

TOWARDS A MODIFIED SOCIO-ECOLOGICAL MODEL FOR HIV CARE  
IN A RESOURCE-CONSTRAINED CONTEXT

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ABSTRACT

The individual person living with HIV/AIDS (PLWHA), attempts to shape his life with HIV/AIDS and on antiretroviral treatment (ART) within the broader social context of his household and community. By integrating the sociological concepts of 'a patient with a hybrid identity' and 'HIV/AIDS competent contexts', this study presents a modified socio-ecological model for HIV care. Based on the research findings of an overarching mixed-methods research project, this conceptual paper shows that not only the responsibility of the individual should be considered to successfully adhere to treatment, but also their social environment and its capacity to actively stimulate a lifestyle that fosters health. With regard to these surrounding environmental levels that enable and support the PLWHA's choice of health-enhancing practices, we should not only focus on the dominant community-level approach but also on the household level when building HIV/AIDS competent environments. The proposed theoretical model could guide future HIV/AIDS research through insights into the importance of a health-enabling context in providing sustainable support for PLWHA. This theoretical framework on the facilitators of and impediments to lasting success of ART is essential, as antiretroviral treatment cohorts are likely to expand in the coming decades in a health system context of limited human resources.

KEY WORDS

HIV/AIDS; Socio-ecological model; PLWHA with a hybrid identity; HIV/AIDS competent household; HIV/AIDS competent community; Community Health Workers

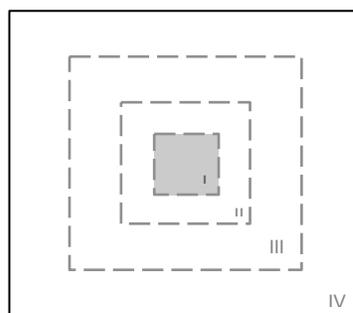
## 1. INTRODUCTION

Since the roll-out of ART, the focus of the HIV/AIDS epidemic has shifted from treating HIV/AIDS as an acute illness likely to result in imminent death – as was the case when it was discovered in the 1980s – to today's treatment of the illness as a chronic, yet manageable condition. In this respect, HIV/AIDS requires patients' continual engagement in the HIV care continuum (van Praag and Swai 2004; Davey, Foster et al. 2009; Ansari, Ansari et al. 2013). PLWHA need to follow sequential steps or stages of HIV medical care from initial diagnosis over linkage to care, ART initiation, retention in care and treatment adherence (McNairy and El-Sadr 2012). As a chronic disease, life-long treatment adherence is thus indispensable (Wouters, Meulemans et al. 2009; Wouters, Van Damme et al. 2009; Russell and Seeley 2010). Adherence is not only essential for the health of individual patients, to achieve viral suppression and improving their quality of life, but also for the public health as a whole (Roberts 2000; Simoni, Frick et al. 2002; Karim, Karim et al. 2004; Kagee 2008; National Center for HIV/AIDS, Viral Hepatitis et al. 2013; Dewing, Mathews et al. 2014). For these reasons, "adherence is considered as both the key to success or the Achilles heel for antiretroviral drug combinations" (García and Côté 2003: p. 37). Non-adherence can take many forms, including not taking the daily prescribed number of pills or self-adjusting the regimen (World Health Organization 2003; Osterberg and Blaschke 2005; Kagee 2008). Non-adherence is seen as a major public health concern because it leads to virologic, immunologic and clinical failure (Lyon, Trexler et al. 2003; Power, Koopman et al. 2003; Battaglioli-DeNero 2007; Abaasa, Todd et al. 2008; Naidoo, Peltzer et al. 2013; Remien, Mellins et al. 2013), results in an increased morbidity and mortality (Karim, Karim et al. 2004), increases further transmission to others (Simoni, Frick et al. 2002; Karim, Karim et al. 2004; Ciambrone, Loewenthal et al. 2006; Battaglioli-DeNero 2007), carries a huge economic burden (Martin, Williams et al. 2005) and increases the risk of the development and transmission of a drug resistant virus (Chesney 2000; Roberts 2000; Cederfjäll, Langius-Eklöf et al. 2002; García and Côté 2003; Power, Koopman et al. 2003; Remien, Stirratt et al. 2006; Battaglioli-DeNero 2007; Abaasa, Todd et al. 2008; Naidoo, Peltzer et al. 2013).

Treatment adherence is "considered as both the key to success or the Achilles heel for antiretroviral drug combinations" (García and Côté 2003: p. 37). Various barriers on both the individual and household level are experienced by PLWHA along the care continuum towards treatment adherence. The individual affected by HIV/AIDS in a physical, psychological and social way, attempts to shape his life with HIV/AIDS and on ART within his/her broader social context – as illustrated by Figure 1. As a result, not only the responsibility of the individual should be considered to successfully navigate the care continuum towards

treatment adherence, but also their social environment and its capacity to actively stimulate a lifestyle that fosters health. In this social environment, extensive efforts are thus required to increase HIV/AIDS knowledge, reduce stigma, stimulate HIV testing, improve health care-seeking behavior, and encourage safe sexual practices—described in the literature as the need for *HIV/AIDS competence*<sup>1</sup> (Lamboray and Skevington 2001). HIV/AIDS competence reflects the idea that “the likelihood that people will choose health-enhancing practices depends not only on individual-level factors, but also on the extent to which they live in social environments that enable and support this choice” (AIDS-Social Drivers Working Group 2010: p.10). Achieving HIV/AIDS competence cannot be done by individuals alone, it is a group phenomenon (Lamboray and Skevington 2001). These ideas are rooted in a socio-ecological perspective, which emphasizes the interrelatedness and interdependency of individuals and their social environment, which in turn affect disease management and its outcomes (Waller 2001; Weihs, Fisher et al. 2002; Latkin and Knowlton 2005; Wouters 2012). Socio-ecological models “help us understand health behavior as determined by a set of interconnected individual and contextual factors” (Golden and Earp 2012: p. 368). Departing from earlier contributions of the socio-ecological theory, recently scholars have been specifying it for the context of HIV/AIDS. In this respect, Wouters (2012) developed the Individual-Family-Community (IFC) model, which draws attention to the importance of studying the PLWHA with a hybrid identity within the context of the household and community level. This framework is suited to comprehensively study the different social contexts impacting on HIV/AIDS care in general and on ART interventions in particular in high-prevalence, resource-limited settings (Wouters 2012).

Figure 1: Traditional socio-ecological model for people living with HIV/AIDS



I. PLWHA II. Household level III. Community level IV. Health policy level

<sup>1</sup> Thanks to antiretroviral treatment, PLWHA who navigate the care continuum successfully now go through life with HIV/AIDS as a chronic medical condition, rather than an acute, fatal disease that will eventually reach the AIDS stage (Rhodes, Bernays, et al. 2009; Gausset, Mogensen, et al. 2012). In this article we therefore make use of the term “HIV/AIDS competence”, instead of the common usage of “AIDS competence”, in line with Mathiot’s (2004) remark on the Self-Assessment Framework for AIDS Competence.

To date, however, little empirical evidence is available with regard to the PLWHA trying to shape their lives with HIV/AIDS and on ART within the broader social contexts of their households and communities. This article will first outline the different social environmental levels surrounding the PLWHA. Then, the interactions between these different environmental levels and the PLWHA will be investigated into detail – aiming to respond to the warning of Kaufman et al. (2014) that separating factors into distinct levels can obscure the mechanisms that link them (Kaufman, Cornish et al. 2014).

## 2. STUDY

In this conceptual paper a consolidation of the research findings of an overarching research project will be presented. The results of this mixed methods study, with a “partially mixed sequential equal status design” (Leech and Onwuegbuzie 2009: p. 270), focus on the intermediate role of the household in community-based support for PLWHA in South Africa. These findings are published in various scientific journals (Wouters, Masquillier et al. 2014; Masquillier, Wouters et al. 2015; Masquillier, Wouters et al. 2015; Masquillier, Wouters et al. 2016). The quantitative research part aimed to investigate the interplay between community-based treatment adherence support and the social environment of the patient, using structural equation modelling to analyse data drawn from the randomized controlled trial “Effective AIDS Treatment and Support in the Free State” (FEATS) in South Africa. Ethical approval was granted by the Ethics Committee of the UFS Faculty of Health Sciences [ETOVS 145/07], and it is registered in the South African National trial register [DOH-27-0907-2025], as well as with the National Institutes of Health in the United States [NCT00821366]. For the qualitative research part, ethical approval was granted by the Ethics Committee of the University of the Western Cape (13/10/55). In the qualitative research part, data was analyzed carefully in accordance with the Grounded Theory procedures, using Nvivo 10. More specifically, we analyzed field notes from participatory observations conducted during 48 community-based treatment adherence support sessions in townships on the outskirts of Cape Town, transcripts of 32 audio-recorded in-depth interviews with PLWHA and transcripts of 4 focus group discussions with 36 community health workers (CHWs).

### 3. RESULTS

Besides identifying the hybrid-identity PLWHA and the health-enabling environments of the HIV/AIDS competent household and community as separate levels, socio-ecological and the IFC models also emphasize the mutual influence and dynamic interplay among these levels (Bronfenbrenner 1977; McLeroy, Bibeau et al. 1988; Stokols 1996; McLaren and Hawe 2005; Sallis, Owen et al. 2008; Wouters 2012). Before outlining the interaction, we will zoom in on the two HIV/AIDS competent levels surrounding the PLWHA.

#### 3.1 DIFFERENT HIV/AIDS COMPETENT LEVELS SURROUNDING THE PLWHA

Ample studies have focused on the individual patient determinants of long-term ART success. The ever growing body of knowledge produced by this line of research has convinced both clinicians and policy makers of the importance of the social and psychological dimensions of life with HIV/AIDS as a chronic illness. To achieve durable ART success “PLWHA should incorporate HIV/AIDS and ART into their identity, but continuously adapt the new hybrid identity to ever-changing internal and external conditions” (Wouters 2012: p. 373). For instance, if there is a need for stigma management, PLWHA may attempt to regulate their roles in the social environment by adopting a hybrid identity. Treatment should become integrated into patients’ daily lives to successfully navigate the care continuum (Médecins Sans Frontières 2013). For PLWHA to become “experts in the daily management of their condition” (Decroo, Rasschaert et al. 2013: p. 174), it is important that they acquire knowledge, share treatment experiences among peers and practice self-management skills (Decroo, Rasschaert et al. 2013).

Families and households have the potential to offer social, psychological and material support which can further buffer the impact of the epidemic and protect the affected individual against the potentially discriminating and stigmatizing reactions from the social environment (Wouters 2012). Inspired by the IFC model and the concept HIV/AIDS competence, we have conceptualized what constitutes a health-enabling environment; i.e. an “HIV/AIDS competent household” (Masquillier, Wouters et al. 2015) – as illustrated by square II in Figure 1. This concept illustrates that the household has the potential to form a health-enabling environment which provides sustainable support to the patient on his or her care

continuum. An HIV/AIDS competent household provides a context in which more effective HIV/AIDS management is possible by making prevention and treatment part of daily life in the household. In such an atmosphere, it is easier for respondents to cope with HIV/AIDS-related markers. It should be noted that HIV/AIDS competence can be thought of as a continuum along which households are positioned and can progress, sensitive to the household dynamics. However, within the challenging context of vulnerabilities and multiple risks, aggravated by HIV/AIDS's devastating impact, the road to HIV/AIDS competence is fragile and liable to encounter various barriers. At any moment, the development of HIV/AIDS competence in the household may be interrupted by complicating factors that emerge at individual or household level, such as stigma, among others.

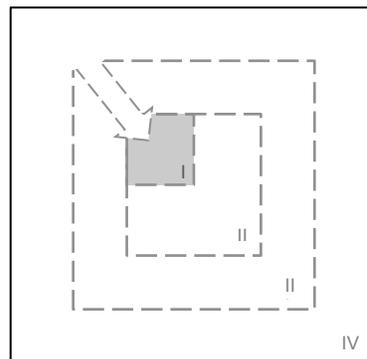
The IFC model does not only incorporate the household level as an important influential environmental level in the durable disease management of PLWHA, but also the community level – as exemplified by square III in Figure 1. The IFC model indicates that a health-enabling and HIV/AIDS-competent community can provide the much needed supportive context to durably adhere to treatment and thus mitigate the impact of HIV/AIDS on the life of the individual patient (Wouters 2012). An HIV/AIDS competent community is defined by Campbell et al. (2012) as “a social setting in which people are most likely to work collaboratively to optimize HIV/AIDS prevention, care and treatment” (Campbell, Skovdal et al. 2012: p.124). A more recent line of research focusses on such community factors, for instance enacted by community health workers (CHWs) in HIV/AIDS care as a response to the tension between the need for additional psychosocial care and the shortage of health professionals. Evidence is emerging that the psychosocial support from the community can significantly improve ART outcomes where the tasks of health professionals are usually limited to medical-technical ones, thus indicating the potential contribution of the community-level in addressing health issues at the individual level. However, the available scientific evidence on this topic reports discrepant findings on the effectiveness of peer adherence support programs (Bärnighausen, Chaiyachati et al. 2011; Wouters, Van Damme et al. 2012).

### 3.2 THE DYNAMIC INTERRELATIONSHIP BETWEEN PLWHA AND HIV/AIDS COMPETENT ENVIRONMENTS

Figure 2 presents a modified version of the ecological model, developed on the basis of a synthesis of the results of this mixed-method research. Square IV, on the outside, represents the health policy level, with the arrow illustrating task-shifting as one response to the human resources shortage for providing care

encompassing care to the growing group of PLWHA in South Africa. Within the context of task-shifting, mobilization of the community brings care closer to the PLWHA and his or her family and household environment (Lehmann and Sanders 2007; Celletti, Wright et al. 2010; Mdege, Chindove et al. 2012; Wouters, Van Damme et al. 2012). Square III illustrates the HIV/AIDS competent community, which is enacted by CHWs in this article, “located at the interface between households and the formal health system” (Schneider, Schaay et al. 2015: p. 10). Square II symbolizes this intermediate household level, at which there is a certain degree of HIV/AIDS competence. Finally, Square I corresponds to the PLWHA, who has a hybrid identity – not positioned centrally in the household as pictured in traditional socio-ecological models, but instead serving as a gatekeeper. The gatekeeping function represents an attempt by the PLWHA to regulate the involvement of the household in his or her HIV/AIDS disease management and the CHW’s visits, depending on their own perception of the household environment. The grey square may represent the PLWHA living either openly as HIV positive in the household or as a fellow household member, whose HIV status is unknown. The dotted lines in Figure 2 illustrate the fact that all of these levels are in continual interaction with each other, in accordance with the socio-ecological and IFC model used as the theoretical framework in this article.

Figure 2: Modified socio-ecological model within the context of community-based treatment adherence support for people living with HIV/AIDS



I. PLWHA with a hybrid identity II. HIV/AIDS competent household III. HIV/AIDS competent community IV. Health policy level

### 3.2.1 INTERACTION BETWEEN PLWHA AND HIV/AIDS COMPETENT HOUSEHOLDS

HIV/AIDS competence is built in the interaction between the PLWHA and his or her household. The road to HIV/AIDS competence begins with the recognition of the reality of HIV/AIDS by the household

members. In the majority of the households studied in this research it was the PLWHA themselves who acted as the change agents and created awareness and openness about the disease by disclosing their status. In line with the IFC model, our results show that contextual factors, such as HIV-related and non-HIV-related household dynamics, can be external drivers of identity adaptation (Wouters 2012). The potential consequences of disclosure depend on the household context in which the PLWHA lives. By adopting a hybrid identity, a PLWHA may attempt to act as a gatekeeper, regulating the involvement of the household in his or her HIV/AIDS disease management. The extent to which this occurs will depend on the patient's own perception of the household environment. Our results are in line with the "Disclosure Processes Model" of Chaudoir et al. (2011), which states that PLWHA are more likely to disclose to confidants and share their status when they have specific goals that encourage disclosure, such as seeking support or encouraging others to be tested, and less likely to disclose when perceived levels of stigma are high and they have specific goals that discourage disclosure, such as avoiding rejection (Chaudoir, Fisher et al. 2011). Following recognition of the reality of HIV/AIDS in the household, some patients in this study began acting as household health advisors by sharing information, encouraging other household members to be tested and preventing the spread of HIV in the household by distributing and using condoms. It is clear that, in more HIV/AIDS competent households, it is easier for PLWHA to deal with HIV/AIDS-related markers, such as visible signs of illness, the presence of ART tablets, a clinic card, among others.

While a PLWHA may embrace the identity of an HIV patient on ART when he or she feels safe at home, we found that PLWHA attempt to hide their HIV-positive status if they fear stigmatization. This finding is in line with Bogart et al. (2008), who stated that "stigma issues were intertwined with disclosure decisions" (Bogart, Cowgill et al. 2008: p. 251). When patients do not disclose to some or all household members, a burden of secrecy is created – as noted by Bogart et al. (2008) in their US-based study among PLWHA. As a consequence, the PLWHA on ART is not able to live openly with his/her status in the household. Non-disclosure may allow individuals to deny the reality of HIV-related illness and the need for behavior change, which inhibits the development of HIV/AIDS competence in such a household context. In line with previous research (Nachega, Knowlton et al. 2006; Rotheram-Borus, Stein et al. 2010), our results show that as a consequence of non-disclosure, the possibility of tapping into support from household members is restrained. In such a household context, visible markers of the disease will also need to be concealed as they may undermine hybrid identity management. The results of this

research show that this also impacts treatment adherence, as Kagee (2008) notes in his research on adherence to ART in the context of the national roll-out in South Africa: “stigma against HIV may be a barrier to medication adherence mainly due to the interaction between adherence and disclosure. If patients are seen by members of their social constellation such as neighbors, family members, or friends, to be taking ART, this is likely to convey a signal that they are HIV positive or living with AIDS” (Kagee 2008: p. 419).

### 3.2.2 INTERACTION BETWEEN PLWHA AND HIV/AIDS COMPETENT COMMUNITIES

The CHWs are seen as an enactment of the HIV/AIDS competent community. By activating bridging social capital, the CHWs surveyed in the overarching study helped PLWHA access resources from outside, such as condoms; helped with housekeeping; provided emotional support; and acted as bridges between patients and official institutions. The CHWs also helped patients overcome various barriers that made adherence more difficult.

However, communities may vary in their capacity or readiness for collective action (Beeker, Guenther-Grey et al. 1998). In addition to their immense potential for strength and support during times of need and crisis (Iwelunmor, Airhihenbuwa et al. 2006), the existing literature has indicated that communities can also be potential sources of stigma (Holzemer, Uys et al. 2007). Results show that when the surrounding community was perceived as stigmatizing, some patients avoided health facilities located in their own communities. In such communities, the association of the CHW with HIV/AIDS is more likely to arouse stigmatizing feelings and to threaten the hybrid identity management of PLWHA, as it may encourage or force disclosure. These findings are in line with Low et al. (2013), who reported in their Kenyan study that stigma deters people from testing. The authors suggest that this stigmatizing effect might be avoided when an entire community is counseled and tested at home, as “it removes this ‘singling out’ effect”, blunting the impact of stigma on HIV testing uptake (Low, Pop-Eleches et al. 2013: p.104).

### 3.2.3 INTERACTION BETWEEN HIV/AIDS COMPETENT HOUSEHOLDS AND HIV/AIDS COMPETENT COMMUNITIES

There is a reciprocal relationship between the two environmental levels of HIV/AIDS competence. For instance, an HIV/AIDS competent community plays an important role in gradually normalizing and

demystifying HIV/AIDS, which assisted some of our respondents and the other members of their household in accepting the reality of their disease and its treatment. The CHWs surveyed in this study also helped in this, in that they assisted in “door-to-door” health promotion visits during which they informed people about health-related topics and invited them to be tested at a mobile testing site as part of an outreach program in the community. Another way in which an HIV/AIDS competent community provides an important facilitating context in which households can gain more HIV/AIDS competence is by providing opportunities to access bridging social capital, such as the CHWs studied in this PhD research. Households require bridging social capital not only to obtain accurate information, but also to access resources from outside that can support them in becoming better health-enabling household environments for patients.

On the other hand, HIV-related stigma and discrimination, and local HIV-related myths within the community, serve to undermine effective HIV/AIDS management and create barriers to effective dialogue about HIV/AIDS (Nhamo, Campbell et al. 2010) and HIV-preventive behaviors (Logie and Gadalla 2009; Brown, BeLue et al. 2010; Sengupta, Banks et al. 2011), among other things. As households are not isolated from events that occur in the community, they might be influenced negatively when located in a less HIV/AIDS competent community. For instance, the household might feel ostracized and isolated if no one visits the household after the realization that they are affected by HIV/AIDS (Hosegood, Preston-Whyte et al. 2007).

#### 3.2.4 INTERACTION BETWEEN PLWHA, HIV/AIDS COMPETENT HOUSEHOLDS AND HIV/AIDS COMPETENT COMMUNITIES

Results of the overarching study show that the HIV care continuum – which determines the pathway a patient will take after being diagnosed with HIV (McNairy and El-Sadr 2012; Gardner and Young 2014) – exists almost entirely independently of the household. The CHWs, as bridging partners of the HIV/AIDS competent household, bring the HIV care continuum closer to the PLWHA and his/her social environment. As a consequence, there is a higher chance of interaction between CHWs and patients’ household members than is the case with regular health care provision at the facility. Thus, the CHW enters the household level. The results indicate that – despite the fact that CHWs attempt to present themselves neutrally when making home visits – their visits are often associated with HIV/AIDS. Because they are often a marker of HIV/AIDS, CHWs can complicate patients’ hybrid identity management,

encouraging or forcing disclosure because community members begin to ask questions or because patients anticipate or react to concerns that may be articulated by their household members. Furthermore, the association between CHWs and HIV/AIDS can have the unintended adverse effect of exacerbating experienced levels of stigma. As mentioned above, PLWHA may act as gatekeepers, regulating the interference of their household in the CHW's visit in an attempt to preserve their hybrid identity. Depending on the HIV/AIDS competence in the household, a PLWHA who acts as a gatekeeper will be more or less likely to accept the support of the CHW and to involve the household in the treatment adherence support sessions.

When living in a more HIV/AIDS competent household, in which the patient feels secure in his or her identity as a PLWHA on ART, it is easier for the PLWHA to cope with HIV/AIDS-related markers such as ART or CHWs' treatment adherence support visits. In such a health-enabling environment, a patient will accept the community-based adherence support visits more easily. Our results showed that, in some cases, another household member may even try to convince the PLWHA to accept the support. It is also easier for the CHW to perform their work when patients feel responsible and live in an HIV/AIDS competent household. In less HIV/AIDS competent households, on the other hand, PLWHA find it more difficult to cope with HIV/AIDS-related markers, such as the CHW's visits, as these may threaten the patient's hybrid identity management and make it more difficult for him/her to regulate the household's role in disease management. In a household which exhibits limited characteristics of HIV/AIDS competence, interaction with CHWs may be difficult from the outset. As mentioned above, a burden of secrecy is created when patients do not disclose to all household members. For some patients, the only means of preserving their hybrid identity is to attempt to avoid the treatment adherence support visits. According to Goffman, "deviating from the standards of the regimen can be regarded as a technique for controlling information" (Meulemans, Mortelmans et al. 2002: p. 262). Patients who do accept the treatment adherence support visit may attempt to disguise its true purpose from those who are unaware of their status and at home at the time of the visit. If a patient does not want the CHW to complete the visit, he or she will try to make this clear to the CHW by winking, whispering or making excuses, saying it is not a good time. If the visit continues, both the patient and the CHW may employ strategies to conceal the purpose of the home visit. These strategies are not always effective, however, since they may themselves be associated with the clinic.

The IFC model indicates that the potentially destructive impact of HIV/AIDS can be mitigated and that the constructive impact of preventive efforts can be increased by factors at the intermediate environmental level surrounding the patient (Wouters 2012). The significant interaction effect found in this research indicates that the better the affected household functions, the stronger the positive effect of the CHWs' treatment adherence support will be on the patient's CD4 cell count (Wouters, Masquillier et al. 2014). In this regard, the quantitative results demonstrate that patients in well-functioning households benefit more from the support provided by the peer adherence support program than do patients living in poorly functioning households. The results also show that households that form tight units and can adapt easily to external changes are the ideal environments for CHW initiatives. In contrast, dysfunctional households that have difficulty adapting to change are not able to translate community-based adherence support programs into better ART outcomes at patient level. However, just as the quantitative results demonstrate that the intermediate household level plays a crucial role in improving physical health outcomes in HIV patients, our qualitative research also shows that HIV/AIDS competence in the household influences the way in which patients and their households can benefit from this support. If the CHW handles the house visits cautiously and the patient – acting as a gatekeeper – allows interaction, the CHW may be able to create involvement and provide support at household level. Similarly, the quantitative results indicate that receiving community-based adherence support has a positive influence on the likelihood that a patient will seek support from a treatment buddy; the qualitative research, too, showed that CHWs encouraged patients to bring a treatment buddy to their counseling sessions. This type of supporter is usually someone with close personal ties to the patient, who is aware of the patient's status and can remind and support the patient once ART has commenced (Stubbs, Micek et al. 2009; Ware, Idoko et al. 2009; Wouters, Van Damme et al. 2009; O'Laughlin, Wyatt et al. 2012). The qualitative results also reveal that CHWs may attempt to involve a patient's household in disease management, for instance, by encouraging patients to disclose in households where the other household members are not yet aware of their disease status. The CHWs surveyed in this study not only helped with the recognition of HIV/AIDS in the household, but also supported the household in the phase of exchanging and sharing knowledge – depending on the degree to which a culture of open communication and a climate of trust were already in place. It is clear, then, that household members can create a safe space for dialogue and critical thinking by sharing the knowledge acquired from the CHW and by talking together in an informed way about the disease and its consequences at the individual and household levels.

In line with the IFC model, our results show that the household context not only increases the constructive impact of community-based adherence support programs in certain conditions, but may also mitigate the unintended negative side effects. For example, the potential unintended negative consequences of CHWs' support visits with regard to stigma may be mitigated by the intermediate household level. More specifically, we found that the increase in treatment buddy uptake fostered by community-based adherence support had a small negative indirect effect on the level of stigma experienced. The qualitative results demonstrate that, while CHWs attempt to present themselves neutrally when making home visits, they are often seen as markers of HIV/AIDS. As a consequence of the adoption of a hybrid identity, self-selection protected most of the patients in our sample from experiencing stigmatizing responses to disclosure. In more HIV/AIDS competent households, PLWHA have less fear of stigmatization and are more likely both to embrace the identity of HIV patients on ART and to seek support from a treatment buddy in the house. In such a household context, it is easier for PLWHA to cope with HIV/AIDS-related markers, such as the visits of the CHW – and thus limit stigmatizing feelings. These findings respond to the research need cited by Decroo et al. (2013), who stated that “the impact of the visibility of HIV related activities on stigma in the community needs further investigation” (Decroo, Rasschaert et al. 2013: p. 178).

The surrounding community can also benefit from the support of the CHW. We found that PLWHA living in HIV/AIDS competent households were typically more confident about sharing their stories with the surrounding community. Our results show that these PLWHA attempted to encourage others to have themselves tested, to practice safe sex and to adhere to the treatment regime. By testifying about their own lived experiences to other community members, these PLWHA can have a positive impact on the community in terms of its understanding and acceptance of HIV/AIDS.

#### 4. DISCUSSION

Living with a chronic condition, such as HIV/AIDS, is complex and requires that self-management behaviors be integrated into patients' lifestyles and households (Ryan and Sawin 2009). The socio-ecological model and the IFC model imply that, in order to respond to the HIV/AIDS epidemic sustainably, patients must not only be able to manage their own health and disease, but also live in a health-enabling environment which fosters good health and provides support (Tawil, Verster et al. 1995; Grey, Knafl et al. 2006; Sallis, Owen et al. 2008; Brust, Shah et al. 2012; Wouters 2012; Aantjes, Ramerman et al. 2014). In line with the

socio-ecological and IFC models, aim of this article was to investigate the mutual influence and dynamic interplay among multiple levels of influence on PLWHA's behavior conducive to health promotion (Bronfenbrenner 1977; McLeroy, Bibeau et al. 1988; Stokols 1996; McLaren and Hawe 2005; Sallis, Owen et al. 2008; Kaufman, Cornish et al. 2014)

Following the emergence of socio-ecological theory, and the IFC model in particular, this article shows that there is a clear need to investigate the dynamic interrelationship of the household level in between the individual and community environmental level (Wouters 2012). Our results build on the socio-ecological model and the IFC model to show that self-managing PLWHA on ART who live in HIV/AIDS competent environments might represent a response to the HIV/AIDS epidemic that is both sustainable and durable. These results have both theoretical and practical implications. With regard to the theoretical aspect, this study extends the IFC model (Wouters 2012), in that it elaborates on the intermediate household level by integrating the idea of an HIV/AIDS competent household within the framework of the PLWHA with a hybrid identity and the HIV/AIDS competent community. By extending the notion of HIV/AIDS competence to the household, this model enriches our understanding of the central role that households can play in stimulating health-enhancing practices. Furthermore, the modified socio-ecological framework presented in this article, responds to the concern of one of the founding fathers of the socio-ecological theory, McLeroy, who states that "one of the problems with many ecological models of social behavior is that they lack sufficient specificity to guide conceptualization of a specific problem or to identify appropriate interventions" (McLeroy in Baral, Logie et al. 2013: p. 2). Moreover, this article adds impetus to the research need cited by Kaufman et al. (2014): "although there seems to be little disagreement that ecological approaches are more comprehensive and potentially more explanatory and effective than frameworks or models only taking one level into account, such frameworks have received relatively little research attention" (Kaufman, Cornish et al. 2014: p. S250).

From a perspective of practice and policy, this article lends support to the conclusion that, in order to achieve sustainable, long-term success, it is essential that PLWHA live in households that support and enable them to choose health-enhancing practices – in other words, to develop HIV/AIDS competence. This is in line with the theoretical framework of this article – in the words of Sallis et al. (2008), "the basic premise of the ecological perspective is simple. Providing individuals with motivation and skills to change

behavior cannot be effective if environments and policies make it difficult or impossible to choose healthful behaviors” (Sallis, Owen et al. 2008: p. 482). Tailoring interventions with the aim of creating a health-enabling environment should therefore be a priority for both research and policy. Since households are generally regarded as the most fundamental and proximal social system influencing an individual’s development, “they are the strategic point of entry for effective and lasting behavioral change that is the objective of family-based interventions” (Pequegnat 2012: p. 15). Yet, to date, studies that emphasize the importance of household or family members over the individual’s responsibility for their own medication adherence have largely been confined to pediatric HIV infection and are not common in the literature on adults (Weihs, Fisher et al. 2002; Davey, Foster et al. 2009; Rochat, Bland et al. 2011; Cordova, Huang et al. 2014; Myer, Abrams et al. 2014). As part of their coaching role, CHWs should focus on helping households become more HIV/AIDS competent, so that household members can eventually take over the role of the CHW. Furthermore, this conceptual framework draws attention to the importance of the patient’s social context in community-based HIV care. The findings indicate that, in order to ensure the quality and effectiveness of community-based adherence support programs on a durable basis, an intervention must be sensitive to household dynamics and the existing self-management skills of PLWHA. Previous research has noted that “most interventions are delivered to a random sample of patients and families without consideration of families’ styles of functioning or abilities and preferences” (Weihs, Fisher et al. 2002: p. 25). This article has shown that generic, broad-based interventions do not necessarily facilitate adherence among the most vulnerable patient groups, particularly those who do not have a supportive household context.

However, this research has several limitations that suggest pathways for further study. No other household members were involved in the data collection, primarily in order to safeguard the patient’s confidentiality. Future qualitative research involving reports from multiple household members could advance our understanding of HIV/AIDS competence at household level while also paying attention to the protection of the patient’s privacy. Moreover, in investigating the interaction between HIV/AIDS competent households and HIV/AIDS competent communities, a future line of research should operationalize the HIV/AIDS competent community more comprehensively. For example, such studies could include other programs – besides CHWs – that attempt to mitigate the impacts of HIV and reduce vulnerability to further HIV infections through bottom-up community participation (Brown 2011) in areas such as stigma reduction; sexual behavior change; support for PLWHA and their carers; co-operation

with volunteers and organizations; and effective access to existing health services (Campbell 2009). Future work should explore in greater depth whether the association of CHWs with HIV/AIDS is less problematic and arouses fewer stigmatizing feelings in more HIV/AIDS competent communities.

## 5. CONCLUSION

The modified socio-ecological model presented in this article highlights the importance of community-based HIV care that is sensitive to the context in which it is implemented. Insights such as these could guide future efforts to cultivate a health-enabling context and thus to provide sustainable support to people living with HIV/AIDS. This is essential, as antiretroviral treatment cohorts are likely to expand in the coming decades in a health system context of limited human resources.

## 6. BIBLIOGRAPHY

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