 60 minutes.

#### **Participant selection**

You are being invited to take part in this focus group because your experience can help us understand if the decision-making tool helps care workers with clients when hard decisions have to be made. You can also help explain how care workers and clients deal with difficult decisions, and how these decisions might affect the services you receive. Only adults aged 18 and older can participate.

#### **Voluntary participation**

Your participation in this focus group is voluntary. This means it is your choice to participate or not. If you choose not to participate, all the services you receive from the place that told you about this group will continue and nothing will change. You may change your mind later and stop participating, even if you agreed earlier.

#### **Procedure**

If you decide to participate, you will be asked about your opinion about experiences with making decisions in this private room.

The information from the focus group is private, and your name will not be included in the notes taken. Your name and signature on this form will be kept in a separate place and will not be used or given to anyone. If you do not want to put your name down, you can make an X. The notes from the focus group will be put in a safe place and will only be used by the Evaluation team. All notes will be destroyed after the evaluation is finished. If there is a report or a publication made about the evaluation, it will never give your personal information and no one will be able to identify you.

If you are uncomfortable answering any of the questions during the focus group, remember that you do not have to answer. If you decide that you do not want to finish, that is fine. You are also welcome to leave at any time.

### **Risks and discomforts**

There should not be any problems for you as a result of you doing this focus group. Your participation will not change the services you receive here or how the staff treats you, nothing will change.

Sometimes people may feel upset when they talk about decisions they have made. Remember that you are free not to answer any questions and to stop at any time. If you do have feelings that you would like to talk about with someone, the Evaluator has arranged that you can talk with a counselor from a different organization.

### **Benefits**

There are no direct benefits for you in this evaluation. The evaluation will give valuable information to the center about the tool, and will be used to improve the tool. It is hoped that the information from the evaluation will be helpful to the center, its care workers and in the end, for clients like you.

### **Incentives or compensation**

There are no incentives or compensation for participating in this focus group. By participating in this interview, you agree that your participation is voluntary. Some snacks and drinks are here if you want some as a small “thank you” for your participation.

### **Confidentiality**

This research is being funded by an international working group in Canada. The project's research records may be reviewed by that international working group and departments at the University of Georgia responsible for regulatory and research oversight.

Any information that could identify you will not be shared with anyone outside of the Evaluation Team. Any sheets used for the focus group will have a number on it instead of your name. There will be no link between your name and that number. I will not talk about our focus group with your care worker or any of the staff here at this center.

By signing this form, we are also asking you not to share any information that your fellow participants say. Everything said in this group is confidential. However, when conducting a focus group the researcher cannot guarantee the confidentiality of participants in the focus group.

The researcher cannot control what participants might say outside the research context. The data will be transported by the researcher to his office at the University of Georgia in two ways – stored on a laptop and a jump drive and carried personally by the researcher.

### **Who to contact**

If you have any more questions about this evaluation, please contact the evaluator, Dr. Larry Nackerud, (706-542-5470; Nackerud@uga.edu). For any questions about the Evaluator or the purpose of this evaluation, please contact Mr. John Miller at [john.miller@ccaba.org](mailto:john.miller@ccaba.org)

Do you have any questions at this time?

### **Certificate of consent**

I have read all the information in the information sheet, or it has been read to me. I have had the chance to ask questions about it. Any questions that I have asked have been answered, and I am satisfied. I have been informed that there is minimal risk for me participating in this evaluation. I consent voluntarily to participate in this evaluation. I understand that I have the right to not be part of the evaluation at anytime without my decision causing any change to services I receive.

**Print Name of Participant** \_\_\_\_\_

**Signature of Participant** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

### **Statement by the person taking consent**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what is being asked.

I confirm that the participant was given an opportunity to ask questions about the evaluation, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this form has been provided to the participant.

**Print Name of Researcher/person taking the consent** \_\_\_\_\_

**Signature of Researcher /person taking the consent** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

### **Semi-Structured Focus Group Questions for Care Workers**

**Instructions and Script:** The Evaluator will read the informed consent instructions to the focus group. Each member of the group will have two copies of the consent form. After reading the form, the Evaluator will ask if there are any questions. After this, the Evaluator will ask the focus group participants, if they agree to consent, to sign both copies (identical) of the form and inform that one copy is for their personal records and the other is for the Evaluator. The Evaluator reminds the participants that the copy retained by the Evaluator will be kept in a secure location with the Evaluator.

The Evaluator then tells the group: “We are now going to begin the focus group”, and proceeds with the questions. The Evaluator then says, “Some of you may know that I am here to talk to you about your experiences with making difficult decisions with your clients and about how the use of the tool has been for you and the organization.

I would now like, with your permission, to begin with the questions. For each question, I may ask some follow up questions.

**Focus group questions:**

1. Since the last time we met, have you had other positive and negative experiences with difficult client situations?
  - a. What type of situations were the most difficult to deal with?
  - b. Did you have to contact the authorities (police or child protection services) about child abuse or neglect since we last met?
    - a. Since we last met, how did you manage difficult situations related to client confidentiality and privacy?
  
2. Since we last met, how did you handle these difficult situations typically?
  - a. How did you decide what to do?
  
3. Now I am going to ask you some questions about decision-making and your use of the Difficult Decisions tool.
  - a. Do you think that the tool made a positive or negative difference, or no difference at all in your ability to make decisions?
    - i. Can you share an example of a positive difference?
    - ii. Can you share an example of a negative difference?
  - b. Do you think that the tool made a positive or negative difference or no difference at all in your client’s life?
    - iii. Can you share an example of a positive difference?
    - iv. Can you share an example of a negative difference?

4. Now I am going to ask you some questions about your experience with using the tool.
  - a. Can you tell me about if you used the tool?
    - v. Did you use it on your own? Provide examples.
    - vi. Did you use it with other colleagues? Provide examples.
    - vii. (If they have Supervision) did you discuss it in Supervision or use it in Supervision? Provide examples.
    - viii. Were there other ways that the tool was used?

Now I have some questions about how the authors can improve the tool.

5. Has using the tool made a positive or negative difference or no difference at all in how you think your clients should behave?
  - a. Do you have the same or different views of your work with clients? Please provide an example.
  - b. If you think about your clients after you go home from work, have your feelings or thoughts changed positively, negatively or no difference at all since I was last here?
6. Now I am going to ask you some questions about decisions and clients.
  - a. Have you ever had to make a decision involving a client, where the rights of the client were in conflict with another person's rights? Can you provide an example?
  - b. Have you ever had to make a decision about a client where doing what you think is in the best interest of your client could possibly harm someone else? Can you give an example?
  - c. Have you ever had to make a decision about a client where another person's rights were in conflict with your client's rights? Can you give an example?
  - b. Lastly, have you ever had to make a decision about a client where doing what you think is in the best interest of someone else could possibly harm your client? Can you give an example?

Thank you for your answers. Is there anything that we have not discussed today that you would like to comment on now in regard to the tool? In regard to difficult decisions.

Thank you for your time!

## APPENDIX C

### **Informed Consent Form for Key Informants Focus Group-Evaluation: Difficult Decisions**

This informed consent form is for **key informants** to participate in a semi-structured interview as part of an evaluation of an ethical decision-making tool. The evaluation is called: Difficult Decisions

#### **Name of Principal Investigator:**

Larry Nackerud, PhD

#### **Introduction**

You are being asked to participate in this key informant interview as part of an evaluation of an ethical decision-making tool developed by an international working group in Canada. I am going to give you information and invite you to take part in this key informant interview as part of the evaluation. If you have questions, or if you do not understand anything, please ask me and I will tell you.

The purpose of this consent form is to ask you to participate in this key informant interview. The key informant interview will not take longer than 45 minutes.

#### **Purpose of the key informant interview**

The purpose of this key informant interview is for the evaluator to better understand: 1) how your agency operates, 2) what ethical dilemmas are faced by the care workers who work for your agency, and 3) how the Ethical Decision making tool developed by the international working group in Canada may be helpful to your care workers. Information shared by you will eventually help changes to be made to the tool.

#### **Participant selection**

You have been selected to participate in a key informant interview as a function of your working/administrative/supervisory role in the agency. Your experience at this agency can help us understand if the decision-making tool will be helpful to care workers. Only adults aged 18 and older can participate in the key informant interview.

#### **Voluntary participation**

Your participation in this key informant interview is voluntary. It is your choice whether to participate in the key informant interview. If you choose not to take part in the key informant interview, your choice will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participation in the key informant interview at any time, even if you agreed earlier. If you are uncomfortable answering any of the questions during the key informant interview remember that you do not have to answer. If you decide that you do not want to finish, that is fine. You are also welcome to leave at any time.

*You will not be asked to share personal beliefs, and you do not have to share any knowledge that you are not comfortable sharing.*

**Procedure**

If you decide to take part in the key informant interview, you will be asked a small number of questions. Your professional opinions, judgments and description of work experiences will all be considered valuable information.

**Risks and discomforts**

There should not be any problems for you as a result of you participating in this key informant interview. Your participation will not affect your performance evaluations, potential future promotions or how you are treated at work.

Sometimes people may feel upset when they are asked to remember decisions they have made. Remember that you are free not to answer any questions and to stop at any time.

**Benefits**

There are no direct benefits for you in this evaluation. The evaluation will give valuable information to the international working group about the tool, and will be used to improve the tool. It is hoped that the information from the evaluation will be helpful to the center, its care workers and in the end, also for the clients you work with.

**Incentives or compensation**

There are no incentives or compensation for participating in this key informant interview. By participating in this key informant interview, you agree that your participation is voluntary.

**Confidentiality**

This research is being funded by an international working group in Canada. The project's research records may be reviewed by that international working group and departments at the University of Georgia responsible for regulatory and research oversight.

Any personal information that could identify you will not be shared with anyone outside of the Evaluation Team. Any electronic files used to store the key informant interview information will have a number on it instead of your name. There will be no link between your name and that number. The project's records may be reviewed by departments at the University of Georgia responsible for regulatory and research oversight. Data will be stored on the researcher's laptop and transported electronically to his home office computer in the United States.

The information from this key informant interview is private, and your name will not be included in any manner. Your name and signature on this consent form will be kept in a separate place and will not be used or given to anyone. The information from the key informant interview will be used only by the Evaluation team. Only the Evaluator will have access to the computer files where the key informant interview data is saved. All electronic files from the key informant interview will be destroyed after the evaluation is finished. If there is a report or a publication made about the evaluation, it will never give your personal information and no one will be able to identify you. The data will be transported by the researcher to his office at the University of



Georgia in two ways—stored on a laptop and a jump drive and carried personally by the researcher.

### **Who to contact**

If you have any more questions about this evaluation, please contact the Evaluator, Dr. Larry Nackerud (706-542-5470, [nackerud@uga.edu](mailto:nackerud@uga.edu)). For any questions about the Evaluator or the purpose of this evaluation, please contact Mr. John Miller at: The Coalition for Children Affected by AIDS, [john.miller@ccaba.org](mailto:john.miller@ccaba.org)

Do you have any questions at this time?

### **Certificate of consent**

I have read all the information in the information sheet, or it has been read to me. I have had the chance to ask questions about it. Any questions that I have asked have been answered, and I am satisfied. I have been informed that there is minimal risk for me participating in this evaluation. I consent voluntarily to participate in this evaluation. I understand that I have the right to not be part of the evaluation at anytime without my decision having a bearing on my job or on any work-related evaluations or reports at this center.

**Print Name of Participant** \_\_\_\_\_

**Signature of Participant** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

### **Statement by the person taking consent**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what is being asked.

I confirm that the participant was given an opportunity to ask questions about the evaluation, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this form has been provided to the participant.

**Print Name of person taking the consent** \_\_\_\_\_

**Signature of person taking the consent** \_\_\_\_\_

**Date** \_\_\_\_\_  
Day/month/year

### **Semi-structure Interview of Key Informants**

Can you please describe your agency: and

- its history
- its mission
- its objectives
- its funding source(s)
- its organizational structure
- its service population
- its staff & their training/credentials?

Can you please describe what you think are ethical dilemmas that are on occasion faced the care workers who are affiliated with your agency?

Can you please describe how the newly developed Ethical Decision making tool might serve useful for your care workers?

Thank you. Is there anything you would like to add?

Larry Nackerud, PhD

## APPENDIX D

### Example of Notes Taken During Interviews

#### Lebanon Endpoint - Key Informant Interviews - July 29, 2015

##### 1<sup>st</sup> Interview

##### Describe Agency

Started in late 80s, More than one nurse visited different people, including homeless children – they had another locations. Helped families during the war – Started with a small group (4 people living with HIV) around 2000 or 1999. Developed into servicing 192 members with 130 active members. Includes outreach workers, mobile units, volunteers & peers. Psycho-social support, follow-up, food support. Advocacy with religious leaders, and police. LGBT, refugees. Some of their funding will end from Canada in September. More funding going to environmental causes. Only 14% of people in the region have access to HIV treatment services.

##### Mission

- Support people with HIV; Advocating for them; Support change of laws
- Objectives - Deliver a message about prevention; Help people living with HIV
- Improve image of HIV; bring information to young people “shock them” by bringing unwrapped condoms. “So many ways to bring the message.” Pass on the message.

##### Funding Sources

“less & less” trend towards environmental causes – HIV isn’t trendy anymore

##### Its service population

Youth, adults, LGBT, people living with HIV

##### Staff Training/Credentials

Responded with “thumbs up.” She said “all dedicated” follow their heart”

**Ethical Dilemma:** Drug users come 2 or 3 weeks have relapse and don’t come anymore, adherence to treatment one or two treatment; opiate drug treatment see the psychiatrist. Come one or two times per week. IF they relapse several times, refer them to other NGO or a residential treatment center. If drug users environment is traumatic, they should be in residential treatment center. What’s best for the patient

No law mandating to call the authorities if drug user or providing drugs to a minor  
Very reluctant to involve police or authorities? If we see police, we don’t take risks?

## APPENDIX E

### **Coding Occurrences & Thematic Coding Sample**

#### Challenges to Disclosure

- Financial (42 data points)
- Social (24 data points)

#### Parenting

- Child Disclosure (14 data points)
- Medical Adherence (9 data points)
- Guilt/Blame (6 data points)

#### Policy Issues (12 data points)

#### Challenges that Impact Treatment Providers

- Financial Strain on Health Workers (39 data points)
- Financial Shifts/Combined Public Health Efforts (32 data points)
- Training Needs (18 data points)
- Distrust of Government (15 data points)
- Harm Reduction Methods (13 data points)
- Pressure to Identify People with HIV (8 data points)

## APPENDIX F

Antenatal Care (ANC)	ANC describes healthcare for women who are pregnant. In countries with generalized epidemics, such as Kenya, estimates of HIV prevalence use surveillance data of pregnant women attending sentinel antenatal clinics (WHO, 2013).
Antiretroviral Therapy (ART)	ART is the general terminology for HIV medicinal treatment, typically comprised of multiple drugs in tablet form that manages and suppresses the HIV virus. Before ART became available, all patients with AIDS were considered highly likely to develop a new AIDS-related illness or die within 2 years. Access to antiretroviral therapy (ART) is a tremendous contributing factor to the many successes in the global battle against AIDS.
Bilateral Financial Assistance	Bilateral financial assistance is funds dispersed from donor governments directly to a recipient country. Example: PEPFAR
Children Affected by HIV	‘Children affected by HIV’ includes children diagnosed with HIV and/or those impacted by HIV – usually describing those children whose parent or guardian is living with HIV.
Community Health Workers (CHWs)	CHWs are health care workers, often with little training or formal education, that link people in their community with supportive services.
Council on Social Work Education (CSWE)	CSWE is the accrediting body for educational social work/welfare programs in the United States and parts of North America.
Four Quadrants Model	Originally developed by Johnsen, Siegler, and Winslade in 1982, the four quadrants decision-making model was developed for health practitioners to support difficult ethical decision. This approach asks practitioners to carefully reflect and document four areas divided into quadrants: medical indications, patient preferences, quality of life, and contextual features. Within each quadrant are specific questions to consider (Johnsen, Siegler, & Winslade, 1982).

Hepatitis C	Hepatitis C is a liver disease caused by a blood borne virus. The virus can cause both acute and chronic hepatitis infection, ranging in severity from a mild illness lasting a few weeks to a serious, lifelong condition. In relation to HIV, this virus is also transmitted through intravenous drug use, and transmission through sexual intercourse is rare.
HIV Transmission	The HIV virus is spread through blood to blood contact, and the sharing of semen, vaginal fluids, or breast milk. High-risk activities include blood transfusions, sharing needles, nursing infants, and sexual intercourse without a condom.
HIV/AIDS	Acquired Immune Deficiency Syndrome (AIDS) is a spectrum of conditions caused by infection of the Human Immunodeficiency Virus (HIV). HIV interferes with the immune system, making people living with the virus more susceptible to disease. The late symptoms of the infection are referred to as AIDS. There is no cure or vaccine for HIV/AIDS, but Antiretroviral Therapy (ART) can significantly reverse the complications of the condition. In this dissertation, the acronyms “HIV” and “AIDS” will be used interchangeably.
Key Populations	Key populations, also referred to as most-at-risk-populations, are people who inject drugs, gay men and other men who have sex with men, transgender persons, and sex workers.
Lesbian, Gay, Bisexual, & Transgender (LGBT)	The term LGBT signifies groups of people who are minorities based on their sexual orientation or gender identity. Gay and bisexual men and transgender women are targeted key populations in the global fight against HIV/AIDS.
Malaria	Malaria is a mosquito borne infectious disease with potentially severe consequences. Symptoms range from a flu-like illness to seizures, comas, and death.
Millennium Development Goals (MDG)	The MDGs are eight international goals developed after the Millennium Summit of the UN in 2000. For the purposes of this dissertation, the most germane target is goal number six which proposes “[t]o combat HIV/AIDS, malaria, and other diseases.” Goals are intended to be met and revisited by 2015. (UNAIDS, 2015).
MSM	Men who have sex with men (MSM) is the preferred terminology in sexual health literature as it recognizes that not all men who have sex with men identify as gay or bisexual.

National Empowerment Network of People living with HIV/AIDS in Kenya (NEPHAK)	NEPHAK is the coordinating agency in Nairobi, Kenya responsible for directing efforts of local clinics and CHWs to ensure prevention and treatment of people living with HIV/AIDS. NEPHAK rarely, if ever, provides direct supportive services with people living with HIV.
President's Emergency Plan for AIDS Relief (PEPFAR)	In 2007 President Bush and the 108 <sup>th</sup> United States Congress created PEPFAR. (National Research Council, 2007). The objective of PEPFAR was to target countries with high HIV/AIDS prevalence, including Kenya, and give them specialized aid.
Pre-Exposure Prophylaxis (PrEP)	PrEP is a new and somewhat controversial HIV prevention strategy in which HIV-negative people use ART, usually implemented to treat HIV infection, to reduce their risk of becoming infected with HIV.
Serostatus/Serodiscordant	Serostatus refers to the presence of a serological marker in the blood, such as HIV. In HIV literature, a serodiscordant relationship typically denotes that one partner is infected by HIV and the other is not.
Sexually Transmitted Infections (STIs)	STIs are a group of infections commonly spread through sexual or intimate contact.
Tuberculosis (TB)	TB is an infectious disease caused by bacteria and mostly attacks the lungs. Active TB symptoms include a chronic cough, fever, and weight loss. When left untreated, active TB kills more than 50% of those infected.
Global Fund, The	The Global Fund to Fight AIDS, Tuberculosis, and Malaria (often shorted to The Global Fund) is an international financing organization that aims to attract and disburse privately and publically funded resources. The Global Fund is a financing mechanism rather than an implementing agency.
United Nations (UN)	The UN is an intergovernmental organization, consisting of many specialized intersystem agencies (e.g., World Bank, World Health Organization, Food Programme, etc.) to promote international co-operation. It was started after World War II as a means to prevent similar conflicts.
UNAIDS	Also known as the 'Joint United Nations Programme on HIV/AIDS,' UNAIDS is the main advocate and coordinator for the global HIV/AIDS epidemic. Under WHO, UNAIDS works in close partnership with other global donors (e.g., The Global Fund and PEPFAR) to allocated international HIV/AIDS funding to countries.

United States Dollar (USD)	International HIV funding from The Global Fund and UNAIDS are distributed in the USD currency.
Victorian AIDS Council (VAC)	VAC is a state government health agency located in Melbourne, Australia. The agency provides a broad range of health services for the prevention and treatment of HIV/AIDS in their local community.
World Health Organization (WHO)	WHO is a specialized agency of the UN focused on international public health. In 1986, WHO started a global program on the growing problem of HIV/AIDS, followed two years later by additional attention to prevent discrimination against people living with HIV. UNAIDS was formed in 1996 under the WHO umbrella.
Soins Infirmiers et Developpement Communautaire (SIDC)	SIDC is a community-based health organization located in Beirut, Lebanon which coordinates HIV prevention efforts and treatment for people living with HIV. L'Escale, founded in 2010, is a partnering agency under the umbrella of SIDC that provides treatment and support for intravenous drug users.