

COMMUNITY RESEARCHERS' EXPERIENCES WITH COMMUNITY-BASED
RESEARCH

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By

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A Thesis

Submitted to the Program in Social Work

In Partial Fulfillment of the Requirements

For the Degree

Master of Social Work

McMaster University

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Abstract

Within Canada, the HIV/AIDS community is an extensively researched population where people living with HIV/AIDS (PLHA) are minimally included in the research process. Community-based research (CBR) has become a widely recognized framework with which to engage in HIV/AIDS research in a response to the need for research frameworks that promote equitable collaboration between community members and community researchers. Coupled with a CBR approach, the Greater Involvement of People Living with HIV/AIDS (GIPA) principle can be incorporated into the research process so that the research is reflective of and responsive to community needs. Drawing on the experiences of five HIV/AIDS community researchers, this study seeks to better understand the tensions and challenges community researchers experience when facilitating CBR with participants with whom they identify with based on race, gender, sexual orientation, immigration status, and HIV status. Within the findings, several themes were explored by participants. The concept of multiple identities was predominately explored as well as the complexities regarding insider and outsider status. Participants also explored the tensions associated with maintaining confidentiality as well as discussing coping and self care practices. Expectations of community members and the research team were highlighted, and participants provided advice or recommendations based on their reflections of their personal experiences of engaging the CBR process. The themes explored by this particular group of community researchers demonstrate the complexities associated with their unique positioning within the research process. As the CBR approach is increasingly being utilized and recognized as an effective tool within a community research context, it is important as practitioners to be mindful of the challenges and benefits of facilitating CBR.

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A: Introduction

Within Canada, the HIV/AIDS community is an extensively researched population. However, despite being highly researched, people living with HIV/AIDS (PHAs) are often minimally included within research processes. Community-based research (CBR) has become a widely recognized framework with which to engage in HIV/AIDS research. This has been in response to the need for research frameworks that promote equitable participation and collaboration between community members and community researchers. Based on the characteristics of CBR, the approach can be utilized as an effective tool to equalize power and participation among researchers and community members, and aid in the creation of knowledge that is accessible, pertinent, and reactive to people's circumstances and future. Coupled with a CBR approach, the Greater Involvement of People Living with HIV/AIDS (GIPA) principle can be incorporated into the research process so that the research is reflective of community need, and responsive in a manner that creates social change for the benefit of the community. However, within the context of CBR, tensions may exist in terms of insider-outsider relations, and differences in power and status in the research hierarchy. For individuals who are in a research role but identify with the community (based on race, ethnicity, gender, sexual orientation, HIV/AIDS status, immigration status, etc.) as a peer, the challenge of meeting both the expectations of community members and the academic world can be a constant tension. This research is aimed at exploring the challenges and tensions that these individuals experience due to their unique position within the research process, and the ways that these challenges or benefits are experienced within CBR. Drawing on the experiences of HIV/AIDS community researchers, this study seeks to better understand the challenges and benefits that community researchers experience when facilitating CBR with participants with which they identify. More

specifically, through the incorporation of an anti-oppressive perspective, this study seeks to highlight the experiences of community researchers when working within a community with which they identify with members based on race, gender, sexual orientation, immigration status, and HIV status.

B: Literature Review

I: Defining CBR

Within existing literature there are multiple terms utilized to define collaborative research processes: community-based participatory research, participatory action research, community-wide research, and community-involved research. However, for the purpose of this study the term community-based research will be used as it is the most widely accepted term within Canadian literature. CBR is defined as:

“a collaborative approach to research, [that] equitably involves all partners in the research process and recognizes the unique strengths that each brings. [CBR] begins with a research topic of importance to the community with the aim of combining knowledge and action for social change” (Minkler & Wallerstein, 2003, p. 4).

Hence, CBR “aims not merely to advance understanding, but also to ensure that knowledge contributes to making a concrete and constructive difference in the world” (Loka, 2002). Accompanying this definition, the CBR approach also proposes a set of principles. In a review of CBR literature, Israel et al. (1998) identified several fundamental characteristics of CBR: acknowledging the community as an individual and collective identity; identifying and building upon the community’s existing strengths, relationships, and resources; promoting collaborative partnerships based on shared control through each research phase; creating and disseminating knowledge and developing plans of action that are equally valuable for all partners; and addressing social inequalities through the mutual transfer of power, knowledge, and skills. The approach also entails an iterative, cyclical process whereby all partners equally engage in

partnership development, identification of community needs, challenges and strengths, development of research methods and data collection, interpretation and dissemination of results, and appropriate social action that is mutually beneficial for all partners (Flicker et al., 2008).

i. Tensions within a CBR Approach

Engaging in a collaborative approach to research with diverse community partners can greatly enhance the quality and relevance of created knowledge. However, it is also important to note that while a CBR approach can develop and engage in processes that create knowledge that are reflective of diverse communities and reactive to their needs, there are also personal and political tensions that need to be revisited and renegotiated throughout each phase of the research process.

CBR literature highlights several challenges of facilitating research within a CBR framework. These include: a) gaining trust and respect; b) defining community; c) allowing for community identified and driven goals; d) tensions with power and control over research processes; and e) balancing research and action. These are key challenges to a CBR approach, and therefore they will be explored further.

Gaining Trust and Respect

Within the CBR literature, one of the more commonly cited challenges is gaining the respect and trust of community members (Minkler & Wallerstein, 2003; Sullivan et al., 2001; Wolff & Maurana, 2001). When examining effective community-research partnerships, respondents from Wolff and Maurana's (2001) study indicated that establishing trust and building relationships based on respect were the most important initial steps in creating a partnership. Within Greene et al.'s (2009) study, one peer research assistant (PRA) discussed the

importance of building relationships based on trust and respect by stating, “Once you build up trust and that confidentiality part, then they trust you, and you feel safe and they feel safe. That is the most important part of working in the community; you have to let people feel it’s safe” (p. 369). However, research has shown that mistrust between academic institutions and communities resulted from mistreatment of communities during the facilitation of projects, dishonesty due to researchers’ hidden agendas, and the use and dissemination of results that did not accurately reflect or benefit the community (Sullivan et al., 2001). In their work, Sullivan et al. (2001) also discussed the lack of recognition and devaluing of local knowledge and community expertise that may occur, and the impact these outcomes have on the working relationship between community members and researchers. Sullivan et al. (2001) discussed how community members felt as though the researchers involved did not truly understand the community and its strengths, and therefore felt disrespected throughout the research process because the community’s knowledge and expertise was often disregarded. Wolff and Maurana (2001) also discussed how respondents felt as though several researchers mainly possessed academic knowledge based on theoretical perspectives that were often not applicable to the community. In this sense, respondents felt that researchers did not have a good understanding of the community, and the approach that should be taken in order for the research process to be successful (Wolff & Maurana, 2001).

Defining Community

Defining the community and identifying representatives of the community are challenges when facilitating CBR (Wallerstein & Duran, 2006, Minkler & Wallerstein, 2003; Kone et al., 2000). In terms of community identity and representation, relevant questions often include: who has influence in the community; who is excluded from the community; are research participants

members of community organizations; are those organizations reflective of the community's interests, needs, and concerns; who agrees to participate in the research; and who determines who will represent the community (Minkler & Wallerstein, 2003)? An additional challenge associated with identifying community representatives is determining who determines the role and extent of participation by representatives throughout the research process. Individuals living with HIV/AIDS come from diverse backgrounds with differing perspectives and experiences that are often shaped by race, gender, age, sexual orientation, and social class. Based on this, individuals may have differing perspectives of community and may have different memberships within multiple communities. Thus, when engaging within CBR, community definition and representation may pose as dynamic and complex processes.

Community Identified and Driven

A key component of a CBR approach is its commitment to ensuring that the research topic is community identified and driven. However, many research projects “paradoxically would not occur without the initiative of someone outside the community who has the time, skill, and commitment, and who almost inevitably is a member of a privileged and educated group” (Reason, 1994, p. 334). In her work, Minkler (2005) discussed how often research topics are identified by individuals located outside the community, who possess little first-hand knowledge of the community and its needs and priorities. In another study, Minkler (2004) questioned whether a true CBR project can occur if the research topic is initiated by a researcher located outside of the community. Sullivan et al. (2001) discussed the difficulty that respondents experienced when attempting to facilitate a project on an issue that was not perceived to be of importance by the community. Moreover, respondents from the study discussed how their perceptions of the community differed significantly from the reality of life within the

community. Similarly, in their work, Wolff and Maurana (2001) discussed how community members felt as though researchers had approached the community with preconceived notions of issues located within the community, and ways in which these concerns could be addressed. In response to these concerns, respondents felt as though projects that involved collaboration between communities and academic researchers could be more effective if the research topic is identified and selected by community members (Wolff & Maurana, 2001).

Power

Equitable distribution of power and control is often a constant tension when facilitating CBR. Among community-based partnerships, inequalities based on education, income, race, ethnicity, gender, sexual orientation, and ability influence who participates within the study, who will be involved and influential in the decision-making processes, and whose opinions, knowledge, and expertise is recognized as valid. Researchers have power and privilege due to the notion that they are experts of scientific knowledge. In addition to this, researchers also have power and privilege through the possession of resources, partnerships with other organizations, funding, and other educational opportunities (Minkler, 2004). In this sense, researchers possess more power and control over many components of the research process, and therefore may have more influence than community members in terms of the processes and outcomes. In their study, Kone et al. (2000, p. 246) examined the notion of 'equal partnership' in CBR with one participant stating,

“if you really want [the partnership] to be useful then you equalize power. And if you want to equalize power, then you bring [community] people in on a decision-making peer basis. An advisory status without power is a token”.

In terms of shared financial control, Sullivan et al. (2001) discussed how community members perceived researchers' power and control over the study based on their access to, and

control of, the available funding and questioned whether an equal partnership could be created when one partner possess or has access to all of the finances. Moreover, respondents within the study questioned the rights that came with possessing and having access to the funding in terms of setting an agenda and prioritizing needs and activities based on those objectives (Sullivan et al., 2001). In this sense, the community felt as though they lacked power and control compared to the researchers and questioned their role and participation with the research. Thus, issues of power, control, and ownership often create ongoing tensions that need to be revisited and renegotiated throughout each phase of the research in order for the process and outcomes to be truly reflective of CBR.

Balancing Research and Action

Within CBR literature, one frequently mentioned challenge associated with methodology is maintaining a balance between action and research (Flicker et al., 2009; Kone et al., 2000; Sullivan et al., 2001). In their work, Israel et al. (2001) discussed the challenges of finding equilibrium between research and action that is mutually beneficial for all partners. Israel et al. (2001) further suggested that it is not a matter of choosing between conducting research or doing action, but rather a question of timing and emphasis. As discussed before, priorities may differ among partners resulting in conflicts over how the research will be conducted, and what form of action will be taken (Wallerstein & Duran, 2006; Kone et al., 2000). For researchers, emphasis may be placed on gathering greater data in order to address research questions whereas community members may be more concerned with promoting change within the community (Wallerstein & Duran, 2006; Kone et al., 2000). In their study, Sullivan et al. (2001) discussed how community participants felt as though there had been little community benefit when engaging within the research process. Similarly, in their work, Flicker et al. (2009)

discussed the challenges of balancing research and action. Within their work, they highlighted respondents' concerns of how they often participate in research but do not any see results in terms of how the knowledge created is being used to benefit the community.

Finally, although these challenges and tensions have been acknowledged within existing CBR literature, it is certainly not an exhaustive list. In fact, as this study will demonstrate, there are a number of other tensions and challenges in CBR that impact on the unique roles of community researchers. It is important to be cognizant of the tensions that exist when facilitating CBR and essential that these key components of CBR are revisited or renegotiated throughout each research phase in order to ensure that process and outcomes are truly reflective of the approach.

ii. CBR as an Approach

It is important to note that CBR is not necessarily a technique or research method but rather an approach to research that is based upon collaboration and participation with the goal of social action (Wallerstein & Duran, 2006; Flicker et al., 2008; Minkler, 2004). In their work, Cornwall and Jewkes (1995) stated that what is unique about this orientation to research "is not the methods but methodological contexts of their application" (p. 1667) and that the approach attempts to blur the line between the researcher and the researched by acknowledging the location of power within each phase of the process. Thus, unlike traditional academic research, a CBR approach differs by being grounded in and serving the interests of communities through equitable participation and ownership, and recognizing the importance of local knowledge and strengths (Flicker, 2008; Israel et al., 1998). CBR also differs by challenging the notion that research is objective and apolitical as it presumes that research is subjective, and encourages practitioners to be engaged, self-critical, and self-reflexive throughout the research process

(Flicker, 2008). Accordingly, the CBR approach draws on critical theory, poststructuralist, postmodernist, constructivist, and feminist paradigms to challenge and critique the positivist epistemological approach to research (Flicker et al., 2008; Minkler & Wallerstein, 2003). These paradigms focus on power, gender, race, and language, and challenge the right of researchers to propose their interpretation of the data rendering the community silenced (Minkler & Wallerstein, 2003). Such paradigms are useful in broadening the understanding of power, participation, and knowledge creation, which are fundamental concepts of CBR.

iii. CBR and the GIPA Principle

Currently CBR is recognized as an effective and useful strategy in addressing social and health disparities that exist in communities within a local and global context (Wallerstein & Duran, 2006). Research has also suggested that the very act of meaningful engagement within the CBR process can be transformative, and that through active participation, communities can become empowered and possess greater resources to create sustainable social change (Flicker, 2008; Wallerstein & Duran, 2003). The term transformative refers to “ways of relieving people’s emotional pain and immediate difficulties while simultaneously working to change the larger dynamic that generates inequity, unfairness and social injustice” (Baines, 2007, p. 3). For example, these larger dynamics include sexism, racism, capitalism, ableism, colonialism, and ageism. The term empowerment includes “the process and the outcomes that occur for people when they begin to access various types of power, both internal (such as personal strengths) and external (such as social networks) that they can then use to improve their lives” (Barnoff & Coleman, 2007, p. 37). It is important to note however that the term ‘empower’ can sometimes be applied with false connotations. For example, within a CBR context community members may be invited to participate within the research process but only in an advisory role in which

their voice, suggestions, and concerns go unheard. This may be mislabelled as an empowering experience in the sense that community members are invited to participate within the research process by having a space to voice their perspectives and concerns, but are not able to meaningfully participate or contribute to the research because their suggestions are not taken into consideration and are not reflected within the process and outcomes. Thus, for community researchers facilitating CBR within an HIV/AIDS community, it is essential that the GIPA principle is applied.

II: What is the GIPA Principle?

The GIPA is a principle that strives to recognize the responsibilities and rights of PHAs in order to facilitate a more effective response to HIV/AIDS at a local, national, and global level. The UNAIDS Joint United Nation Programme on HIV/AIDS stated that GIPA “aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision making processes that affect their lives...GIPA also aims to enhance the quality and effectiveness of the AIDS response” (UNAIDS, 2007). Thus, GIPA seeks to involve PHAs at every level of response through equal participation and collaboration of valuable experiences and knowledge. GIPA aims to ensure that people living with HIV are equal partners, and therefore meaningfully involved rather than involved in a way that is based on tokenism (UNAIDS, 2007). The GIPA principle is essential to research because it enhances the relevance, accessibility, and appropriateness of knowledge created through the direct involvement of PHAs (Flicker et al., 2009). As the CBR approach is committed to equitably involving community members throughout each phase of the research process, CBR can be a useful tool in applying the GIPA principle. Also, as capacity building is a primary goal of a CBR approach, the GIPA principle can be incorporated in CBR through providing research

training, mentoring, and employment opportunities to PHAs who are interested in collaborating in research (Harris, 2006; Greene et al., 2009). Research has shown that when the GIPA principle is successfully applied, it has resulted in enhanced policy development, greater quality in care programming and prevention, reduced isolation and stigma for individuals living with HIV/AIDS, as well as enhanced feelings of personal empowerment and greater credibility of AIDS service organizations (Travers et al., 2008; Roy & Cain, 2001).

However, while research has shown that the greater involvement of PHAs in research projects generates more relevant knowledge and effective outcomes, there are challenges when applying the GIPA principle. In their work, Travers et al. (2008) discussed CBR in relation to the application of GIPA and highlighted several barriers to the meaningful engagement of PHAs in CBR: HIV-related stigma, lack of research capacity, trust, health-related challenges, and other social and health issues taking priority. Travers et al. (2008) also highlighted effective strategies for engaging PHAs in CBR: providing training and mentoring opportunities as well as financial compensation, building trust and valuing lived experiences, and accommodating needs. Thus, if CBR is to be truly reflective of community, reactive to needs, and to foster feelings of empowerment, it is important to be cognizant of the challenges and benefits of applying the GIPA principle to CBR.

III: Insider and Outsider Status

Within the context of research there has been a historical shift from privileging outside researchers' knowledge, expertise, and perspectives to valuing insider knowledge and voices (Haviland, Johnson, Orr & Lienert, 2005; Kanuha, 2000). This shift has in part been reflective of the critique of outside professional involvement within research projects, and the power and privilege that outside researchers often possess within communities in which they work. In their

work, Wallerstein and Duran (2006) noted even outside researchers, who perceive and pride themselves as trusted community allies, often fail to recognize the power and multiple privileges they possess, and the adverse effect it can have on the research process, relationships and interactions, and outcomes. Consequently, the importance of insider knowledge, power, and expertise in research has gradually become recognized and valued. However, insider and outsider positions within research are not distinct categories but rather are often complex, dynamic, and shifting positions (Wallerstein & Duran, 2006). Essentially, the tension between insiders and outsiders in CBR is a result of the difference between an academic understanding and perspective compared to a lived experience of an issue. But what are the experiences of individuals who are conducting research within a community with which they identify? In this sense, insider and outsider status may also be influenced by several factors: history of involvement in the community, perception of role or position with the research team, and differences or similarities of personal experiences compared to participants' experiences (Haviland et al., 2005). For example, in their work, Greene et al. (2009) examined the experiences of PHAs as PRAs working on a CBR HIV/AIDS research study. She found that PHAs experience their social and professional positioning as having both insider and outsider status throughout the research process by identifying with specific commonalities with research participants while also having different lived experiences and other social identities in comparison to research participants. As one PRA noted "I think as PHAs we are not homogenous you know, we all come from different communities and sort of communities within communities" (Greene et al., 2009, p. 366). In this sense, the respondent highlighted the diversity among the PRAs and research participants by noting that while PRAs had their HIV status in common with research participants, their lived experiences may have differed

depending on their identities and histories. Similarly, within the study, a gay, white male PRA stated “If I’m interviewing someone who is an African woman for instance, we have that disability connection but I can’t assume to know anything else about her. You feel like an outsider in a way” (Greene et al., 2009, p. 367). These comments highlight the complexity surrounding an insider and outsider status in that while an individual may hold insider status based on one commonality they may also be an outsider due to other differences. Further, researchers who identify with the community may also experience insider and outsider tensions among other members of the research team. Depending on their position within the research hierarchy, individuals who identify with the community may hold insider status in one respect, but might also feel like an outsider to the research team.

Research has identified that both the insider and outsider statuses have associated benefits and challenges when working within communities (Wallerstein & Duran, 2006; Kanuha, 2000). The insider status may have benefits in the sense that insiders possess local knowledge and shared experiences that enable them to connect to and understand research participants’ perspectives, knowledge, strengths, and lived experiences (Greene et al., 2009; Wallerstein & Duran, 2006). In her research, Kanuha (2000) discussed how collecting data as an insider differed in the sense that shared laughter, the use of specific terminology, and unfinished phrases demonstrated the ‘knowing’ that characterizes interactions between individuals who share lived experiences and histories. Consequently, outsiders may miss meanings or place emphasis on aspects of the research that community members might not deem important or may misinterpret or under-represent issues or experiences that are of importance to the community (Haviland et al., 2005; Kanuha, 2000). Insiders may also be emotionally impacted by the experience of research participants when the experience reflects their own: one participant stated

“You are talking to people, interviewing them and asking questions, and hearing their stories...then it makes me look at myself and say, ‘Oh my God’ – so that was actually what my experience was” (Greene et al., 2009, p. 370). This comment highlights the challenges that insiders may experience in terms of seeing their own life experience reflected in the current life struggles of research participants. Thus, separating the personal from the professional may be a challenge for insiders as it inevitably impacts how they conduct research.

As this study seeks to better understand the challenges and tensions that community researchers experience when engaging with the HIV/AIDS community to facilitate CBR when they identify with participants, it is important to be cognizant of both the challenges and benefits of being an inside and/or outside researcher that are identified within existing literature.

IV: Summary

This review of literature demonstrates both the challenges and advantages of engaging research within a CBR process. As a CBR framework is concerned with the creation of knowledge that is reflective of and reactive to community identified needs through the mutual transfer of power, resources and knowledge, it is essential that individuals who participate within CBR are cognizant of the tensions that exist. Within CBR HIV/AIDS related research it is essential to have a firm knowledge base and understanding of the GIPA principles, and the importance of incorporating these principles into research that directly affects individuals who are infected or affected by HIV/AIDS. For community researchers who are engaging within the CBR process within a community with which they identify, challenges with insider and outsider roles and power relations may impact their partnerships with community members and academic co-workers. This review of literature supports the need for research to examine the tensions and benefits that community researchers experience when conducting CBR within communities that

they identify with based on race, ethnicity, gender, sexual orientation, immigration status, and/or HIV/AIDS status.

C: Theoretical Framework

The CBR approach is concerned with addressing social inequalities through the mutual transfer of power, knowledge, and resources within a collaborative approach to research that is reflective of and responsive to community needs (Israel et al., 1998). As this study seeks to better understand the challenges that community researchers experience when facilitating CBR within a community in which they identify with participants (based on race, gender, sexual orientation, immigration status, and/or HIV/AIDS status), issues pertaining to privilege, power relations, and insider and outsider tensions are often highlighted. For the purpose of this study, an anti-oppressive perspective (AOP) was used to guide and inform the research.

I: Defining AOP

An anti-oppressive framework is an epistemological perspective that recognizes multiple truths about society and that supports the concept of multiple ways of knowing (Strega, 2007). Positivist assumptions are challenged and knowledge is understood as subjective and situated by an individual's social location, and their resulting experiences of privilege and oppression. Thus, AOP is grounded in both collective and individual lived experiences, and recognizes that knowledge is owned by individuals as a product of their lived experiences (Strega, 2007). The concept of intersectionality is essential to an anti-oppressive perspective and is defined as "the interweaving of oppressions on the basis of multiple social identities" (Moosa-Mitha, 2005, p. 62). Essentially, AOP asserts that individuals simultaneously belong to multiple social groups that are heterogeneous (based on differing factors such as gender, age, race, ethnicity, ability, sexual orientation, and class), rather than occupying a single social identity or group that is

homogeneous (Strega, 2007). Thus, the concept of intersectionality is a fundamental component of AOP because it asserts that while individuals may be privileged, and have access to power and resources due to membership in certain social groupings, they may also simultaneously experience oppression and marginalization due to membership in other social groups. Thus, rather than analyzing oppression on the basis of a single social identity, an anti-oppressive perspective is concerned with better understanding how the multiple experiences of oppression and privilege intersect with one another (Strega, 2007). The concept of power is also an essential component to AOP and is perceived as relational. In her work, Strega (2007) stated, “while anti-oppressive theory acknowledges that injustice and inequality exist and are maintained in part through political and economic arrangements, it also points out that power is dispersed widely throughout society and culture” (p. 73). In this sense, it is the continual individual involvement and interaction with these inequalities and injustices within society that maintains and perpetuates power imbalances and places certain individuals at a greater disadvantage.

AOP differs from other social theories by being both critical and difference-centred (Moosa-Mitha, 2005). The concept of difference-centred is an orientation that is opposite of normative theories that presume singular, universal truths and ways of knowing. Having a critical stance refers to theories that are engaged in the creation of knowledge that is oppositional and challenges mainstream ideology (Moosa-Mitha, 2005). Thus, AOP takes a critical and difference-centred stance by being resistant to mainstream theories that support a singular, universal truth, and by challenging normative assumptions (based on White, heterosexual, and able-bodied perspectives) that exist in both privileged and marginalized spaces which situate differences in social identities (from an assumed norm) as problematic.

Instead, AOP recognizes difference as fluid and changing based on individuals' multiple social identities rather than on a singular, fixed social location (Moosa-Mitha, 2005). In this sense, AOP challenges essentialism, "a way of thinking about identities that assumes that factors such as gender, race, and class have natural, intrinsic, unchanging qualities that determine what a person can be in the world" (Brown, 2007, p. 132). AOP challenges this way of thinking by presuming that an individual's identity is socially constructed, fluid, and changing based on their belonging to multiple social groupings (Moosa-Mitha, 2005). This way of thinking also challenges the notion of a 'norm' by arguing that people belong to multiple social groupings and have differences based on their belonging to those groups. AOP is also resistant to a binary approach to oppression which asserts that individuals are either in the position of the oppressed or the oppressor (Moosa-Mitha, 2005). Rather, AOP deconstructs the binary approach by acknowledging that multiple relationships exist in which an individual can simultaneously be the oppressed and the oppressor.

II: What is an AOP Researcher?

When examining AOP and research, Potts and Brown (2005) stated, "being an anti-oppressive researcher means that there is political purpose and action to your research work. Whether that purpose is on a broad societal level or about personal growth, by choosing to be an anti-oppressive researcher, one is making an explicit, personal commitment to social justice" (p. 255). The purpose of anti-oppressive research is also to expose, examine, and shift the power relations that exist. In their work, Potts and Brown (2005) outlined three tenets of anti-oppressive research that can be used to reflect on and evaluate whether research is truly anti-oppressive research; these tenets will be used as a guideline throughout the research process.

The first tenet is that anti-oppressive research is social justice oriented, and that it is resistant in both process and outcome (Potts & Brown, 2005). Social justice can be defined as: “transforming the way resources and relationships are produced and distributed so that all can live dignified lives in a way that is ecologically sustainable. It is also about creating new ways of thinking and being and not only criticizing the status quo” (Potts & Brown, 2005, p. 284). In his work, Ife (2002) stated that “social justice means acting from a standpoint of those who have the least power and influence, relying on the wisdom of the oppressed” (p. 88). Anti-oppressive research is social justice oriented by engaging in the process of knowledge creation that collaboratively creates and re-discovers knowledge that emancipates and can be acted on, and used, by marginalized and oppressed groups within society. In addition to this, to be an anti-oppressive researcher means to support research that challenges mainstream norms and ideologies in both the process and outcomes (Potts & Brown, 2005). It also means to acknowledge and resist oppression within one’s own self and work. Thus, anti-oppressive researchers are often challenged to be reflexive within and critical of their work, as well as to make a connection between knowing and doing. As a result, knowledge is not seen as being neutral, but rather as political and possessing the potential for social change (Potts & Brown, 2005).

The second tenet is that anti-oppressive research acknowledges that knowledge is political and socially constructed (Potts & Brown, 2005). Recognizing that knowledge is socially constructed and thus created by social interactions and power relations is a core component to AOP because it enables the creation of knowledge to be owned by individuals who have lived experience of it. Moreover, as research can and often is used as an oppressive

function, anti-oppressive research seeks to utilize research as a means of resistance and empowerment (Potts & Brown, 2005).

The third tenet is that the anti-oppressive research process is grounded in relationships and power (Potts & Brown, 2005). In positivist research, the researcher is often perceived as the scientific expert, and thus usually possesses power and control over the research process and outcomes. In this sense, a positivist researcher possesses the ability to create and disseminate knowledge, and consequently often solely benefits from its creation (Potts & Brown, 2005). Moreover, those who participate in positivist research are often not able to contribute to or have real involvement in the research process as well as the opportunity to create meaningful, interpersonal relationships with the research team. As a result, there is often a lack of recognition of power relations and imbalances between the researcher and those being researched (Potts & Brown, 2005). However, in anti-oppressive research, it is crucial that power relations are analyzed, and that there is a process in which power is shifted from outside researchers to insiders, towards those who have lived experiences of the issue (Potts & Brown, 2005). It is also important to note that within the AOP, epistemic privilege is valued. The concept of epistemic privilege is that “members of an oppressed group have a more immediate, subtle and critical knowledge about the nature of their oppression than people who are non-members of the oppressed group” (Narayan, 1988, p. 35). In anti-oppressive research, those who are being researched are perceived as the experts due to their insider knowledge from lived experiences, and thus priority is placed on ensuring the experts have agency within the research process, and in this sense possess a degree of power.

III: Why AOP?

AOP was the chosen theoretical framework for this study because of its analysis of power, the valuing of epistemic privilege, and self reflexivity. As this study sought to better understand the challenges and tensions that community researchers experience when facilitating CBR within a community with which they identify, the concept and analysis of power within relationships between community researchers, community members, and the academic team is essential. As one of the fundamental components of CBR is to address social inequalities through the mutual transfer of power, knowledge, and resources, it is important to understand how CBR researchers perceive power relations within the research process. Moreover, it is important to understand how community researchers perceive the privilege and oppression that they experience in relation to their research role and position within the research hierarchy, as well as their relationship with and commitment to the community. Thus, AOP and its analysis of power is important to this study because it seeks to expose, examine, and shift the power relations that exist within research partnerships, and to examine the processes that exist or need to be created in order for power to be shifted from outside researchers to insiders. In relation to this, an AOP framework was chosen for this study because of its recognition of the value of epistemic privilege or insider knowledge.

An AOP framework is important to this study because it recognizes the value of epistemic privilege, and the power and agency that individuals possess with insider knowledge. It is important to understand how influential insider and outsider knowledge and perspective is within the research process and the way in which community researchers who identify with the community utilize their insider knowledge within the research process. In addition, AOP was chosen for this study because of its commitment to self reflexivity. Within an AOP framework,

researchers are challenged to be reflexive and critical of their role and involvement within research. For all individuals engaged in the research process, it is important to be aware of the power and privilege that they possess and the influence that it has on both the research process and outcomes. Moreover, within an AOP framework it is important to collaboratively create knowledge that can be acted upon and used to create social change.

IV: Linking AOP to CBR

For social workers, a CBR framework can be utilized as a method to collaboratively create knowledge that is truly reflective of community needs and experiences. As CBR is an approach to research that is based on collaboration and participation with the goal of social action, an AOP theoretical framework is pertinent. Similar to CBR, an AOP framework presumes that there is political purpose and action to research. In this sense, AOP is social justice oriented by being engaged in a process of knowledge creation that collaboratively creates knowledge that can be acted upon and used by communities. An AOP framework is applicable to CBR because a CBR approach starts with a topic of importance identified by the community, and strives for equal participation of community members and researchers in all phases of the research process with the goal to combine knowledge and action for social change. In this sense, within both an AOP theoretical framework and a CBR approach, knowledge is not seen as neutral but possesses the potential for social change. In addition to this, with an AOP approach, knowledge is understood as being socially constructed and presumes that the creation of knowledge is to be owned by individuals who have lived experiences of it. This is applicable to CBR because within a CBR approach, knowledge is understood as being subjective and situated within an individual's social location and resulting experiences of oppression and privilege.

Moreover, the aim of a CBR approach is for research to be grounded in communities' lived experiences, and for knowledge to be owned by those involved.

Another important component to both AOP and CBR is their attention to power relations. Within an AOP framework, the purpose is to expose, examine, and shift power relations. This results in an attempt to create a process whereby power is shifted from outside researchers to insiders. Likewise, a CBR approach also encourages the acknowledgement of the location of power in each research phase with the aim to transfer power and resources from academic researchers to community members. In terms of outsiders and insiders within research, the notion of epistemic privilege is also essential to both an AOP framework and a CBR approach. Within AOP and CBR, insiders are seen as possessing knowledge that is a direct result of their lived experiences of oppression and privilege. As this type of knowledge is valued within the research process, individuals with this form of knowledge, as a result, often possess a degree of power and agency within the process.

Self-reflexivity is also another central component of both an AOP theoretical framework and a CBR approach. Within the CBR approach, researchers are encouraged to be constantly engaged, self-critical, and self-reflexive throughout the entire research process. Thus, it is important for researchers to be aware of their role and influence in each research phase and recognize the power and privilege they possess. Moreover, as in AOP, it is essential for researchers to be reflexive and critical of the process and outcomes of CBR projects.

D: Methodology

I: Research Design

Drawing on the experiences of HIV/AIDS community researchers, this study seeks to better understand the tensions and benefits community researchers experience when facilitating CBR with participants with which they identify. More specifically, this study seeks to better

understand community researchers' experiences with working within a community in which they identify with members based on race, gender, sexual orientation, immigration status, and HIV status. The review of existing CBR literature confirms that there is a need to better understand the experiences of HIV/AIDS community researchers working with participants with which they identify in order to highlight the challenges and benefits associated with working within a CBR context. The lived experiences of community researchers in this study brought forth recommendations for change for individuals seeking to engage within a CBR framework.

II: Methods

For the purpose of this study, a qualitative research approach was used as a method to explore and describe the experiences of community researchers. Qualitative research can be defined as “social research in which the researcher relies on text data rather than numerical data, analyzes those data in their textual form rather than converting them to numbers for analysis, aims to understand the meaning of human action and asks open questions about phenomena as they occur in context” (Carter & Little, 2007, p. 1316). Thus, a qualitative approach to research tends to emphasize exploring, describing, and interpreting social phenomenon compared to a quantitative approach which is characterized by statistical data and measurement. As this study sought to better understand the experiences of community researchers with CBR, a qualitative research approach to the study was appropriate.

III: Recruitment

The Ontario AIDS Network (OAN) is comprised of community-based organizations that were formed as a grass roots response to the increasing need for services and information relating to HIV/AIDS. The members of the OAN have agreed to work collaboratively and in accordance with principles pertaining to empowerment, inclusiveness, community, and

improved quality of life for PHAs. The Program Director for community-based research for the Ontario Aids Network assisted in the recruitment process for this study by identifying potential participants. She assisted in the recruitment process by initially contacting potential participants by email inviting individuals interested in the study to contact the writer by email or telephone indicating their interest in the study or if they required further information. A recruitment email (See Recruitment Email Appendix B) was created that outlined the details of the study, and the letter of information and consent form (See Information Letter and Consent Form Appendix A) was attached within the email. She sent the recruitment email to a wide variety of HIV/AIDS related community-based agencies across Ontario. Potential participants were requested to contact the researcher via email. When a participant initiated contact with the researcher, more information about the study was provided (if required) and an interview time and place to meet was negotiated.

IV: Participants

Five qualitative interviews were conducted with community-based researchers. For the purpose of this study, a community-based researcher is defined as an individual who is presently employed by a community-based social service agency whereby their primary focus is to conduct research for the agency. Thus, the experiences of participants may or may not be related to the research that they are presently conducting in their current place of employment; however, individuals must have had experience with conducting CBR within the HIV/AIDS community with which they identify with participants involved in the study. This includes identity on the basis of immigration status, sexual orientation, HIV status, race, and gender. It is important to note that the majority of participants had experiences of working within a community in which they identified with research participants in more than one of the following

ways: immigration status, sexual orientation, HIV status, race, and gender. All of the participants were currently employed in research projects and had more than one experience working within a CBR project in which they held a position as a research coordinator, principle investigator, and/or a community development coordinator. Participants also had varied backgrounds in education and also varied in terms of their geographic location within Southern and Northern Ontario.

V: Data Collection: Qualitative Semi-Structured Interviews

Participants were invited to participate within a one hour, semi-structured interview (See attached interview guide Appendix C). Four of the interviews took place in a location where the participant felt most comfortable such as the individual's place of employment or a local coffee shop, at a mutually agreeable time. One of the interviews was conducted over the telephone due to geographic location. Participants were asked to share their experience and role within CBR projects, and what compelled them to become involved in research and more specifically CBR. Participants were also asked to discuss their relationship with the community before their involvement in the research project, their relationship with the community during or after the research project; their relationship to academia and research before their involvement in the research project; and their relationship with the academic team and research during or after their involvement. In addition to this, within the interview, participants were asked to comment on any tensions that occurred during their involvement in the research project as well as to comment on any benefits that may have occurred. Participants were also asked to provide advice for individuals who are seeking to engage in CBR as well as to consider the future direction of CBR. Each interview was audio-recorded and transcribed verbatim by the researcher.

VI: Data Analysis

For the purpose of this study, a constant comparison method (CCM) was used to analyze the data. By utilizing a CCM approach within this study in a purposeful way, and reflecting on the process in terms of themes or stories highlighted and terms used to accurately reflect those stories, the credibility of the data analysis was increased. A CCM is important in relation to developing a theory that is grounded in the data (Boeije, 2002). In CCM “the researcher is able to do what is necessary to develop a theory more or less inductively, namely categorizing, coding, delineating categories and connecting them” (Boeije, 2002, p. 393). At the beginning of the data analysis phase, comparison is conducted within one transcribed interview. The transcript is read through thoroughly and is studied to determine meaning and sense of what the participant has said. Then the transcript is re-read in its entirety. Each passage within the interview is then labelled with a representative term or code that is reflective of the meaning within the passage. As the transcript is read, if other segments within the interview relate to an existing category, then the new segment is given the same code or placed in the same category. Within this first phase of the data analysis, the aim is to create categories from the data, and to label them with a term that accurately reflects the meaning of the segments. Essentially, “in this way it is possible to formulate the core message of the interview with the codes that are attached to it and to understand the interview including any difficulties, highlights and inconsistencies” (Boeije, 2002, p. 395). In her work, Boeije (2002) recommended a list of important questions that the researcher should ask at this phase of the data analysis: “Which codes are used to label the categories in this particular interview?; What characteristics do fragments with the same code have in common?; How are all the fragments related?; What is the core message of this

interviewee?” (p. 397). These questions will help the researcher reflect on the process, and identify any concerns or contradictions relating to the segments and categories created.

The next phase of CCM is to continue with the same steps described above for each interview conducted. Then the researcher will compare each interview for similarities or patterns in terms of themes that are predominate within each interview. The aim of this phase is to further develop categories or themes that are predominate within the interviews. This means to search for characteristics relating to each concept in order to further establish and define those concepts. Again, Boeije (2002) outlined several questions that are useful to the researcher during this phase of the analysis: “Is interviewee A talking about the same category as B?; What do both interviews tell us about the category?; What are the similarities and differences between interviews A, B, C, etc.?; What are the criteria underlying this comparison? What combinations of codes/concepts occur?” (p. 398). These questions enable the researcher to reflect on the codes created and whether they accurately reflect the themes within the interviews. Then the researcher will put all of the coded segments that belong to a specific code together to further discover the relevant characteristics of these coded segments in order to describe the concept or theme.

VII: Ethical Considerations

Prior to the study, the researcher completed and submitted an ethics application to the McMaster University Research Ethics Board (MREB). The MREB approved the study and provided ethical clearance.

i. Consent/Confidentiality

Potential participants were provided with an information letter detailing the nature and scope of the study as well as an informed consent form within the recruitment email. When

participants initially contacted the researcher, they were invited to ask any questions or raise concerns regarding the research process and confidentiality. Within the information letter and consent form, as well as verbally by the researcher, participants were informed of their right to withdraw from the study at any point in time without any consequence. When participants agreed to participate, they were invited to sign two copies of the consent form before participating within the scheduled interview. One copy of the consent form was obtained for the researcher's records, and the participant was invited to keep a copy of the information letter and the second signed consent form. In terms of the telephone interview, the participant was invited to ask any questions or raise concerns relating to the study at the beginning of the telephone interview. Also, the researcher invited the participant to sign a copy of the consent at the beginning of the telephone interview which the researcher provided through email. The researcher received a signed copy of the consent form from the participant through email. In terms of anonymity, any identifying information pertaining to participants was changed so that they were not recognizable within any phase of the research.

ii. Ethical Tensions in Recruitment

I think that it is important to note that there were several challenges encountered during the recruitment process. Initially there was difficulty securing four to five participants for the study due to concerns regarding anonymity. For example, during the initial recruitment and data collection phase, I met with one potential participant (after they initiated contact with me) to discuss the study, and conduct an interview. Unfortunately, due to the sensitive nature of the focus of the study, the individual felt as though they would be identifiable based on their stories and comments related to their experiences on past and current CBR projects. Since the CBR community is relatively small, the individual was concerned about anonymity based on the fact

that they identified with participants in a very specific way. Moreover, the individual was also hesitant to participate in the study because they felt as though it would not be in their best interest to comment on the current tensions within the study with which they were presently engaged. Thus, the individual felt as though they would be identifiable based on their experiences, and any quotes used within the findings and discussion section of the study. As a result, the individual felt uncomfortable continuing with the interview, and unfortunately did not participate within the study. This would have been my second interview within the data collection phase, and my discussion with this individual raised several questions and concerns pertaining to why I was having difficulty recruiting participants.

E: Findings

The diversity of participants in this study provided unique perspectives regarding the challenges that community researchers experience when facilitating CBR within communities with which they identify. Within the interviews, participants explored both the tensions and benefits of engaging within a CBR approach as well as the challenges related to research partnerships, insider/outsider status, and power relations. Five themes emerged from the data. These themes included: a) the tensions associated with possessing multiple identities within the research process; b) expectations of community members and the research team; c) challenges associated with maintaining confidentiality; d) exploring self care practices; and e) advice or recommendations based on their reflections of personal experiences of engaging within the CBR process. Within the following section of the thesis, these themes will be explored further.

I. Multiple Identities

A major theme emerging from the participants' interviews was the concept of multiple identities. The participants within this study highlighted the complexities of having multiple

memberships in varying communities, and the way in which they perceived their identity as multi-layered and interconnected. For this group of community researchers, the concept of having multiple identities within the research process was defined as a person who possesses peer membership in multiple communities in addition to being a member of the research team. One participant explored the complexities associated with having multiple identities within the research process and stated:

“I think that often there are a lot of tensions that happen when doing this research because very rarely are you a member of just one community, and very rarely are you a peer of all of them. Sometimes you’re an ally, sometimes you’re a peer, sometimes you’re not involved at all”.

This participant explored how community researchers involved in community-based research often have membership in multiple social groupings, and therefore their identity within the research process is multi-layered. She also discussed that while community researchers often have peer membership to multiple social groupings, they do not necessarily possess this form of membership in all of the communities with which they are involved. Thus, in some instances community researchers may have limited knowledge of or involvement in the community or may not have had any previous involvement with or knowledge of the community prior to the research. This participant spoke to the tensions that exist in terms of having multiple identities within the research process, and the way in which an individual’s positioning within these identities is constantly fluid and changing based on whether they identify as an ally or peer.

In terms of the complexities of having multiple identities within the research process, one participant stated:

“When we talk about community engagement and peer involvement, I think we don’t look at the layers of peer membership and often times, especially in HIV research, one predominates - which is people living with HIV. However, sometimes that HIV infection is heightened, you know, magnified by the other types of membership. What is it like to be HIV positive and black? You know,

what is it like to be HIV positive and an immigrant? Those issues are very relevant and sometimes one peer membership dominates the others. And I guess for me, my fight is to make sure that as a person of colour gets represented. As a woman, that gets represented”.

This narrative demonstrates the complexities regarding possessing multiple identities within the research process, and the tensions associated with negotiating which social identity gets represented. She discusses how within the HIV/AIDS community, a positive HIV status is the point of identity that is most predominant but that there are also other multiple points of identity that are pertinent in terms of diversity of lived experiences and histories. Within her comment, she also discussed her conscious decision to represent certain points of her social location in her work related to research with which she strongly identifies. As a person of colour and as a woman, the participant explored how she works towards ensuring that those two points of identity are represented in the work with which she is involved. In relation to this, one participant stated:

“The first problem is: what do we mean by community? I am heavily engaged in gay right issues. I am heavily interested in black issues. Those are two communities that I consider to be involved with. Also, I am a woman, there is another one. My parents are immigrants, that’s a fourth. I represent, or am involved or interested in many communities. And then being a woman, I am a black woman. Sometimes being a woman, I have to kind of put my...sometimes I feel as though I have to put my ‘blackness’ aside to represent my women issues and vice versa”.

This participant highlighted several challenges in terms of having multiple identities. Firstly, the community researcher discussed her multiple identities in relation to the communities with which she is engaged, and explored how these points of identity are often intricate and multi-layered. She also discussed the challenges of addressing specific issues within each community by highlighting the fact that she often felt as though she had to occupy one corresponding identity in

order to accurately represent or effectively address issues or concerns. Consequently, this meant that she often felt as though she had to shift her other points of identity aside in order to do so.

In relation to the challenges associated with possessing multiple identities and negotiating representation, one participant stated:

“It would be nice if I could just wear all my colours at one time. But it’s almost like I have to change my colours depending on which community I’m in or which group whether it be academic, peer or you know, ally communities”.

With this comment, the participant highlighted the tension that exists related to having multiple identities or being an insider in multiple social groupings, and the challenges of negotiating her identity and role within those groups. In her comment, the community researcher explored the challenges of identifying as a researcher and member of an academic team as well as identifying as a peer in relation to the community that she is working within. She discusses how it would be nice to show or represent all of her multiple points of identity at the same time instead of having to negotiate, and consciously choose which point of identity she will represent, and consequently which she will silence. Her narrative reflects the pressure that she feels in relation to changing her ‘colours’ in order to fit in or be a part of each community with which she is involved, whether it is peer or academic. Her narrative also highlights the tension of not being able to be her authentic self in the sense that she feels as though she is unable to truly wear all of her colours at one time. Her experiences as well as the narratives from other community researchers within this study highlight the complexities of possessing multiple identities within the research process. The narratives also demonstrate the tensions that exist in terms of negotiating which points of identity are predominately represented, and which are silenced within the process.

i: Insider/Outsider Status

Participants discussed the challenges of negotiating insider and outsider status. Within the interviews, participants explored the way in which they were an insider in relation to their role and positioning on the research team but also possessing insider status in terms of having peer membership in relation to the communities they were working within. In this sense, the participants had inside knowledge of both the research team as well as the community, and therefore were positioned as an insider in both ways. Paradoxically, the participants also identified as being an outsider in relation to the research team because of their peer membership and as a result of having outsider status in relation to the community members they were working alongside as a result of their positioning on the academic team, and role as a researcher. In relation to her dual positioning (as both an insider and outsider) within the research process, one participant discussed the tensions that exist in terms of having to defend both the academic team and community. She stated:

“I always feel that I have to defend the other side. I think researchers are not seen in a very positive light amongst a lot of Africans that I know at least. So whenever I am in their circles, whenever I am talking to them I have to defend what researchers do. I have to defend the research process. I have to stick my neck out and say, ‘No, it’s not that we have forgotten about you or it’s not because we are spending the governments’ money on ourselves, and not really care about the community. It’s the way the research process works. And then when I am with researchers I have to defend the participants as well”.

This participant highlighted the fact that within a CBR framework, tensions still exist between community members and researchers. She also emphasized the tensions that exist in terms of being an insider in relation to the research team as well as the community, and the struggle of having to defend both groups. In this sense, she also highlighted the challenges of having to use her unique positioning within the research process to defend or advocate for the perspectives,

needs, and concerns of both the research teams and community members. In relation to this, another participant stated:

“And I even noticed that my interviews, when I am reading the transcripts, I noticed that I insert myself into the interviews. Like I say, ‘Oh as a social worker and as a black person...’ and I notice how that affects the interviews. I notice that there is a lot more laughter in the interviews that I do, and it seems that we talk about other stuff. And then when we get to those issues I notice some people got a little more heated, and I am wondering is it because I insert my identity of marginalization, and it shows that like I get you or I’m hanging out with you? I’m not one of those academics, I am one of you? Sometimes I feel as a research coordinator I’m not expected to do that. I am supposed to be more on the academic side, not the peer side”.

Within this narrative, the participant explored the way in which she reveals or asserts her identity of marginalization in order to better identify with her peers, and demonstrate her ability to be a part of the community despite her role as a researcher. She also highlights the way in which this enables her to engage with a participant, and gain credibility and trust within interviews. In this sense, possessing insider status within the community increases her ability to effectively engage with individuals, and gain information that an outside researcher would not necessarily be able to collect. However, she further explored how she sometimes felt as though she was not expected to reveal her identity or experience of marginalization in relation to her peer membership but rather to assert her identity as an academic. In this sense, she highlights the tensions that exist in terms of having dual membership (as both an insider and outsider) and the challenges of negotiating both roles effectively within a research context. In relation to this she also stated:

“It’s almost as if you have to be a chameleon when you are not a peer researcher. Even if you could be a peer it’s almost like you have to be a designated peer researcher to truly wear the hat, and I’ve never been designated that way. I’ve inadvertently been a peer for many reasons, some overt and some covert and because of that I feel that I have to make a conscious choice to show my peer hat”.

This highlights the tensions and challenges that exist in terms of being both a research coordinator and peer. She further explored how she felt as though she often had to make a conscious decision to demonstrate her peer membership or insider status, and negotiate that role within the research process. In this sense, her comment is reflective of challenges discussed previously in relation to having multiple identities within the research process, and the tensions that exist in terms of representing certain points of her social identity. This demonstrates the tensions that exist in terms of possessing insider and outsider status within a research context. These comments also highlight the challenges that community researchers constantly experience related to negotiating their role within the research process, and the conscious decisions that they make in terms of being an insider and outsider.

II: Expectations

Due to their peer membership and insider status in relation to the community they were working within, participants discussed how they felt that community members often had preconceived expectations of them due to their role on the research team in terms of having power and influence within the research process. Similarly, participants also discussed how they felt as though the research team had specific expectations in terms of their role within the research process. In relation to this, participants explored the concept of tokenism, and the way in which they sometimes felt as though their involvement in specific research projects was used in a tokenistic manner.

i: Expectations of the Research Team

Participants explored their role and involvement within research projects, and discussed how they felt as though there were preconceived expectations of them in terms of their role on the academic team. Participants discussed the concept of tokenism, and the way in which their

positioning within the community, in terms of having peer membership and inside knowledge, was sometimes used in a tokenistic manner. One participant explained:

“And I think that researchers expect certain things as well because since I am an African woman they might expect me to know more or to speak on behalf of the entire community, if I am in a research meeting for example. And so my word seems to matter a little bit more sometimes, depending on what the topic is. And they’re like, ‘Oh you’re an African woman, tell us what they think’”.

This participant explored the way in which she was often expected to represent the community based on her race, gender, and associated peer membership and resulting inside knowledge of the community. Within the interview, she also highlighted the tension related to being a representative or person speaking on behalf of an entire community in which there is diversity in terms of differing histories and lived experiences apart from her own. In this sense she felt as though her peer membership and involvement in the research and role on the research team was sometimes used in a tokenistic manner. She further states:

“I found there is to be tensions related to, how do I say this, researchers may sometimes use people who are considered community researchers in a tokenistic fashion. So as long as I am here or as long as I am included in a meeting or as long as I am included in a particular research project as either a coordinator or investigator, pretty much the entire African community has been included. As long as I am there, you know, and my colour is still the same that mean adequate representation, you know, has been met”.

This narrative further highlights the way in which her participation within the research process or on a particular research project could sometimes be described as used in a tokenistic manner. This participant explored how her involvement in the research project ultimately meant that the research team was actively representing the entire African community. She also explored the tension that exists in terms of the expectation of a community researcher, who also possesses peer membership to effectively and fully represent the needs, and concerns of a large and diverse community. Within the interview, she discussed the tension that she felt in terms of

being a representative for the entire community and the tension of adequately identifying the needs and concerns of the entire community. In relation to this one participant stated:

“Regardless of whether I say anything or regardless of the power that I have to direct or make any difference in the entire research process. Regardless of that, even if I take the minutes, our research team will sign off saying that our research team has effectively represented all communities that are affected by HIV”.

As the community researchers in this study do possess peer membership within the communities that they are facilitating CBR within, their presence on research advisory committees, and involvement in particular research projects may be used in a tokenistic manner. As this participant highlighted, despite her power or influence over the research process, and her level of involvement, her presence on the research team translates into accurate representation of communities in which she possess peer membership. The experiences of these particular community researchers highlight some of the preconceived expectations placed on them due to their peer membership and inside knowledge of the community they are working within. These narratives also highlight the perception that a community researcher with peer membership has the appropriate inside knowledge, and understanding of the needs and concerns of the entire community, and has the ability or desire to be a representative of the community throughout the entire research process.

ii: Expectations of Community Members

Participants explored how they also felt as though there were preconceived expectations of them by community members or peers. Within one interview, a participant discussed the expectations of community members in terms of her role as coordinator and her influence within the project. She explained a situation where, during the final phases of the recruitment process, a community member that she knew through her own social circles approached her,

and requested that she be selected as a participant for the study. The community researcher further explained:

“She was like, ‘Ah come on girl you know me. You know I don’t have a job and I need this thing’. And how do you deal with that? Because you know I am going to see her, I am going to see her on Saturday at church and she is going to look at me. And so yeah, they expect certain things”.

This comment highlighted the tension that can exist in terms of meeting the expectations of community members with respect to the perceived power and influence that the community researcher has within the project. Moreover, this narrative highlights the tension that exists when a person has knowledge of individuals within dual settings, and the pressure that is placed on the community researcher to respond in a way that does not negatively influence his or her relationships within the community.

Similarly, another participant discussed the tensions that exist related to the perception of the power and influence that the community researcher has in relation to decisions made through the research process by the community itself. The participant further explained:

“Because it is a really large scale project with a lot of money, and with really big goals in a community that has very few resources. So it tends to illicit very strong reactions from people; either very strong reactions of support or not because it is not solving all of the problems and it can’t. And I guess that has affected my relationships with people because of my role I was expected to liaise with the community around, and this is perhaps just my perception, but I felt that I was being held accountable for things, decisions that were not mine”.

This participant explored the tensions that exist in terms of the preconceived expectations of the community researcher in relation to his role, power, and influence within research processes by community members. Ultimately, as a result of the community members’ misperceptions regarding his role and power within the research process, the community researcher felt as though he was being held responsible by community members who were in disagreement with

respect to decisions made by the entire research team. As a result, he further discussed how this negatively affected his relationships with individuals from the community.

One participant discussed the expectations of community members with respect to her positioning on the research team and as an academic. She further explained:

“They come up to me and go, ‘This is a really cool research project on black women, why don’t you do it? You’re an academic, you should do it’”.

She further discussed how she felt as though the community often expected her to facilitate studies that were predominantly reflective of her own social identities. She further explored this and stated:

“As a black academic, even though it is getting better, if you have your PhD and you’re black, everyone expects you to do the research for the community. What if you don’t want to do that research? What if you don’t have time to do that research?”

The participant highlighted the expectations placed on her by community members and other academics, in terms of the type of research that she should be involved in due to her social positioning. She further explored the tensions that exist related to the perceptions and expectations that she should predominantly facilitate research that directly involves communities in which she has peer membership despite her other research interests and careers pursuits. Thus, this participant explored the tensions that she felt related to the community’s expectations to predominantly engage in research that is beneficial to the communities in which she has peer membership. Her narrative and the experiences of other community researchers within this study highlight the tensions that exist in terms of the expectations of community members related to a community researcher who is also a peer. Specifically, these experiences highlight the perceptions of these particular community researchers in terms of the preconceived expectations

of community members in relation to their role, power, and influence within the research process.

III: Confidentiality

Participants explored the tensions related to having peer membership with the communities they were working within, and the challenge of maintaining the confidentiality of community members. Within the discussions, the community researchers explored the challenges of working within a community in which they had personal knowledge of research participants. This knowledge was gained through their work related to research projects as well as from personal interactions with community members in a social setting. One participant highlighted the challenges of being a community researcher and a peer, and the tensions regarding confidentiality:

“When you talk about confidentiality with participants, as a community researcher, that is one of the most important things ever because unlike other researchers it is very likely that I will meet this person in another way with other people around them. I have to make doubly sure that whatever I say is something that they have either revealed to me outside of the interview process or is something that is simply common knowledge that everyone kind of knows. So yeah, sometimes in my community I am regarded as pretty...what’s the word...not really reclusive but not as social or sociable because I don’t want to fall into these pitfalls”.

This participant explored the challenges that community researchers experience when they possess dual membership (as both a peer and researcher) and the tension that exists when they have intimate knowledge of community members from both a professional and social setting. Her comment demonstrates the complexities of having multiple identities within the research process, and the impact it has in terms of maintaining confidentiality. In order to further express the challenges that she experiences related to maintaining confidentiality, the participant highlighted the fact that sometimes she feels as though she has to be less sociable in social settings in order to ensure that the intimate information gained within a research setting remains

confidential. Consequently, due to her dual status as both an insider and outsider, the participant explored how she feels as though she has to be more guarded when in the community in a social setting, a stance which ultimately impacts her social and personal life. This participant further discussed her experiences with maintaining confidentiality in terms of gaining intimate knowledge of community members' HIV status within both a professional and social setting. She explained:

“Second thing is that it also, I guess, inadvertently disclosed people’s HIV status to me. So because I was involved in a research study, for example, and someone would tell me, ‘Oh, I met her at a certain HIV specialist’s office’ or ‘Oh yeah, we did this research together’, I would end up knowing, you know within my own social circle, who was HIV positive and who was not. And this presented a whole lot of hurdles especially if I hadn’t heard it from that particular person that they were HIV positive. And so in some instances where I would try not to show it...but I would feel very tense amongst or with them, for some stupid reason, because I felt really burdened by that knowledge”.

She further stated:

“So having to handle the knowledge that you gain and having to piece it out according to where you got it from and making sure that it stays there is difficult”.

With this comment, she explored feeling burdened by possessing intimate knowledge of research participants gained through both a professional and social setting. Again, her comment highlights the tensions that exist in terms of maintaining confidential information gained through other community members. She further explored how she would often feel uneasy or tense when she was around the individual because of the intimate knowledge she had, and perhaps because she was unsure of how to handle the information. Her experiences demonstrate the tensions that community researchers may experience related to the challenges of maintaining confidentiality in relation to possessing intimate knowledge of research participants who are also peers, and the impact it has on their working and personal relationships.

Participants also discussed the challenges of listening to research participants' personal lived experiences and histories and the challenge of finding confidential ways in which to cope with sensitive information gained within a research setting. For example, one participant stated:

“And even though I had just heard this awful story about this poor woman who had just been diagnosed with HIV, and had awful experiences with all her Canadian healthcare providers, I couldn't call up on the phone and talk to my girlfriend about it because I knew that in some way she might know this person somehow”.

This participant explored the challenge of finding confidential ways of self care that enable her to unburden herself of the tumultuous lived experiences and histories of research participants who are often also peers. In terms of maintaining confidentiality, she further commented:

“So I have developed ways of taking care of myself and unburdening myself that do not breach confidentiality. So you have to have strong ways of doing that”.

Within her narrative, she highlighted the personal impact of possessing intimate knowledge of the lived experiences and histories of her peers in the context of research, and the way in which it is influential in her personal life in relation to her self care practices that enable her to unburden herself while simultaneously maintaining confidentiality. Her experiences, as well as the experiences of other community researchers, highlight the tensions that exist in terms of working within a unique position of power (as a research coordinator) in which her role is to gain personal and intimate information of the lived experiences and histories of community members while simultaneously being a peer. It also demonstrates the tensions that exist related to maintaining confidentiality, and the conscious measures taken in order to ensure that the stories and histories that participants shared within a research context are not divulged in a social setting. In addition to this, the experiences of participants also highlight the impact that their professional role as a HIV/AIDS community researcher has on their personal and social lives.

IV: Self Care

Participants also discussed how their unique involvement in the research process had a personal impact on their lives in terms of burden and self care practices. Participants explored the personal impact of listening to research participants' lived experiences and histories that were reflective of or similar to their own story. One participant discussed the difficulties that she experienced in terms of reviewing transcripts and immersing herself in the stories and lived experiences provided by research participants because they ultimately forced her to immerse herself within her own story. She stated:

“But it was too much, so I sat for a winter with a thousand pages of pain, and I thought I would lose my mind. And I was writing it, and thought that I would lose my mind. So I got a puppy. I mean I did what I could to survive because I needed to be immersed in their stories which then immersed me in my own story”.

This participant highlighted the difficulty of immersing herself within the data analysis process by reviewing transcripts and reading often painful personal experiences described by research participants who were also inadvertently her peers. She discussed the difficulties of immersing herself within the stories of research participants because of how they reflected her own life history. She also highlighted the way in which she coped with reviewing transcripts because she felt she had to do something in order to survive this particularly difficult phase of the research process. She further discussed the challenges that she experienced in one research study in which she had difficulty facilitating focus groups because of the unexpected flood of emotions that she experienced within her own life. The participant discussed how she found that she could only facilitate research groups or conduct a certain amount of research interviews before she found that she needed to have time to herself to reflect on the content, and spend time doing other activities that took her mind off of the stories and experiences of research participants. In this

sense, the participant found that she had personal limits within the data collection and analysis phase, and had to utilize self care practices in order to work effectively as well as take care of herself. One participant explored the emotional impact of listening to participants' painful experiences. She stated,

“So any story that comes with battery, rape...my worlds collapsed...so I ended up having to do therapy once a week which frankly my job didn't pay for, which they should have”.

This participant further stated:

“So part of the challenge is that that was too emotionally, psychologically tough and I am a tough cookie”.

The participant explored the challenges of listening to participants' painful experiences, and the overall impact it had on her personal life. In relation to self care practices, she discussed how she attended therapy in order to be able to better cope within her role. In relation to self care practices, another participant stated,

“I love to walk long like three hour long walks to the lake. I love music, and so I have developed ways of taking care of myself”.

This participant discussed the way in which she incorporates activities such as walking and listening to music into her life as a method of self care. She further discussed that she had to find ways to unburden herself of the painful stories and experiences of participants gained through her role as a community researcher. Her narratives, as well as the narratives of other participants, highlight the way in which the research process has personal implications on the lives of this group of community researchers in terms of their coping and self care practices. These experiences also demonstrate the importance of utilizing self care practices in order to cope with the sensitive information, and personal lived experiences of community members gained through their role as community researchers. In this sense, for community researchers who are working

with research participants with which they identify, the ability to separate the personal from the professional may be a constant struggle, and ultimately may impact their personal life as well as the way in which they engage in the research process.

V: Reflections

Through reflection on their own experiences and sharing personal stories, participants provided advice for other community researchers who are engaging within the CBR process in a community in which they also have peer membership. Participants discussed the challenges associated with having peer membership and working as a community researcher, and shared advice in terms of negotiating those roles within the research process. In relation to identifying as a peer, one participant advised:

“Acknowledge your privilege and your marginalization. And there’s privilege in being a peer. Sometimes we don’t admit that...because I use my colours in a way as a weapon...sometimes I use the colour of my skin”.

This participant highlighted the importance of reflecting upon your privilege and marginalization and having an awareness of both within the research process. She also discussed the importance of recognizing that identifying as a peer is a privilege that has benefits and power that can be utilized within the research process. She also commented on the way in which she sometimes uses her peer membership as a tool within the research process and further explained:

“Sometimes I find that when we’re a member of a marginalized group we always think of it as a point of oppression but especially in community-based research, it is actually a privilege to be a peer. Know it...because sometimes you have to use it as a tool and sometimes you have to use it as a weapon in order to get the research done”.

Within the CBR process, inside knowledge and peer membership is significantly valued and is perceived as a benefit, a fact this community researcher recognized when she commented that

having peer membership within CBR provides an individual with a certain form of power and influence. Within the interview, the participant further explored how peer membership can sometimes be used as a tool. She further explored this, and highlighted the fact that with peer membership and inside knowledge, an individual has the ability to influence the research process in a way that generates information that is reflective of the community's needs and concerns, as well as in a way that facilitates the research that is reactive to those needs. Participants discussed the importance of being reflective of their role and involvement within research projects. In relation to this, one participant stated:

“And I guess back to the insider/outsider, be both. Try to find a way to be true to yourself and be both. Especially if you go up into like a Masters or PhD because once you get there, if you don't have a true sense of yourself as a researcher, a peer or as an ally, how can you do research? It's going to be tough”.

This participant explored the importance of having an awareness of one's role in research whether it is as a researcher, peer, or within multiple roles. She also discussed the importance of knowing yourself, and being true to yourself so that when you are within the research process you already have an awareness of your role, privilege, and power. In addition to this she added:

“And also as a reflexivity process, maybe within quantitative you couldn't do it but I know with qualitative, as a subjective self you can't be reflexive about who you are in the research whether you're a peer or ally or both or neither. How are you going to truly look at your analysis? How are you going to truly use your lens if you don't know what lens you're using?”

Again, this participant discussed the importance of using self-reflexivity within the CBR process in order to have a true understanding of oneself as a peer, ally, researcher, or a combination of those roles. She further highlighted the importance of having awareness of your multiple positioning within the research process in order to have a firm understanding of the values, perspectives, knowledge, and power that you bring to your work and analysis of the research.

In addition to this, in the interviews, participants also explored the importance of having strong relationships within the community as well as a solid reputation amongst your peers. For example, one participant stated:

“Have a very good relationship with the community. Initially, even before you get into research because if you are known within your social circles as a blabbermouth, as someone who can not be trusted, as someone who would be considered morally grey, then your representation as a researcher has already been tarnished even before you become a researcher. Since you will be going to those same people asking them to divulge a lot of personal information, it’s important to have that reputation beforehand because whatever you say as a researcher will not carry as much weight”.

This participant discussed that as a peer, it is important to have a good reputation in your own social circles in terms of being trustworthy, and to have demonstrated your ability to maintain confidentiality amongst your peers. She also explored the fact that as a researcher, you will be asking your peers to share sensitive, personal information, and therefore it is important to have a strong relationship with members of the community in order for them to feel safe and comfortable sharing their lived experiences and histories with you. In relation to this, participants discussed the importance of having allies with individuals who are committed to the goals and processes of CBR. Echoing this, one participant stated:

“I would say that one is always in better shape if you have allies. Allies and partners with who you can work with, right? So allies in terms of universities and in terms of relationships between academics and research projects...and so even though we have different parts of or different sets of goals, the set of those goals can be put together. But you have to have people who are committed to that”.

This comment highlights the importance of building a team in which each member is committed to fulfilling the goals and principles of CBR. She explored that while some of the goals of the team may differ, it is important to work on a team in which the main goal is to be committed to facilitating CBR that is in collaboration with the community, and is reflective of and responsive to community needs and concerns.

F: Discussion

A CBR framework is concerned with collaboratively creating knowledge that is reflective of and responsive to community needs through the mutual transfer of power, resources, and knowledge. However, the CBR approach is not without its tensions. Power relations between community members, the academic team, and community researchers are a constant struggle that needs to be revisited and renegotiated throughout the research process. The purpose of this study was to examine the experiences of community researchers who are engaging within a CBR process within a community with which they identify, with specific respect to working within a unique role in which they have multiple identities and memberships within the research process. As this study sought to better understand the challenges that community researchers experience when facilitating CBR within the HIV/AIDS community in which they identify with participants, the community researchers within this study explored their unique experiences, and highlighted five predominate themes.

One predominate theme highlighted within the interviews by this particular group of community researchers was the concept of having multiple identities, and the way in which these multiple identities are often fluid and interwoven. Within their discussions, participants highlighted the tensions associated with negotiating which social identity gets represented within the research process in order to better represent the community, while consequently having to shift other points of identity to the side in order to do so. In relation to this, participants discussed the challenge of having both insider and outsider status, and the tension that exists in terms of negotiating both the role of a researcher and a peer.

A second theme explored by participants was how they often felt as though there were preconceived expectations of them from both community members and the academic team.

Within the interviews, participants explored the concept of tokenism, and discussed the way in which their involvement and participation (as identifying as a peer or insider in relation to the community) was sometimes used in a tokenistic manner. Participants also discussed the tensions that exist in terms of knowing community members in both a social and professional setting, and the challenges associated with responding to the expectations of community members in terms of their role as both a community researcher and peer.

A third theme highlighted by participants was the challenges associated with possessing dual membership (as both a peer and researcher), and the tension that exists with respect to having intimate knowledge of community members from both a professional and social setting. Within the discussions, participants explored the tensions associated with maintaining confidentiality in relation to possessing intimate knowledge of research participants who are also peers, and the impact it has on their working and personal relationships. In relation to this, participants also explored how their unique involvement in the research process had a personal impact on their lives in terms of burden and self care practices. Within the interviews, participants explored the personal impact of listening to research participants' lived experiences and histories that were reflective of or similar to their own story.

Through reflecting on their experiences of being both a community researcher and peer within the research process, participants provided advice or recommendations for individuals who are seeking to be involved in a CBR project in which they are a member of the research team and have peer membership with the community they are working within. When reflecting on their experiences, participants explored the challenges of being both an insider and outsider within the research process, and highlighted the tensions and benefits of having peer membership within a CBR context. These themes explored by this particular group of

community researchers demonstrate the complexities associated with their unique positioning within the research process. Both existing research that focuses on community researchers' experiences of conducting CBR within a community in which they identify with participants and responses from this group of community researchers, demonstrates the need for these individuals to have the opportunity to reflect on their experiences, and provide recommendations for change in the context of CBR and research partnerships. As the CBR framework is increasingly being utilized and recognized as an effective tool within a community context, it is important as practitioners to be mindful of both the negative and positive impacts that the process and outcomes have on the individuals committed to upholding CBR principles. It is imperative as practitioners to encourage one another to be reflexive and critical of our role and influence within the research process, and to be cognizant of the power that we have.

As this study sought to better understand the tensions that community researchers experience when facilitating CBR with participants with who they identify, the concept and analysis of power emerged an essential issue for consideration. This was most predominant in relation to research partnerships between community members, the academic team, and community researchers. Moreover, it is important to better understand how this particular group of community researchers perceives the privilege and oppression that they experience in relation to their role, position within the research hierarchy, and relationship with and commitment to the community. This particular group of community researchers understood their unique position as a member of the research team and peer of the community as both a point of privilege and oppression. The community researchers within this study understood their privilege as a peer in the sense that they had inside knowledge of community members' lived

experiences and histories as well as strengths, perspectives, and needs. In this sense, they were better enabled to represent the community throughout the research process in comparison to an outside researcher who has little to no knowledge or understanding of the community's experiences, histories, and perspectives. As a result, they understood their peer membership as a privilege in relation to having the knowledge and understanding to influence research processes in order to ensure that outcomes are reflective of and reactive to community members' needs and concerns. In this sense, these community researchers had a form of power by possessing peer membership and inside knowledge, and having the ability and resources to use that knowledge in an influential manner. However, these community researchers also explored their peer membership as a point of oppression.

At the same time, through discussions about their relationship with the research team, in particular the academic members, participants explored the concept of tokenism, and highlighted the tensions associated with their involvement within research projects when they were seen as being used in a tokenistic manner. Several participants explored and discussed the tensions associated with how their involvement in specific research projects ultimately translated into the academic team perceiving that they had actively represented the entire community. These participants explored the tensions associated with their ability or desire to fully represent the needs and concerns of a large and diverse community. In this sense, certain community researchers felt as though their peer membership status and inside knowledge were sometimes used in a tokenistic manner instead of in a meaningful way. As the community researchers reflected on their experiences within CBR projects, it is evident that they have a firm understanding of the privilege and oppression that they experience within the research

process, as well as their power and the way in which it is influential in research partnerships, processes, and outcomes.

Reflections

At the start of the study I was aware of the fact that I was asking individuals within a unique position to comment on tensions and challenges with relationships between community members, the research team, and themselves within a CBR context. Thus, I was aware that some of the questions asked within the interview would elicit experiences and feelings that might reflect negatively on their peers and co-workers. Moreover, I was aware of these concerns and the potential impact it would have on recruitment and data collected pertaining to the study. As I continued with data collection, other participants continued to make comments during and at the end of each interview about confidentiality due to their honest responses within our conversations. During my last interview the participant asked that before I incorporate any quotes from their interview, that they review those specific quotes, and have final say of whether or not they can be incorporated within the final paper. At each point in time in which a participant raised concerns about confidentiality, I assured them that I would take every possible step to ensure their confidentiality, and clearly outlined that they were able to withdraw from the study at any point in time, without any consequences to them. As I continued through the process of data collection, I reflected on my experiences of facilitating interviews in which participants were often hesitant to honestly share their experiences, and this raised several questions for me. I began to wonder why these community researchers felt as though they could not honestly share their experiences, and whether they had the opportunity, apart from this study, to share or reflect on their involvement within CBR projects and their experiences with co-workers and peers. These questions made me further wonder whether these

community researchers were receiving the type of support needed to fulfill this specific and unique role.

As I reflect on this experience, I think that the responses of participants highlight the tensions and challenges that they experience within the research process. I think it also highlights power relations among research relationships, and the difficulty or lack of space to honestly reflect on their experiences and provide recommendations for change. From my experiences within the research process, and the response from community researchers who also have peer membership within the community, I think that this is a topic of great importance to research processes in terms of research relationships, and power dynamics.

G: Conclusions/ Implications

The diversity of participants within this study provided unique lived experiences in relation to their involvement in CBR projects. However, it is evident from this particular group of community researchers that their unique role and positioning within a CBR context holds challenges and tensions that need to be revisited and reflected upon. When engaging within a CBR approach, it is important to be aware and critical of power dynamics within research partnerships, and to ensure that there are processes in which power is shifted from outside researchers to insiders. In addition to this, it is imperative to constantly engage within a process of self-reflexivity in order to be aware of the power and influence that each individual has within the research process.

CBR is an effective tool that promotes equitable collaboration and participation between community members, academic teams, and community researchers. It is an approach that can be reflective of and responsive to community needs and concerns. However, in order to ensure that CBR continues to be an effective tool that is beneficial to all groups involved in the

process, it is imperative that as practitioners and researchers we allow for reflection of our role and influence within the research process. As CBR is an approach that is becoming more widely accepted and recognized as an effective community research tool, it is essential that we better understand the challenges and tensions that community researchers experience, particularly for those who personally identify with research participants' because of the impact this has on their experience of themselves within the research process and outcomes.

While a CBR approach can foster research that is beneficial to all partners involved, it is imperative that we are critical of research partnerships that are formed, and provide support to maintaining effective and meaningful research relationships. As academic or social work researchers, if we do not engage in a process of critically reflecting on our research partnerships in terms of power dynamics and support then ultimately we do a disservice to the community we are working with, and the process of creating knowledge that is reflective of and responsive to community needs. Thus, I think that it is imperative to encourage and provide space and time for use of self-reflexivity in order for community researchers to reflect on their experiences, and provide recommendations for change.

While reflecting on their experiences within this study, the narratives of this particular group of community researchers highlight the impact that the CBR process has on them in terms of their professional and personal lives. For academic researchers who are seeking to engage within a CBR process, I think that it is important to be aware of the unique experiences of community researchers who identify with research participants and the associated challenges and tensions that they may experience, and how it affects the research process and outcomes. I think it is important to be reflective of power dynamics in terms of research partnerships as well as in relation to the dynamics of the research team. In addition to this, I think it is important to

have a firm understanding of the role and expectations of each member of the research team, and the opportunity to be reflexive of each person's role, power, and influence within the research process.

In terms of the future direction of CBR, I think that there is a need for greater research that focuses on the experiences of community researchers within this unique role in order to further our understanding of the challenges, tensions, and benefits that they experience within both their professional and personal lives. In addition to this, I think that there is a need for research to examine the type and form of support that this group of community researchers needs in order to continue to engage within the CBR process in a manner that is meaningful and beneficial to them.

Ultimately, there is value in conducting research that is truly reflective of and responsive to community needs and concerns. A CBR approach can be an effective community research tool that can foster research relationships based on collaboration and participation through the mutual transfer of power, resources, and expertise. The meaningful participation of community researchers who identify with the community can greatly enhance the quality and relevance of created knowledge. Within a CBR and AOP context, the effective role of community researchers who identify with the community is imperative, and therefore greater research is required in order to discover beneficial ways to support and foster their involvement in the process.

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Appendix I: Letter of Information

June 2010

LETTER OF INFORMATION



A Study of: Community Researchers' Experiences with Community-Based Research

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Purpose of the Study:

This study seeks to better understand the tensions and benefits that community researchers experience when facilitating community-based research (CBR) within the HIV/AIDS community in which they identify with the participants. It is particularly concerned with exploring the experiences of community-based researchers who personally identify with the research participants as a result of their immigration status, race, gender, sexual orientation, HIV status etc. The findings may support recommendations for addressing the tensions, challenges and opportunities of facilitating CBR.

Procedures involved in the Research:

I would like to invite you to take part in a one hour, one-on-one, semi-structured interview. With your permission, the interview will be audio recorded and transcribed verbatim by myself. The interview will take place within the community in a location and at a time that is most comfortable and convenient for you. For example, I could meet you at your place of employment or at a local coffee shop or any other mutually agreeable location. Within the interview, you will be asked questions regarding your experience with conducting CBR within the HIV/AIDS community.

Potential Harms, Risks or Discomforts:

It is expected that this study will not pose any risks to you. Within the interview you will be asked questions regarding your experiences of facilitating CBR within the HIV/AIDS community. However, you are not required to answer questions if they make you feel uncomfortable. You may also change your mind about including something you said. You are welcomed to take breaks throughout the interview process and you can withdraw from the study at any time without consequence.

Potential Benefits:

The research may not benefit you directly. However, I hope to learn more about the challenges and tensions that exist for community-based researchers who conducting CBR with communities that they personally identify with. The study findings will potentially result in providing a greater understanding of the tensions, challenges and opportunities that are experienced by community-based researchers and recommendations for how these issues can be addressed with the CBR process.

Confidentiality:

This research is confidential and both your identity and the identity of your agency will remain anonymous. Any identifiable information will be changed. The information that you provide me with will be kept in a locked desk where only I will have access to it as well as a password protected computer. Upon, one year after the completion of the study the data will be destroyed.

Participation and Withdrawal:

Your participation in this study is voluntary. You can withdraw your participation at any time even after signing the consent form or part-way through the study. If you decide to withdraw there will be no consequence to you. If you decide to withdraw after or part-way through the interview process, any data you provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions within the interview you do not have to but you can still be in the study.

Information about the Study Results:

I expect to have this study completed by approximately September 28, 2010. If you would like a brief summary of the results, please indicate how you would like me to send it to you on the consent form.

Questions about the Study:

If you have questions or require more information about the study itself, please contact me at focklela@univmail.cis.mcmaster.ca

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Thank you for considering participating in this study.

Appendix II: Consent Form

CONSENT

I have read the information presented in the information letter about a study being conducted by Lindsey Fockler, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time and I do not have to answer any questions that make me feel uncomfortable. I understand that the interview will be audio-recorded and transcribed verbatim by the researcher. I understand that the data will be stored by the researcher in a locked desk and on a password protected computer. I understand that the data collected will be kept by the researcher for one year prior to submitting the thesis on September 28, 2010 and that upon one year the data will be destroyed. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____:

Date: _____

Yes, I would like to receive a summary of the study's results. Please send them to this email address _____ or this mailing address _____.

No, I do not want to receive a summary of the study's results.

Appendix III: Recruitment Email

Recruitment Email

Email Subject Line: A Study of Community Researchers' Experiences with Community-Based Research

I would like to bring to your attention the opportunity to participate in a study which examines researchers' experiences with community-based research. Under the supervision of Dr. Saara Greene, Lindsey Fockler is conducting a small study on the tensions and benefits of conducting community based research with and for communities that they personally identify with. This research is a requirement of Lindsey's Masters degree in Social Work at McMaster University. Participation in the study involves a one hour, one-on-one, semi-structured interview regarding your experiences as a community researcher facilitating community-based research (CBR) within the HIV/AIDS community.

Attached is further information about the study. If you are interested in participating in this study or would like further information, please contact Lindsey Fockler at focklela@univmail.cis.mcmaster.ca or at (647) 308 9609.

Appendix IV: Interview Guide

Interview Guide

Background Questions:

- 1) What has been your involvement in CBR?
- 2) What was your role in the projects?
- 3) How did you get involved in this type of work?
- 4) What compelled you to get involved in research and CBR specifically?

Community Relations:

- 5) What was your relationship with the community prior to your involvement in regards to research?
- 6) What was your relationship like throughout the research process?

Academic Relations:

- 7) What was your relationship with academic partners prior to the research project?
- 8) What was your relationship with academic partners during the research process?

Challenges and Benefits:

- 9) Were there any specific tensions that occurred that you can speak to? How did you respond?
- 10) Were there any specific benefits that occurred? How did you respond?

Recommendations:

- 11) If you knew then what you know now what advice would you give to individuals seeking to engage within CBR?
- 12) What does this mean for future direction of CBR?

Appendix V: Ethical Approval Certificate

	McMaster University Research Ethics Board (MREB) c/o Office of Research Services, MREB Secretariat, G11-335H, e-mail: ethics@mcmaster.ca		
	CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH		
Application Status: New <input checked="" type="checkbox"/> Addendum <input type="checkbox"/> Project Number: 2010 384			
TITLE OF RESEARCH PROJECT: Community Members' Experiences with Community-Based Research			
Faculty Investigator(s)/ Supervisor(s)	Dept./Address	Phone	E-Mail
S. Greene	Social Work	23732	greene@mcmaster.ca
Student Investigator(s)	Dept./Address	Phone	E-Mail
I. Fockler	Social Work	1847-308-8609	fockler@mcmaster.ca
The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethical certification is provided by the MREB: <input checked="" type="checkbox"/> The application protocol is approved as presented without questions or requests for modification. <input type="checkbox"/> The application protocol is approved as revised without questions or requests for modification. <input type="checkbox"/> The application protocol is approved subject to certification and/or modification as appended or identified below.			
COMMENTS AND CONDITIONS: Ongoing approval is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and approved before any alterations are made to the research.			
Reporting Frequency: <input type="checkbox"/> Annual: Apr-22-2011 <input type="checkbox"/> Other:			
Date: Apr-22-2010 Co-Chairs, Dr. D. Maurer, Dr. A. Pawluch: Acting Vice-Chair, Dr. R. Storey: 			