STORIES AND STRATEGIES OF RESISTANCE:

MULTI-STAKEHOLDER ADVOCACY EFFORTS IN PUBLICLY-PROVIDED HOME

SUPPORT SERVICES IN ONTARIO

by

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Stories and strategies of resistance: Multi-stakeholder advocacy efforts in publicly-provided home support services in Ontario

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ABSTRACT

This Major Research Paper conducted analysis of narrative interviews that explored the experiences of individuals involved with a multi-stakeholder advocacy group, Quality Care Alliance. During its period of operation, the Alliance advocated around intersecting issues facing home care workers, service users, and family members. The research sought to learn about the efforts of QCA and experiences of its members, in terms of the enabling factors, successes, barriers and challenges faced. This research aims to contribute to knowledge about multi-stakeholder advocacy within the context of neoliberalism. Six themes were uncovered around: participants' roots of involvement in advocacy, (dis/non)engagement, making solo struggles shared, value of connections and relationships, group processes and challenges related to the work. Anti-oppressive social work practitioners could benefit from supporting advocacy efforts that involve diverse stakeholders, and employing decolonizing practices while engaging in such efforts, especially within the constraints of a neoliberal context.

KEY WORDS: Narrative research, anti-oppression, neoliberalism, advocacy, home care, home support

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CHAPTER 1. INTRODUCTION

Publicly-provided home care in Ontario has been documented in the scholarship as a site of changing levels of quality and continuity of care for service users, and as fraught with tension around issues of employment conditions and pay for workers. For over a decade, there has been a push toward privatization of home care services, by way of systemic restructuring within the sector in Ontario and in other Canadian provinces. Privatization of services occurs within a wider neoliberal movement within health and social services, often at the peril of paraprofessional home care workers and vulnerable service users. Within this context, advocacy becomes increasingly important and increasingly difficult.

Despite this difficulty, publicly-provided home care services have been the focus of advocacy efforts of one particular group, Quality Care Alliance (QCA). QCA, a loose alliance of stakeholders, was active in five Ontario cities between 2010 and 2012. Diverse stakeholders included for-profit and not-for-profit home care providers, non-profit health and social service organizations, colleges, seniors' coalitions, cultural and community groups, labour unions, related charities, family support groups, representatives from municipal and provincial government, and individual seniors, family members and home care workers (Quality Care Alliance, 2010).

QCA's goals were broadly aimed at advancing the quality of home care for seniors and improving working conditions for home care workers. The group rallied around five key priorities: the launch of a provincial personal support worker (PSW) registry; a living wage for PSWs and homecare workers; standardized education and certification of PSWs; continuity of care for clients; and, support for family caregivers (Quality Care Alliance, 2010). Regional

committees formed in each of the five cities, and although they met independently of one another, information and strategies were shared between cities. Each committee organized community events and panel discussions, which featured the voices of experts in the home care field and people with lived experiences of the issues (Quality Care Alliance, 2010). Regional committees circulated petitions, met with local Members of Provincial Parliament, and engaged with municipal-level politicians.

Summary of Research

The purpose of this narrative inquiry is to explore the experiences of individuals involved with a multi-stakeholder advocacy group (QCA). Exploration was undertaken through interviews with three people involved with the Alliance: a community leader/activist, a QCA volunteer coordinator and a labour union employee. Participants were asked abou**t** about their impressions of the enabling factors, successes, challenges and barriers in doing their advocacy and organizing work. I do not attempt to explicitly evaluate the efforts of QCA, but instead aim to use the experiences of connected individuals as an entry point to explore larger themes about what helps and hinders multi-stakeholder advocacy groups within the context of neoliberalism. I am particularly interested in learning about the experience of service users and home support workers involved in the group.

The task of examining advocacy efforts in home care is a worthwhile endeavour for "resistor" social work researchers and practitioners interested in pushing back against the current neoliberal influences on health and social services (Dominelli, 1999, p. 21). There is a need for research that offers alternative stories of resistance, and illustrates that service users and workers can and do speak out.

Findings from this exploratory research are varied. Participants tied their decision to become involved in QCA, and in advocacy work more generally, to a significant past experience, to thoughts about their own aging, and a sense of reciprocity. Participants theorized around larger issues of public (dis/non)engagement from/in formal political processes. They theorized around the importance of speaking and hearing shared experiences, and the value of working collectively to bring about change. Discussion emerged from the research about the ability of QCA organizers to bridge cultural, religious and ethno-racial communities, and to connect and maintain friendships with stakeholders from older generations. Challenges were discussed with relation to the diversity of stakeholder needs, advocacy done 'after hours' outside of work and family commitments, and tensions between ideologies that underpin a choice of group organizational structure.

Positioning Myself

I am a Masters of Social Work student at Ryerson University, and a new social worker. I am also a white, middle class woman who lives, works and studies in downtown Toronto, although I was born and raised in New Brunswick. My path into social work follows time spent pursing a career in the arts, and my background as an actor has bred an affinity for storytelling and digging deep into the narratives of others. Although critical thinking and self-reflexivity were honed in the seemingly-disparate world of the arts, they serve me well in the practice of anti-oppressive practice (AOP) social work and inform my current curiousities about narrative research.

The foundation of my wish to examine home care as a site of resistance rests on two key experiences. Firstly, my interest in this topic is connected with childhood memories of watching

my paternal grandmother receive care from personal support workers (PSWs) in the home she shared with her husband in Saint John, New Brunswick. After a half a lifetime living with rheumatoid arthritis, my grandmother required substantial support once the disease had painfully immobilized her extremities. Although I was young, I could see that the skill and company of the women who visited daily were crucial. I recognize now that their familiarity with the mysterious and sometimes frightening affairs of aging bodies helped me feel more at ease with the reality of my grandmother's significant needs. When they were there, her dependence was not so alarming.

Also relevant to the roots of my interest in the research, is a more recent experience in which I spent two and a half years volunteering with a community agency in the west end of Toronto that pairs adults with (often marginalized) elderly community members; most of the participants I met were women, many of them recipients of public home care. While getting to know participants, I heard stories about limited time allotted to the intimate tasks of bathing and grooming, and witnessed their frustration with frequently-changing staff due to turnover. When I learned about the work of QCA in conversation with a former supervisor at the program, I was initially encouraged and intrigued by the inclusion older adults in the group's efforts to generate change in publicly-provided home care through grassroots organizing. I engaged in conversation with home care workers, advocates, and others connected with the sector to deepen my understanding of the issues. These past experiences and present interests lay the groundwork for this research.

CHAPTER 2. THEORETICAL FRAMEWORK

The theoretical frameworks employed in this project are multiple and interconnected, but before delving into them, I will lay out some assumptions underlying the research problem. Firstly, the problem is hinged on the critical assumption that neoliberalism exists as part of the larger phenomenon of globalization, and that it has certain negative consequences for the groups of interest in this particular study: PSWs and home care service users. Secondly, the problem is rooted in the idea that changing or resisting the current home care system is a worthwhile undertaking, given the consequences of neoliberalism on this system in particular. Finally, I believe that the knowledge of those who are advocates is worthy of exploration, and is best understood by talking directly to them.

Selected Frameworks

My theoretical framework is "intentionally eclectic, mingling, combining, and synthesizing" theories and practices as I conceptualize, carry out and (co)interpret what I data find (Kaomea, 2003, p. 15). I employ Eurowestern methodologies, but borrow from postcolonial theory in an attempt to decolonize research practices using an AOP framework. In organizing this section I have approached the theories somewhat categorically. This is not because they are discrete, as they leak and bleed into one another; difficulty in their categorization reflects the non-linear messiness of this kind of research.

My approach to the selected theoretical frameworks is informed by Connell's (2007) dirty theory. Dirty theory is that which seeks to multiply rather than slim down theoretical ideas, challenge dominant concepts, and uncover knowledge mixed up with specific places, situations and social contexts (Connell, 2007, p. 206). In its specificity and multiplicity, dirty theory stands

counter to Eurowestern grand theories that make sweeping claims of 'objectivity', and by doing this, dirty theory opposes a neoliberal value system (Connell, 2007). Neoliberal systems take up universalizing, placeless and abstract dominant theoretical frameworks; we see this in the strength of neoclassical economics within our current economic system (Connell, 2007, p. 207). Further, neoclassical economics prioritizes unencumbered market competition, and its implementation has resulted in a preference for 'market-mentality', or the increasing imposition of the market on all spheres of life (Baines, Evans & Neysmith, 1998).

Bearing this in mind, I choose instead to engage dirty theory as a framework for my approach to postcolonial and AOP theory. By taking the approach that theory should be rooted in specific situations, social contexts and people, the breadth and quality of ideas that can be known are multiplied, and dominant ideas about the groups under exploration can be questioned. Dirty theory's tenets frame my employment of postcolonial and AOP theories.

Postcolonial theory informs my way of conceptualizing the research problem, and by extension the research design. The term 'postcolonial' does not refer to what occurs after the supposed demise of colonialism, but refers to a continuous contesting and struggling against colonial domination and the legacy of colonialism (Loomba, 2005, p. 12). Postcolonial theories point out that there is a long history of (white, Western) researchers like myself employing unacknowledged positivist assumptions in their study of marginalized and colonized Others (Ladson-Billings, 2000, p. 267). Postcolonial theory within this research context sees that Eurowestern ideas are claimed as the only legitimate knowledge, which is found most often through a deficit-focused lens (Chilisa, 2012). The knowledge produced from such scholarship has consequences for the groups under study, as its emphasis on weakness and deficit can then be

used as a tool of marginalization, by focusing on 'problem stories' rather than narratives about ability and strength.

It is my hope that through research I can highlight such stories of strength and resistance, and trouble existing academic knowledge about the involvement of community members, like home care users and PSWs, in advocacy efforts (Kumashiro, 2004). While participants for the project were not intentionally recruited from colonized communities I was aware that those coming forward to participate may have experienced marginalization, considering the diversity of stakeholders involved in QCA. Given this, I have incorporated lessons from postcolonial theory and from scholars like Chilisa (2012), Ladson-Billings (2000), and Reyes Cruz (2008). These lessons are further detailed in the Methodology section.

A complete, critical exploration of the work of QCA requires acknowledgement and examination of intersecting points of oppression around race, class, age and gender (among possible others) that crisscross the home care system and which heighten the need for advocacy. Home care workers are predominantly women and in metropolitan areas the workforce is increasingly composed of racialized and immigrant women with limited employment choices and who sit at "the precarious margins of the new economy" (Aronson & Neysmith, 1996; Aronson & Neysmith, 1997; Aronson & Neysmith, 2006, p. 29; Lowry, 2002; Montgomery, Holley, Deichart, & Kosloski, 2005; Vosko, 2000). Further, in the field of publicly-provided home care, the literature indicates that service users are often economically marginalized and are categorized as either frail seniors who wish to remain at home for as long as possible, or as individuals of any age living with long-term disabilities or with chronic illness (Clark, Dyer, &

Horwood, 1998). Given the group of people supporting and supported by the home care system, an AOP lens is essential in order to highlight the intersection of race, class, age and gender.

Within an anti-oppression framework, oppressions are characterized as points of difference, which become the basis for social divisions and structural inequalities (McLaughlin, 2005; Dominelli, 1996). These oppressions are conceptualized as intersecting rather than hierarchical to avoid prioritizing between different forms of oppression (McLaughlin, 2005; Mullaly, 1997). Anti-oppression theory is also influenced by a Foucauldian understanding of power as dynamic, complex and capillary, rather than top-down and pyramidal; this allows complex narratives of power to be uncovered, rather than a small number of dominant metanarratives (Foucault, 1980, as cited in Heron, 2005, p. 347; McLaughlin, 2005).

An anti-oppression model, and practitioners and researchers that work within it, not only acknowledge inequalities and power, but seek to move toward a world free of domination and privilege (Bishop, 1994). Further, anti-oppression practice (AOP) seeks to question normative assumptions in discourse, call attention to the multiplicity of social positions, and unsettle essentialist perspectives (Moosa-Mitha, 2005, p. 64). Anti-oppressive practitioners and researchers make the political processes of creating knowledge explicit, attempt to shift the power relations in their work, and critically reflect on the impact of their own subjectivity and social location on the work (Potts & Brown, 2005).

The assumptions underpinning my understanding of the research problem, laid out in the beginning of this section, are connected to these theoretical frameworks in a number of ways. Firstly, I acknowledge that neoliberalism and globalization have certain negative consequences, specifically for PSWs and home care service users. I believe that these consequences, as per an

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anti-oppressive framework, are related to the intersecting oppressions and marginalization stemming from race, class, age and gender, and which impact many individuals in these groups.

Secondly, the research problem is rooted in the idea that changing or resisting the current home care system is a worthwhile undertaking. This is again connected with anti-oppressive and dirty theory, as the research problem highlights QCA's efforts to shift power imbalances and structural equalities as the result of their demands for change within home care. This occurs while I simultaneously attempt to shift these imbalances within the research process itself, as well as challenge existing knowledge about the topic.

And finally, in line with postcolonial and dirty theory, I believe that the knowledge of those who are advocates is worthy of exploration. As such, the research problem should be explored by speaking directly with QCA members (ideally PSWs and service users) with the goal of centring multiple narratives and theories that emerge from stories describing their specific experiences. These theoretical frameworks not only shape my understanding of the research problem, but influence my choice of research process, outlined in the Methodology section.

CHAPTER 3. LITERATURE REVIEW

In reviewing empirical literature concerning the topic of interest, I have found that the scholarship pools around four major themes. The themes and their associated findings were discovered through a review of grey literature (i.e.: government website content, policy papers and reports from advocacy organizations) academic books, and peer-reviewed journals of social work, social services, health care, gerontology, labour, economics, and immigration. I will first begin by introducing my understanding of the home care context, key concepts and the background of the current home care context in Ontario. Following that I will review what is known from the scholarship and highlight some of the gaps in what is currently known. Finally, I will lay out my research questions, explain how they address gaps in the literature, and elaborate on why I believe this research is important.

Neoliberal Context

The theoretical frameworks outlined in the previous chapter lead me to conceptualize the landscape of health and social services in Ontario and across Canada as guided by a value system that works hand-in-hand with globalization, its goals and its processes: neoliberalism (Dominelli, 1999). Neoliberalism has been described as a set of economically-driven values which necessitate private sector involvement in the provision of health and social services, and which promote the integration of corporate management values and practices into government work (Teghtsoonian, 2009). Neoliberalism is set within a wider context of globalization.

As pointed out by Smith (2011, p. 204), neoliberalism constitutes far more than a set of economic or immigration policies. It imposes a market-mentality on all spheres of life, and is embodied in and reproduced by not only policies but by the inner workings of people subjected

to its ideology (Brown, 2005; Rottenberg, 2013). We are forced to become rational, productive, and efficient ideal citizens (Davies, 2005). Brodie (1996) describes the contemporary dominance of neoliberal values in Canada as a departure from a rights-based citizenship discourse toward one which emphasizes instead the privileges and duties of citizenship. So in addition to policy and individual-level changes, we see a cultural shift in which "concern for the greater good" has been edged out by commercially-driven interests that provide services to individuals who are entitled to them (Dominelli, 1999, p 18). In this context social problems become 'responsibilized' as individual issues, and so individuals and families are obligated to cope alone with experiences of distress that may come with aging or illness (Teghtsoonian, 2009). We see this discourse shaping the home care system, its funding structures and policies, and by extension the experiences of the people who do and receive home care work.

Key Concepts

The home care sector is primarily comprised of medically and therapeutically-oriented services provided by professional workers such as nurses, physiotherapists and social workers (Aronson & Neysmith, 2006). The home support sector is a smaller component of the broader home care field, and is carried out by non-professionals who bathe, dress, lift, groom and perform light household tasks in the homes of service users (Sims-Gould & Martin-Matthews, 2010). Preventative, 'soft', paraprofessional home support skills are typically less valued than medically-based and professionally-administered home care services (Penning, Brackley, & Allen, 2006).

Although scholarship written about home support work employs a variety of terms to describe its workers, in the interest of clarity the term 'personal support worker' (PSW) will be

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employed throughout the paper. Personal support work is classified as an unregulated health profession, which relates to an absence of mandatory, standardized educational requirements and lack of a governing professional body (Martin-Matthews, Sims-Gould, & Tong, 2013; Quality Care Alliance, 2010). Wages of PSWs in home care are significantly less than those for similar work in hospitals and long-term care facilities, and poor compensation adds to the perception of their work as low status (Aronson, Denton, & Zeytinoglu, 2004; Lilly, 2005; Quality Care Alliance, 2010).

Background: Shifts in Policy and Restructuring of Services

Before reviewing the literature, it is necessary to understand something of the history and current context of publicly-provided home support and home care services in Canada and Ontario. In 1984 the Canada Health Act was introduced to ensure universal public access to physicians and hospital services, but it did not include a minimum basket of home care services (Canadian Healthcare Association, 2009; Wells & Taylor, 2001). The provision of home care was the product of cost-sharing programs between the federal and provincial levels between 1977 to 1995; however, this system ended with the advent of block funding transfers (Aronson & Neysmith, 2006, p. 30; Department of Finance Canada, 2011). The creation of the Canada Health and Social Transfer (CHST) reduced the workload generated from cost-sharing, but with its institution, funding to the provinces was slashed by a total of seven billion dollars (Hicks, 2007, p. 18). Critics viewed it as a method of financial constraint, whereby the federal level places clear limits around the amount intended for welfare purposes (Dominelli, 1999, p. 15). In the absence of federal standards the provinces developed distinct and mixed economies of home care (Aronson & Neysmith, 2006, p. 30; Penning et al., 2006; p. 745). A cheaper model, community-

based care (promoted as "de-institutionalization") aligned with provincial cost-reduction strategies necessitated by reduced support from the federal level (Hicks, 2007, p. 18).

In 2004 the CHST was separated into the Canada Health Transfer (CHT) and Canada Social Transfer (CST), which permitted the provinces more freedom in the designation of dollars for health and social services, while improving "transparency and accountability of federal support to provinces and territories" (Department of Finance Canada, 2011, para. 6). Critics point out that this permitted the federal government to take credit for popular health programs, while social services remained under-funded (Hicks, 2007, p. 49). Current reduction in federal spending forces provinces to provide only the most necessary and effective services, and is a signpost for neoliberalism's "ideology of scarcity" (Brotman, 2002, p. 46). This, combined with restructuring of services due to "fiscal restraint" forces citizens to become self-reliant (Arat-Koc, 1999, p. 32). Self-reliance is a paradoxical and mean-spirited goal, when taking into account the needs of frail elderly service users.

In Ontario a system of market competition emerged in which for-profit home care companies compete for contracts dispensed by regional, provincially funded service access points, called Community Care Access Centres (CCACs) (Aronson & Neysmith, 2006; Department of Finance Canada, 2011; Penning et al., 2006; Vogel, Rachlis, & Pollack, 2000; Wells & Taylor, 2001). Aronson and Neysmith (2006) describe this as managed competition, in which government services are offloaded into the market, the mechanics of which are obscured from public view through public service access points. Market and managed competition are beneficial to larger forces implementing them; increasingly lower bids from home care companies are solicited and worker wages are reduced to remain competitive and win care

contracts (Aronson & Neysmith, 2006). Nonprofit home care organizations, more likely to pay higher wages, are less able to survive in such a climate (Aronson & Neysmith, 2006).

After recommendations were put forward in the *Romanow Report* in 2002, and as the impacts of Canada's aging population set in, the federal government took a more direct role in funding home care by mandating that provinces provide three categories of home care (Health Canada, 2013). While these efforts have established home care as part of the spectrum of guaranteed services, its emphasis is on short-term acute and end-of-life care, which ignores the longer-term care needs of seniors and those living with chronic illness or disability (Department of Finance Canada, 2011). This narrow scope of services underlines the value of medical home care and has resulted in cuts to home support (Aronson & Neysmith, 2006, p. 31).

Key Themes

Home care/home support and neoliberalism.

In examining literature about the impact of neoliberalism on the delivery of government services and programs, it is noted that discourses of responsibilization direct individuals and groups to be "enterprising", by working on and investing in themselves (Rose, 1998). In this context the public is required to take up responsibility for social risks such as illness, poverty, and unemployment (Lemke, 2001). Government discourse re-articulates responsibilization as 'responsible citizenship', language which neatly frames a drastic societal shift from social to private responsibility (Ilcan, 2007). Teghtsoonian (2009) suggests discourses of responsibilization become a tool to help government reduce spending on social services to support individuals and families in times of distress.

The CCACs' system of market competition sees the majority of contracts won by for-profit care companies, which are more willing to make the necessary cuts to staff, hours and wages than non-profit care agencies (Aronson et al., 2004). Persson and Berg (2009) bring to light the divide between the rhetoric of choice within publicly-provided elder services in a similar welfare state. There is striking contrast between the manner in which service users are described as "valued consumers" and the actual local practices where there is seldom choice afforded to this group (Persson & Berg, 2009). Choice is exercised by those who can afford to leave public services arena and hire private care. Older adults are pushed toward independence through reduced access to community care services, when medically-based home care is prioritized while access to social and supportive home care is reduced (Penning et al., 2006).

There are efforts within the literature to bring attention to larger systemic issues by shining a light on small, private spheres within the home care context. Gerontology researchers recognized salient issues and coping strategies of workers that have experienced underemployment or job loss due to restructuring (Sharman, McLaren, Cohen, & Ostry, 2008; Sims-Gould & Martin-Matthews, 2010). Aronson and Neysmith (2006) point to the impacts of restructuring in the disappearance of a trained, caring and competent workforce. Within this context, PSWs are under pressure to conform to agencies' managerial standards, which devalue the relational quality of the work in favour of a task-oriented approach to care; studies featuring the voices of workers and service users show this as inappropriate framing of the work (Aronson 2002; Aronson 2003).

Restructuring home care, the ideology that underlies it, and the resulting lack of continuity of care, also have effects on the service users and their unpaid carers (Aronson, 2002;

Brotman, 2002; Sharman et al., 2008; Vezina & Roy, 2010). The current push toward a

profitized system has been criticized as contributing toward workers' inability to adequately care

for vulnerable populations, and as connected with a reduction in service hours per client,

increased number of clients per worker, reduced number of full-time positions with benefits, and

reduction in pay (Aronson et al., 2004; Aronson & Neysmith, 2006; Penning et al., 2006;

Sharman, et al., 2008; Sims-Gould & Martin-Matthews, 2010). Further, it has been argued that

neoliberalism is associated with greater socioeconomic and health inequalities, seen in the

budget-driven efforts of hospitals to discharge patients "sicker and quicker" (Vogel, et al., 2000,

para. 25). Early discharge into the less-costly home care system puts a strain on stretched

resources and shifts responsibility to families (Coburn, 2001; Teghtsoonian, 2009; Vezina & Roy,

1996).

Resistance to neoliberalism.

The scholarship that involves an assessment or critique of the Canadian context often

focuses on the experiences of PSWs and recipients of home support. However, implications

drawn in this research tend to point to broader solutions, beyond the everyday experiences of

these groups. Responses to neoliberalism in the literature include a push for policy change,

critiques of home care restructuring at the provincial level, and a call to revalue home support

and caring labour (Aronson & Neysmith, 1996; Aronson & Neysmith, 2006; Aronson et al.,

2004; Brotman, 2002; Neysmith & Aronson, 1996; Martin-Matthews et al., 2013).

There is discussion in social work literature around micro acts of resistance in the

everyday experience of workers operating within and around for-profit home care companies.

Aronson and Neysmith (2006) reframe what counts resistance when looking at the ways PSWs

cope with new pressures of restructuring in Ontario. They highlight "subtle, routine, low level forms of struggle and challenge" by way of changing Care Plans to suit clients' immediate needs, ignoring a Care Plan in lieu of sharing a meal together, and performing tasks beyond what is permitted by their employers (Aronson & Neysmith, 2006; Thomas & Davies, 2005, p. 220). In this body of writing, everyday and sometimes indirect acts of resistance to neoliberalism are not framed as singular, but as diverse; the form of resistance that occurs depends on the worker and the context (Guo & Tsui, 2010).

Home support/home care and marginalization.

The scholarship gathers around a third theme concerning the gendered nature of caring, a concept imbued in the work itself, in those who do it, and in the recipients of this care. Rockwell (2010) attends to the idea that housework is value-laden and, as 'women's work', resides outside the market economy; these perspectives result in its frequent removal from the list of services covered by CCACs. The literature notes that the vast majority of PSWs and unpaid carers are female, and in this context the burden of neoliberal restructuring is carried by women (Aronson, 2002; Brotman, 2002; Neysmith & Aronson, 1996; Teghsoonian, 2009).

Home care is not only a site for discussion around oppressions related to gender, as a number of scholars have addressed the connection between class, race and immigration status at it relates to this field. As discussed previously, ever more in Canada and globally, home care positions are filled by racialized immigrant women with minimal employment choice, and who are often vulnerable to the unregulated nature of the work (Aronson & Neysmith, 2006; Vosko, 2000). Also addressed in the scholarship are specific issues that racialized service users face, such as the assumption of family support in immigrant communities, a dearth of appropriate

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services and language barriers (Brotman, 2002; Giuntoli & Cattan, 2012; Martin-Matthews, Sims-Gould, & Naslund, 2010).

Immigration policy and globalization.

Scholarship has linked local economic restructuring to processes of globalization by noting changes to state immigration policies in Canada. Goldberg (2006) points out that after policy reform in 2004, immigration criteria began to reflect Canada's short-term economic needs, and new emphasis was placed on an individual's potential 'fit' into the Canadian economy. Changing immigration policy impacts the care work done in countries that send and receive people that perform caring labour; on a global scale this is a group primarily comprised of women of colour (Browne & Braun, 2008; Misra, Woodring, & Merz, 2006). The global care chain, a set of personal links between people living around the world based on paid or unpaid caring work, has been connected with not only a "brain drain" of trained workers from the global South, but a "care drain" of women from poorer countries to richer ones like Canada (Hochschild, 2003, p. 1). Economic migration occurs in tandem with the realities of structural and interpersonal barriers in labour markets which prevent skilled individuals from accessing employment for which they have been educated (Danso, 2009; Girard & Bauder, 2007).

Gaps in the Literature

From the body of research examined, there were very few examples found of inquiry that employs components of AOP or postcolonial theory, and many that incorporate feminist theory. Due to my focus on qualitative methods while searching the literature, I found that a diversity of (primarily women's) voices were consulted and mined for data through interviews and focus groups. These groups include: home support and home care service users (Aronson, 2002;

Aronson, 2003; Aronson & Neysmith, 1997; Brotman, 2002; Giuntoli & Cattan, 2012; Martin-Matthews, et al., 2013; Persson & Berg, 2009; Vezina & Roy, 1996) unpaid and family carers (Aronson & Neysmith, 1997; Brotman, 2002; Martin-Matthews, et al., 2013; Vezina & Roy, 1996) home support and home care workers (Aronson & Neysmith, 1996; Aronson & Neysmith, 1997; Aronson & Neysmith, 2006; Martin-Matthews, et al., 2010; Martin-Matthews, et al., 2013; Neysmith & Aronson, 1996; Sharman et al., 2008; Sims-Gould & Martin-Matthews, 2010) social service administrators (Persson & Berg, 2009); and, home care managers (Martin-Matthews, et al., 2013).

However, the construction of knowledge is completed by researchers (all of the previously cited authors) who buttress lived experience with 'legitimate' and sturdy theoretical frameworks (i.e.: ecological, feminist, social constructionist). While this is a common practice for research, and one that I partially employ myself, the dearth of research lead by the theories and ideas of participants limits what can be known about the issues surrounding publicly-provided services.

I theorize that this gap could be connected with the lack of larger-scale resistance by workers and service users around the context of home support. The literature tells us that workers' micro acts of resistance and service users' choice to restrain expectations of care are tactics commonly used in coping with and resisting oppressions in the home care system (Aronson, 2002; Neysmith & Aronson, 1996). Struggles are individualized and become exhausting, which perhaps blocks larger ways of resisting and making change. The authentic inclusion of these two groups in transformational and critical research processes and in community-based dissemination of research could perhaps help alter this current reality.

Although I am not able to undertake community-based research within the current format, this provides inspiration for future work.

Further, there is room in the body of home care research for explorations of advocacy work and shared resistance between workers and service users. Aronson and Neysmith (2006) point to the need for home care workers to have the opportunity to gather and share their experiences collectively, as a way to mobilize change. However, no other researchers cited above point to collective action in their discussion of possible solutions.

Research questions

With this project I aim to learn about the experiences of individuals involved with a multi-stakeholder advocacy group (QCA). These experiences are used as an entry point to explore larger themes about what helps and hinders multi-stakeholder advocacy groups within the context of neoliberalism. I am particularly interested in learning about the experience of involved service users and workers. The two central research questions are as follows:

1. What can be learned about the efforts of QCA, in terms of the enabling factors, successes, barriers and challenges they faced, that contributes to knowledge about multi-stakeholder advocacy within the context of neoliberalism?

2. What can learned from the experiences of people involved with QCA that contributes to knowledge about multi-stakeholder advocacy within the context of neoliberalism?

By making small but intentional efforts to decolonize research processes, I hope to fill some of the methodological gaps in the existing body of knowledge. Additionally, by focusing on a larger-scale example of resistance that involves both PSWs and service users, I hope to inject stories of shared resistance of these two groups into the available home care scholarship. The

presence of service users and PSWs in QCA's work contradicts literature that states that home care service users are unlikely to voice objection to reduced hours and quality of care, and that workers have few opportunities to find a productive means of voicing their objections to working conditions and poor compensation (Aronson & Neysmith, 2006; Persson & Berg, 2009; Sharman et al., 2008). There is a need for research that offers alternative stories of advocacy, and that illustrates that service users and workers can and do speak out in acts of shared resistance. To my knowledge, such a project has not previously been undertaken around the work of Quality Care Alliance.

The task of examining this kind of advocacy in home care is a worthwhile endeavour for "resistor" social work researchers and practitioners interested in pushing back against the current neoliberal influences on health and social services (Dominelli, 1999, p. 21). It not only suits social justice aims to stand in solidarity with personal support worker colleagues and to support opportunities for home care service users to pursue self-advocacy, but it has been suggested that collective action beginning at local levels is productive, and potentially revitalizing for those involved, considering the angst which can come from confronting neoliberalism (Dominelli, 2004, p. 21).

CHAPTER 4. METHODOLOGY

Background

My methodological approach fits itself into existing research on the topic of home care that take up feminist and critical methodologies. Over the course of ten years, a team of key Canadian researchers from the faculties of social work at University of Toronto and McMaster University took up a critical and feminist lens to explore many of the issues surrounding home care. They explored such topics as: how workers make sense of employment insecurity, service users' perspectives of care, and issues underlying the low value placed on caring labour (Aronson, 2002; Aronson, 2003; Aronson & Neysmith, 1996; Aronson & Neysmith, 1997; Aronson & Neysmith, 2006; Aronson et al., 2004; Neysmith & Aronson, 1996). Narratives of workers and service users are framed by critical analyses of both the processes of restructuring and privatization, and the power dynamics shaping distributions of power in long term care. Many of their articles feature women's subjugated knowledges by intentionally choosing female participants, consequently centreing "naive" and "inferior" knowledges (Foucault, 2003, as cited in Holmes, Murray, & Perron, 2006).

A second team of Canadian gerontology and social work researchers from British Columbia utilize a post-positivist approach to examine home care across Canada (Martin-Matthews et al., 2010; Martin-Matthews et al., 2013; Sims-Gould & Martin-Matthews, 2010). They make space for the subjective experiences of interview participants, but also focus on validity, reliability, and rigour of results (Martin-Matthews et al., 2010; Sims-Gould & Martin-Matthews, 2010). A more recent publication employed a more critical perspective on policy, as

seeded in the personal experiences of a diverse group of research participants (Martin-Matthews et al., 2013).

Why Narrative Methodology?

After familiarizing myself with bodies of existing research, I believe that narrative inquiry serves as the most solid platform on which to build more creative and decolonizing approaches to this particular project, as it draws from feminism, critical theory and postmodernism (Fraser, 2004, p.183). My qualitative methodology follows a framework of narrative inquiry, glued together from the ideas of Fraser (2004), Creswell (2007), and Minister (1991). At its most basic, narrative research begins with "experiences as expressed in lived and told stories of individuals" (Creswell, 2007, p. 54). Creswell (2007) asserts that narrative research is best for capturing the detailed stories or life experiences of a small number of people (p. 55). Bearing in mind that I examine the stories of three participants, reflect on their personal reasons for involvement with QCA and their ideas about the systemic context of these experiences (and my analysis of them), I determined narrative inquiry would be the best methodology to explore these ideas.

According to Riessman and Quinney (2005), narrative interviewing in research is relevant to the aims of social work as it allows the investigator to not only focus on individual circumstances but on context and history. Narrative approaches can also help social work researchers move from a problem focus by engaging in meaningful dialogue informed by critical ideas (Fraser, 2004). Narrative methods fit with this project, given that the research questions aim to highlight stories of strength and resistance, and explore experiences that lead to participants' involvement in QCA.

What is (My Kind of) Narrative Methodology?

I wish to stretch research methodologies into more decolonized territory. There are

limitations in traditional narrative approaches around representation, due to an absence of

collaboration with participants in typical narrative inquiry. Although I was unable to collaborate

as fully with QCA members as I would have liked, partially due to issues around the project

framework and timeline, I made attempts to address this in my design nonetheless. Taking into

account the tendency of Eurowestern research to dismiss certain kinds of knowledge, and given

my own alignment with AOP, dirty and postcolonial theory, it was my aim to centre the voices of

participants as best as I could.

I push past Minister's (1991) recommendations for narrative research by not only sharing

my interpretations during the interview, as she suggests, but by inviting participants to co-

theorize with me about the 'bigger picture' that informs their experiences of advocacy, with the

aim of valourizing the collective construction of knowledge (Chilisa, 2012, p. 206; Peile &

McCouat, 1997). While I guided the interview topics with a set of questions, I was explicit about

my openness to participants taking the lead in the direction of conversation; we oriented to the

interviewee rather than the instrument (Fraser, 2004). I also attempted to position myself as a

non-Knower, by rejecting the convention of researcher-as-distant-expert in the ways I

communicated and asked questions during the interviews (Potts & Brown, 2005).

AOP academics critique the notion of the rational subject who can create His identity

from an unlimited number of choices (Strega, 2005). With this in mind I attempted to engage in

analysis that did not give in to my deep-rooted, socialized affinity for the rational. Throughout

the process, I have needed to fight my inclination toward and expectation of rationality for

myself and participants. I have at times demanded it from myself to prove my design and data analysis as 'correct', while fumbling through an unfamiliar process. I have also needed to resist the urge to value neat linear stories while listening to and analyzing the narratives of participants.

By 'dirtying' and decolonizing narrative research as much as possible I make an effort to move from viewing paradigms and methodologies as "water-tight compartments" (Connell, 2007; Guba & Lincoln, 2005). It is my hope that, by taking steps like elaborating theory *with* participants, encouraging a plurality of truth, multiplying sources of theoretical thinking, and engaging in critical self-reflexivity I can resist dominant ideas about who is allowed to create and assert knowledge (Connell, 2007; Reyes Cruz, 2008).

It is important to note that although my methodological approaches may resemble components of grounded theory method, which aims to discover or generate theory, that due to the small number of participants (among other factors), I cannot claim to generate theory from this research (Creswell, 2007, p. 62). In the future, the research questions explored here could inform deeper study using grounded theory methodology to produce new theory about the nature of shared resistance in home care settings.

The Research Process

    Preliminary work.

It is important to lay out the ways in which I have incorporated intermingling theoretical frameworks in the process of conceptualizing the research. The topic was inspired by conversations with two key informants about their work with QCA, who were introduced to me while completing the groundwork for research. The beginnings of my exploration of the topic began with one key informant's words: "the QCA story should be told". This statement,

combined with an absence of critical literature about advocacy in home care and a lack of research reflecting the presence of both service users and workers in advocacy, informed the need for research. The research questions were heavily influenced by these initial conversations with key informants.

My postcolonial and anti-oppression lens influenced the way I read existing scholarship and relevant grey literature. I noticed I connected best with a small body of research that promotes social justice and resistance in both processes *and* outcomes of inquiry (Potts & Brown, 2005). I attempted to mirror this in my own work in numerous ways. I attempted to engage in continual and critical self-reflection on the ways in which my positionality and privilege intermingle to influence the way I conceptualized and designed the project. Continual reflection is of particular importance as I am an outsider to QCA and to the experiences of workers and service users. As per another tenet of anti-oppressive and postcolonial research, I have chosen to locate myself in the story of this research in acknowledgment of the subjective, political and social construction of knowledge (Potts & Brown, 2005, p. 261). As Ladson-Billings (2000) states, this is "not merely a new narcissism; rather, it is a concern for situating myself as a researcher - who I am, what I believe, what experiences I have had - because it affects what, how, and why I research" (p. 268).

Recruitment strategies.

Participants were recruited through the electronic and online networks of QCA. I was given permission by a key informant involved in the Alliance's organization to disseminate recruitment materials electronically via email lists. In order to mitigate any undue pressure on group members to participate, recruitment materials clearly stated that a choice to participate (or

not) would not have consequences on relationships with key informants, QCA or Ryerson University, and that the research was unconnected with the organizers of the Alliance. It was also made clear that the choice to participate could be kept confidential, so that organizers would not know who had chosen to participate and who had opted out.

Purposive criterion sampling strategies were used, as only those who had attended QCA meetings were on the mailing lists, and therefore only these members received recruitment materials. Interested individuals were invited to contact me directly by email. Snowball sampling was also employed, as those who received materials were invited to share them with others.

Data collection.

Three 60 to 90 minute individual interviews were held between May 8th and June 16th, 2014. All interviews were audio-recorded and consent to audio-recording was a condition of participation. During the interviews, participants were invited locate and theorize about their reasons for involvement, about successes, challenges and barriers met by the group, and about about the ability of the group to find common ground. They were asked about their perceptions of the involvement of service users and home support workers in the work of QCA. Participants were also invited to discuss if and how they made connections between their experiences, their participation in the group and the current political and economic climate in Ontario and Canada - how and if they connect their involvement with 'big picture' trends of privatization and restructuring in the field of home support services.

Final sample.

The inclusion criteria required that participants were over the age of eighteen and identify in one of the following ways: as a member of a QCA committee, as a former or current staff of

QCA-affiliated organizations, or as a QCA-involved community member, home care worker or home care service user. As interviews could only be conducted in English due to a lack of budget for services like translation, it was necessary that participants had relative comfort with English.

Three participants were selected on a first-come, first-served basis. The participant group identified themselves in a variety of ways: one participant identified as working for a labour union, one identified as a volunteer coordinator, and one as a community leader and community activist. All participants had direct or indirect experiences with the home care system. Two participants were or had been significantly involved in the care of older family members receiving home care services, and one participant works with a labour union that represents many home care workers. Participants ranged from aged 39 to 62 at the time of their interview. One of the participants identified as male, and two as female. Those interviewed represent a diversity of cultural and ethno-racial backgrounds, however, several participants requested that these specific identifiers not be revealed in the interest of anonymity and confidentiality.

Data analysis.

The first step of data analysis occurred during the interviews, when I made attempts to invite and leave space for participants to theorize about connections between the 'big picture' context and their personal experience. These ideas and theories were highlighted during the following process of solo data analysis, described here.

Following Fraser's (2004) suggestions for analysing personal stories as part of narrative research, I completed the data analysis in six non-discrete phases. Interview transcripts and notes taken during and after interviews were included in the data considered for analysis. These notes detailed salient ideas not made apparent in audio-recordings, as well as feelings and curiousities

evoked during interviews (Fraser, 2004). Preliminary analysis began during the transcription when I repeatedly listened to the nuances of words and began to interpret their meaning. Once transcripts were typed, I began by reading the collection of three narratives one after the other, to ensure that I was beginning to understand the stories as connected to one another. I then listened to audio recordings of the narrative while simultaneously re-reading transcripts, in order to begin identifying and soaking in the emotional content of the interviews. I was re-familiarized with the climate of the conversations, and reminded of my in-the-moment responses to the stories (Fraser, 2004). This focus on emotion is key, as I work within a methodology which seeks to disturb a preference for rationality, and to unsettle the dominant epistemology which underlies this perspective.

Next, I re-listened to transcripts in a stop-and-start fashion as I disaggregated the narratives into smaller stories, which were named and numbered (Fraser, 2004, p. 190). This process was easier for some participants than for others, as some stories ended illogically as participants lost interest or were reminded of other stories; at times they wove into one another and were (sometimes) returned to. I named the stories based on themes found within them, and frequently used participants' words in their naming (Fraser, 2004, p. 191). During this process I paid special attention to inflection and vocalizations, and often found myself correcting the transcripts to include sounds, pauses and partial words not previously recorded as I had deemed them unimportant; I began to perceive the minutiae as key indicators and clues.

A third pass through the narratives was undertaken to interpret the stories across four domains of experience: intrapersonal experiences, interpersonal experiences, cultural aspects of stories and structural aspects of stories (Fraser, 2004). These particular interpretations were made

to avoid individualizing the experiences of participants (Fraser, 2004, p. 191). I noticed and recorded similarities and differences between, contradictions within, and my own curiosities about the stories. I began to preliminarily analyse the stories for connections between personal experiences and cultural or structural context, and took cues from the theorizing done by participants. This required moving between stories and participants' accounts as the process became less linear.

Once I interpreted across domains of experience, I began to explicitly draw out themes found between participants, and connect these ideas to popular discourse and structures like class and gender (Fraser, 2004). This helped to pinpoint stories used as the basis for writing the academic narrative. I attempted to highlight moments in the interviews in which participants theorized about connections between context and their personal experiences.

Ethical Considerations

Participating in a narrative interview presents potential, and in this case minimal, psychological risk. Risk was addressed by emphasizing that participants were able to pause or discontinue participation at any point without consequence, and were not required to answer any question(s) they did not feel comfortable answering. I was unexpectedly troubled by a second ethical consideration around the idea of confidentiality versus participant visibility within the research. Participants were initially given the opportunity during the consent process to waive their confidentiality in the research, with the option to review this decision after the interview. I suspected that some participants may be proud of their work with QCA and may prefer to be identified. At the very least, they should be able to exercise agency around their individual notion

of acceptable risk, and be given the choice to remain visible in the research if they wish (Chilisa, 2012, p. 207).

Ultimately all but one participants except one requested to remain confidential, and against my earlier thinking I have decided to keep all names and identifying details out of the research. Before analyzing the data I came to this decision, as the bulk of data analysis and all of the report writing occurred without participants' input or approval. I did not feel comfortable associating a participant's name with research over which they had little or no control.

Limitations

There are four limitations present in the research. As I was unable to recruit individuals who identify as current service users or home care workers, there is a considerable gap in perspective offered within the narratives. The use of English in recruitment materials, the requirement of comfort with English in interviews, and the chosen electronic recruitment methods most likely restricted the range of participants who were able to respond or participate. The length of time available for data analysis was brief due to difficulties with recruitment and scheduling interviews, and this is reflected in the depth of data analysis. And finally, there are limitations in narrative approaches due to an absence of collaboration with participants around the analysis of their narratives. Although I have attempted to address this limitation in my design, it is still important to note that my interpretation of narratives may unintentionally misconstrue participants' words, or I may draw political implications from the meaning of stories that are different that what the narrators intended (Fraser, 2004, p. 194).

CHAPTER 5. FINDINGS

This chapter will discuss the narratives uncovered during three interviews with three participants. Interviews were completed in person, and by Skype where distance made it impossible to meet face to face. All participants identified in one or two of the following ways: as an employee of a QCA-affiliated organization, as a member of a QCA regional committee, or as a QCA-involved community member or family caregiver. Participants have been identified by pseudonyms in lieu of actual names, and identifying details have been omitted or changed to protect their confidentiality. Some narratives around sensitive topics have not been connected to the speakers to further assure confidentiality. Participants come from a spectrum of cultural and ethno-racial backgrounds, but at the request of several participants I have chosen not to be explicit about these details to maintain confidentiality and anonymity.

First I will introduce the participants. I will pay close attention to six key themes found in the data, derived from conversations and the theories laid out by participants. Although I have categorized the data into themes for the sake of the structure of traditional academic writing, it should be made clear that these ideas, much like my theoretical frameworks, intermingle and mix into one another. I will do my best to relegate my own analysis and discussion to the following chapter, where I will incorporate outside theory from published academic writers with the ideas and words of participants. But, because in narrative inquiry transcripts are interpreted and themes are selected with an acknowledgement of subjectivity in the process, there are undoubtedly parts of me infused into these findings. The six themes are as follows:

1. Participants' personal roots of involvement in QCA

2. Theorizing about (dis/non)engagement

3. Theorizing about solo struggles as shared

4. Connections and relationships across communities and generations

5. Group processes

6. Challenges related to diversity of needs, 'after hours' advocacy, and organizational structure

Participants' Personal Roots of Involvement

While writing introductions for participants I decided to incorporate their self-identified reasons for involvement, to help the reader get a better sense of these individuals beyond demographic data. Perhaps unsurprisingly, this uncovered the first key theme from the narrative: that the roots of participants' involvement were grown in personal parts of their individual histories and in their thoughts about the future.

Ahmed.

Ahmed, 40, is a labour union employee. Although his involvement was somewhat more formalized than that of other participants, he was involved in QCA from its beginning stages. His employer provided significant support to the group through in-kind donations of materials, staff and meeting space. Ahmed was initially recruited to the Alliance by one of its key community organizers, and brought to the table his expertise in evidence-based research as well as knowledge of the health care system from past work in government. He made the choice to move from the public sector to a not-for-profit organization for reasons described below.

> I joined the union and put my expertise in health care to the benefit of the advocacy efforts that the organization was pushing at the time. Which is to improve the situation, the conditions in the home care sector for clients and for the workers themselves. And to me in general why I made this decision was because I felt I was a product of the not-for-profit sector. I wouldn't have had my education if I didn't have access to scholarships, generous people who opened doors for me.

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So it was my way to kind of give back to the community by working for the community not-for-profit organization. [Ahmed]

His past experiences in post-secondary education and early in his career contributed to his thoughts looking forward; Ahmed had desire to "give back" to the community by way of his choice of employment.

Yvonne.

Yvonne, 62, identifies as a community leader and community activist. She has spent significant time and energy caring for her aging parents, both of whom live with her and receive home care. She has experience in the health and home care systems, both as an unpaid caregiver and as a recipient of services. She connects her engagement to multiple past experiences, when responding to a question about her reasons for involvement in QCA. Here she highlights her expertise in community leadership and in the issues around home care.

> Well it's kind of double-edged question, because there were events in my life. My mother had a stroke and my father keeps breaking every bone in his body, so they have become clients of CCAC and home care. But at the same time there was an election and when QCA organizers started looking for people in my city... And she saw that I have my hands in so many pots, that it would be a good idea to have a chat with me [...] I was already experiencing some of the issues she was talking. In a sense I was the perfect draftee for the program. [Yvonne]

She goes on to explain that there were historical factors influencing her choice to be active around issues affecting seniors. In addition to sharing that she was "exposed to the issue of senior age" while volunteering with seniors shortly after she moved to Canada, she disclosed a profound experience in which she required major surgery at a relatively young age.

> And I experienced what you would have as an older person. I was in the rehab for over two months, being fed and lying and all this. The only thing spared me was the diapers, but everything else I experienced. So this sort of make me more open to those issues, and more aware what does it mean if you are really vulnerable yourself. [...] Well it's amazing you know, you go to the hospital on your own legs,

you feel young and the life it's front of you, and in a couple of weeks they wheel you to the chair, put the bib on you and help you eat. And you keep thinking oh my God this is not happening to me. (laughs) [...] And then they send you this young chick who is teaching me for a week how to wash myself. Ohh. (long exhale) [Yvonne]

Yvonne begins to recount this story with animation and levity, despite discussing an experience of intense vulnerability. As she describes being taught how to wash herself, I sensed a sudden shift in the story's emotional tenor, as her pitch raised and her laughter faded. Although at her lead we began the interview quite casually, without a formal distance I associate with typical research, I found myself leaving my 'researcher' thinking aside for the next moments to acknowledge what I could only imagine was a difficult experience. I responded to her emotion by sharing gratitude for her choice to disclose the experience to me.

Later, during the final minutes of our conversation, Yvonne again connected her involvement with QCA to something intensely personal, this time to her worries about the future.

Well, I worry that our system for seniors is broken, so I'm not quite sure what will happen. That's basically what it is. [...] I'm worried that by the time I will need the senior support there won't be any. And that frighten me a bit. Because I don't know what's in my brain. It's the whole point, I don't know what I will be. And I don't like the solutions that right now everybody is start doing the private retirement residences and everything. You need a huge amount of money to do those. They're very expensive. [Yvonne]

She openly reflects here on an unknown future, and alludes to something I have found myself pondering in my work with older adults. The "not knowing what she will be" that Yvonne describes is unsettling. The 'what-ifs' she expresses around developing dementia or illness is what makes some of us regard growing old with trepidation. And for Yvonne, this worry is compounded by the increase of private retirement and assisted living residences, as our

population of seniors grows. Like private home care, they are an option for only those who can afford them (Oucault, 2013).

Parvati.

Parvati, 39, identifies as a volunteer coordinator for the Alliance and also speaks from the perspective of a family caregiver of a senior receiving home care. Earlier experiences around her late grandmother's health and need for home care were a significant reason for her involvement in QCA.

> [My grandmother] was the 100% reason, yeah, why I got involved. So the problem with her was that she went from being a perfectly healthy person to having a stroke and needing home care. So it put our whole family in a like, we don't know what to do. So we were depending on home care workers to help us out. [Parvati]

The impact of dealing with a sudden decline in her grandmother's health, and the need to search for appropriate and substantial care was felt by not just her but her whole family.

Similar to Yvonne, Parvati described part of the basis for her involvement with seniors issues as connected with her own future, and the future of (unlike) others, illustrated in the form of a metaphorical story.

> Parvati: So my grandmother had already passed away but for me it was a thing like... You know that story... Someone was being hurt and no one came to his aid? And then a Black person was being hurt, and no one came to his aid. A Jewish person was being hurt, and no one came to *their* aid. And then eventually you were being hurt but there's no one left to come to help you? You know that story?
> Amy: Uhmm.
> Parvati: So if you don't help others, eventually you're not going to be helped either when *you* need it. And I was thinking I'm going to be old one day. I mean we're all going to be old one day, right? It's just an inevitable fact.

I got the sense that she sees the benefits of reciprocity among generations and groups; working on issues that affect others will eventually assure that she is helped someday. This mirrors

Ahmed's desire to "give back to the community", and Yvonne's decision to address a "broken" system for seniors.

Parvati and Yvonne also indicated that other factors contributed toward to their decisions to engage in the QCA: an increase in media reports on the occurrence elder abuse in home care in their respective areas; the government's public response to the abuse; and, increased knowledge about the systems and institutions supporting home care in Ontario, like Local Health Integrated Networks (LHINs) and CCACs. Education and knowledge-sharing around systemic issues helped to fuel their interest in participation, although they did not remember how this came about or who shared this information.

Theorizing About (Dis/non)engagement

A second theme emerged from the data around the idea of disengagement and non-engagement. I noticed in the narratives discussion of the public's disengagement from formal political processes, as well as public non-engagement in alternatives to formal processes like QCA. From her perspective as an organizer of Alliance stakeholders, Parvati reflected on people she interacts with in her paid work in the not-for-profit sector. She noticed that clients she encountered are frequently disconnected from formal political processes and events.

> I just ask are you going to vote, it's a big thing happening. [...] But many of my clients say to me, "Vote? What? Today's election day?". People are just not in the know-how. But when it came to their *own* issue of them being old one day, them having to lose their home that they really worked hard for cause they're no one to come to their home to look after them...? [Parvati]

She theorized that feeling an immediate threat and having a personal stake in an issue is part of what compels people to learn about it, to transform themselves from "not in the know-how" to Knowers. But a lack of public understanding around issues of political concern is not the only

trouble Parvati sees. Also present is a deep disconnect that 'everyday' people feel between

themselves and political processes.

> And politics to some people feel so far away. Oh, whatever, whoever's in
> government. Whatever. But they realized that politics is what's making the
> situation unbearable almost to some seniors. [Parvati]

She reflects on an attitude of ambivalence toward political processes or systems (or,

"politics"), which is what I suspect we see manifested in statistics of low participation in

elections at many levels of government. Indifference, Parvati says, comes from politics feeling

"far away", and from the public finding little connection between their immediate reality, and the

larger systems and institutions 'out there'.

But for those individuals heavily invested in formal political processes, QCA's

'alternative' ways of engaging politically are not necessarily credited as legitimate. In QCA's

early stages, the Alliance was initially unendorsed by larger institutions and unsupported by

political groups; some individuals outside the group viewed it as "radical".

> The barrier sometimes it was politics. And when I say that it's because just, this is
> kind of like an advocacy group. And people who were involved in the [local riding
> associations] they kind of thought I was radical. [...] They thought that doing this
> change and asking the government to do something, they felt we should be status
> quo. Is the government is doing something? Just leave it, just trust in them. It
> wasn't until we got the [PSW] registry and the government was on board that some
> party members said okay, wow. And then they would come to the [registry launch]
> party. But they wouldn't come to advocacy sessions before that, or meetings we
> have with the government. [Parvati]

Parvati points to a divide between those who were content with the existing conditions of

home care at the time of QCA's work, and those who were involved in this kind of advocacy. The

supporters of the status quo, in this case members of a local riding association affiliated with a

provincial political party, did not support QCA until it had received support around the creation

of a PSW registry from elected members of the provincial political party in power at the time.

There are common features between the outcomes of disconnect experienced by "not in

the know-how" and the outcomes of politically engaged individuals who choose to remain

unconnected with "radical" advocacy (Parvati). The result of disengagement and non-

engagement appears to be an undisturbed status quo. While listening to her stories on this topic, I

sensed the participant's frustration with being seen as "radical". I wondered whether her

dissatisfaction was perhaps connected with her earlier stated intention to "make sure everything

[was] done professionally" throughout the process of advocacy work with QCA, which she

placed in contrast with other groups that attempt to bring about change by "rallying", or

protesting [Parvati]. Despite employing organizing tactics familiar and comfortable for

individuals involved in formal political processes (i.e.: meeting with officials, collaborating with

riding associations, petitioning), QCA was initially viewed as radical.

Theorizing About Solo Struggles as Shared

Using my position as Outsider to the experience of being involved in QCA, I am able to

build Yvonne's theorizing onto Parvati's to find a third theme that intermingles with the second.

It is not only the immediate threat and a personal stake in home care issues that caused people to

engage in QCA's work, as Parvati suggested, but also the arrival of a new way to engage - the

emergence of the group itself. For those who did not see its work as radical, QCA became a

forum for uncovering shared experiences like those resulting from reduced access to home care

services, and discontinuity of care. It is important to note that there were likely many other kinds

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of experiences shared, like the differing stories of PSWs, but the perspectives of these particular participants guide me to focus on the viewpoints of family members of service users.

> Advocacy is always important because dealing with those little issues, in the wider public... (pause) We all have our issues, we don't have a forum. And a forum can only be there if there is one group leading to constructive discussion. I was surprised how many people came to the Quality Care forum. So that's when you really need the advocacy to bring all these issues in the open. To kind of clean the air and say look, here you are [home care] providers, here they are supervisors, here they are recipients. [...] And you'd be surprised, [PSWs] are also complaining. So it's not just recipients. [...] It's needed. Some guiding light, someone there saying... You know from time to time maybe you get depressed because otherwise this is all hidden. [Yvonne]

Yvonne highlights the need for one group to lead a collective and constructive discussion between diverse stakeholders about their interconnected issues. She suggests that QCA meetings provided an opportunity for the air to be cleared between diverse groups, alluding to tensions between workers, their supervisors, service users and family members. This connects with stories she told earlier in the interview about conflicts she had with PSWs and case managers around the quality of frequency of services her parents receive.

In the above quotation, she indicates surprise resulting from two things she noticed from QCA's community forums: the number of people present at community forums, and the fact that PSWs also had complaints about the home care system. Firstly, her surprise at the number of people who attended the community events struck *me* as surprising. As an outsider who has familiarity with the widespread nature of home care issues in Canada due to access to academic research, I naively assumed that individuals living these issues day-to-day would recognize that others also struggled too. This is both a reminder of the difference between a lived understanding of the phenomenon and my own, and of the privilege that comes with access to academic literature.

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Secondly, Yvonne's surprise at the dissatisfaction of PSWs, as evidenced by their complaints in the forum, seems to suggest that the events were an opportunity for family members of service users to not only fit themselves in as part of a larger pool experiences of others, but a chance for them to find similarity between their struggles and those of other groups, like PSWs. This seems especially important, given the stories she shared about her concerns with the home support system, which often focused on her experiences with individual workers.

Yvonne spent considerable time on her own, previous to her work with QCA, advocating for her parents and for improvements in their care. Throughout the interview she described the many times she relayed her "constructive concerns" to care providers. Here she explains the aftermath of an incident at a healthcare facility involving one of her parents:

> So all of this, it unfortunately can only be broke if there is other advocates involved. Because I went through lots of - They made me, because of the mishap, they made me do big formal report, and we sat and we chat how they can improve and blah blah blah. But it was all internal. I don't even know if it has seen anything past the little ward. [Yvonne]

Despite being given the opportunity to make her concerns known, she expressed doubt that any change would happen as a result of her contributions, or have effect beyond the immediate area of the incident. Although this incident was not specifically related to home care, I interpret it as influencing her belief in the importance of banding together with others to make change.

Yvonne also reflected what I suspect is a common experience for those advocating (individually) from a service user or family perspective: a feeling of isolation.

> Yvonne: You know from time to time maybe you get depressed because otherwise this is all hidden. No one else likes to hear that your father or mother stays in the diapers for two days at a time.
> Amy: Yeah, you're right. There's something about it that isn't easy to talk about, but that is very important.
> Yvonne: Sure. It's not comfortable. We don't like to bring this, but it exists.

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For me this exchange and the preceding quotation are a reminder that struggles are frequently individualized within the neoliberal context. The significance of finding ways to share individual experiences and connect them to 'big picture' patterns is brought to light. Within a culture that insists on self-sufficiency, there may be few outlets for collective engagement or resistance. I see evidence in this exchange that issues affecting older people (and by extension, those who support them) may be further individualized as their bodily, emotional struggles are not viewed as appropriate or palatable for public discussion.

Perhaps, as Parvati and Yvonne suggest, it is the experience of having distant politics suddenly become 'closer to home', and personal struggles recognized as shared ones, that generated community members' interest in QCA. And it is likely for these reasons that Yvonne described meetings as "very uplifting. Because we all had the same goal. We all wanted something to change". To her, sharing a previously hidden experience and finding a group of individuals and organizations interested in making change was important.

Connections and Relationships Across...

In the previous two themes, we see how personal reasons for involvement tied into collective experiences, as distant "politics" became more immediate. This helped to unify the group and move it toward successes like the launch of the PSW registry. It also appears that another key to the QCA's success was the ability of organizers and community members to connect with others of varied social locations.

...Communities.

QCA connected stakeholders who were diverse in relation to their roles as workers, services users and family members. Participants reported too that home care issues crossed

cultural, ethnic and religious groups, and attendance at events reflected this. Ahmed, in his role

as a researcher, attended various regional events, and was able to reflect on what he saw as the

universal impact of the issues the group attempted to address.

> For the purposes of Quality Care Alliance I don't think there was... It kind of
> crossed the line of any ethnic or cultural background. Like for example the same
> issues raised in Brampton which is a very ethnic community, were the same issues
> that were raised in Sudbury which is a more caucasian community. So the issues
> are pretty much the same for the Quality Care Alliance. [Ahmed]

Parvati notes the interconnected meaning imbued in access to home care across cultures,

while underlining home care's particular significance to people in immigrant communities.

> But for me like I come from immigrant parents. Although I was born here. For
> parents who came from - like there are not even houses back in my family's area.
> [...] So to them, to come to Canada all they want is their house, right? And now for
> this immigrant population to be told that they may have to go to a nursing home
> and lose their - What they worked so hard for. [...] So that's a thing. And it was
> touching people. Like one key QCA member is Polish. Um, one key member is
> Pakistani. Another is Canadian. Another is Somalian. Once again a war-torn
> region where a house is so big to us. [Parvati]

While living at home for as long as possible is important to most seniors, regardless of cultural,

ethnic or racial identification, I interpret in Parvati's words the particular significance that

keeping one's home has for immigrant seniors. This speaks to the importance of connecting with

immigrant communities and diverse cultural and ethnic communities in this work.

Ahmed repeatedly noted the skills of one QCA organizer, with regard to her ability to

connect with and involve a wide variety of cultural and religious communities. On many

occasions during the interview, he attributed the success of the group coming together to this

person's ability to establish relationships with diverse groups.

> She makes these connections with individuals as she goes. She reached out to
> different ethnic groups. So for example in one city there is like community group
> that cares for Sikh seniors, there is a group that cares for Hindu-speaking seniors,

or like for family support groups. So she somehow manages to connect with these churches, mosques, temples. [...] Somehow she connects with each of them. Whether she belongs or doesn't belong with these groups. [Ahmed]

From his perspective, this ability to form relationships was central to "getting a buy-in from different stakeholders", and ultimately to earn support behind the Alliance's list of priorities for action.

...Generations.

I think it is significant to a discussion about intergenerational connections that older adults were sometimes constructed in the narratives as "poor seniors" who require someone to advocate for them (Yvonne). Conversely, older adults were also described as vocal and passionate; part of a larger group of community participants who were capable of offering a brand of honesty not available other (professional) stakeholders.

Lots of seniors and their workers spoke with a passionate voice. And same thing for their family members of the clients. They spoke with passionate voice. They added, you know, human element to the issues that were at hand. [...] Everybody speaks you know measured words 'cause they're representatives of their own organizations. But the clients they speak their mind, same thing with the workers. [Ahmed]

Meaningful connections were formed across age groups, with respect to the outreach work done by key QCA organizers.While Parvati elaborated on some of the ways she connected the Alliance with older stakeholders, she seemed delighted by the social element that was key to connecting with this group.

Some nights we would meet at like the apartment building of where a lot of seniors live. So it's easier for them because of mobility issues. Some seniors are like ninety-five years old and high heels and lipstick, and glamourous and they will come with me wherever. But some of them did have serious issues, so you know. So it was their social night, and so sometimes it was just before the social night we'd get together for a meeting. They're going to come out anyway. [Parvati]

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By accommodating their particular needs, she demonstrated that their voices counted. She also transformed the 'work' of advocacy and outreach to something more accessible by incorporating it into existing social activities. I appreciate that advocacy work and community organizing can be about more than "serious meetings" (Parvati).

She also alluded to a level of trust that can come from building social relationships, as exemplified in the exchange below.

> Parvati: I would be invited, they'd say - I'd say I need a petition signed, where do you think it can go? By now we're friends so: why don't you come to my bingo group, there's like twenty seniors there. And usually they're very protective of their bingo groups.
> Amy: I didn't know that.
> Parvati: [laughter] Yeah, they are. It's their thing that they do. It's their outing. And so to be invited it was a very big thing. I didn't realize how but until I was invited and I went and I was like woah. [laughs] This is serious business. And the sewing group, it's membership-based and they'd bring their own food, they all know each other for decades. And here's this girl coming in, walking in. And they were really good to me.

Parvati recognized the meaning in being invited to long-standing gatherings; it was, in her words, "a big thing". I think this speaks to the quality of relationships she had built with groups of seniors to that point. After all, she referred to them as her friends, not as 'stakeholders' or some other formal title. Her stories about this group were always told with a smile in her voice.

Parvati alluded to a challenge that comes with forming strong relationships with stakeholders, which is perhaps of particular significance when working with older adults.

> The unfortunate part of this whole thing, and this is what was really hard for me, was that just say a couple months go by 'cause we all get busy in our lives, and another thing comes up and so you call. Like I call, hey did you hear about this? And one of the QCA members passed away. Cause they're older. And that to me was real life. She was a huge advocate for this group, and in her area. And now there's a void. [Parvati]

Forming relationships required emotional investment on the part of the organizer. This narrative illustrates the personal impact or toll emotional investment can take.

Group Processes

Connecting across cultural, religious or ethno-racial communities, as well as across intergenerational lines, appeared to be facilitated by time spent forming relationships, and in some cases, friendships. QCA meetings were facilitated in ways that helped to maintain these connections, by emphasizing process as important.

Yvonne indicated that in meetings that the stakeholders "all had the same goal". In her eyes, establishing their five priorities initially involved sharing and hearing people's experiences. Each little "morsel of information" shared, contributed toward establishing the larger five goals of the Alliance.

> So each meeting we kind of talk like right now we're talking, like oh this is so bad, this is so bad. How can we bring the change? Who we have to approach? I think the basic idea from the beginning was to organize people, get as much of their experience as possible. And then eventually have it recorded and delivered to the Minister in charge of seniors' healthcare. [...] At every meeting you felt that you didn't really waste your time. Maybe some little morsel of information was included that can go further. [Yvonne]

Conversely, Ahmed helped me understand some of the nuances involved in QCA's process of determining group direction and goals. Community events began with a panel of speakers, followed by open-floor discussion and a qualitative survey was distributed to determine what attendees thought were salient issues within home care.

> Ahmed: Yeah, I don't want to make it sound as it was 100% organic, the conversation during was guided by strong voices. Some of them are like health care professionals like a senior nurse or doctor or health policy expert. And the themes obviously would be influenced - The opinion or the feedback from the attendees was I have no doubt influenced by the guided conversation.
> Amy: Of those individuals?

> Ahmed: Yeah, so typically the community event would be a panel of three experts, sometimes it would be one client and one doctor and one nurse, or health policy expert. Sometimes it would be someone from seniors' advocacy group.

He points to the ways in which the Alliance's direction events were shaped by by input from professionals. However, I am heartened by the fact that service users were among the individuals invited to speak as part of panels, as this implies consideration for their experiences and expertise.

Also related to the idea of process, was a concern expressed by one participant around their perception that the group was moving toward "institutional" methods of working.

> But I remember, at one point I was thinking why are we having so many meetings? Like it was almost like we were institutionalizing ourselves. But then I realized it can't just be what I say. [laughs] And it has to be what people say. I know it sounds weird, but it's like they all have to feel that their voice is being heard and that's what was happening with those points. So some of them might not be something I'm advocating for, but it was a group, a collective decision. [Anonymous[1]]

This person's discomfort with becoming "institutionalized" was clear, although ultimately they saw that holding frequent meetings could be a tool to help achieve a balance of contributions from stakeholders. The meetings appeared to be key to collecting information required to accurately establish a diverse list of priorities.

In summary, group processes appeared to prioritize relationships that were built by considering lived experiences. However, there were some tensions between these ideas and "strong [professional] voices" and institutional processes (Ahmed).

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[1] I have chosen to keep quotations critical of QCA and its processes anonymous, to further assure participants' confidentiality.

Challenges...

The final theme in the narratives pooled around the particular challenges participants found in their work. These challenges are related to the kind of advocacy QCA engaged in: that which involved diverse stakeholders, operated primarily 'after hours', and did not ultimately have an 'institutionalized' structure.

... Related to Diversity of Needs.

Ahmed pointed to a challenge in maintaining relationships with a diverse set of stakeholders, related to discrepancies between demands for change expressed at community events, and the pace at which government works. These demands for change were based on very real and daily needs.

> Real change takes time and I think one of the challenges was that the community participants, especially seniors, family caregivers, they don't have the luxury of waiting years for care to come or improvements in the sector. Also PSWs they don't have that luxury, they're dealing with the day to day expenses. [...] So these are the issues that they live day to day, and for them to be told that you know we've reached out to the government and we're speaking to MPPs, that doesn't solve their day to day problems. [Ahmed]

Community participants' need for immediate change was left unsatiated when they encountered "the slowest moving objects on earth", government bodies (Ahmed). Despite this discrepancy in urgency between community participants and institutional stakeholders, Ahmed notes that the presence of the community was central to advancing the goals of the Alliance.

> I see that when we go to advocate as labour union, we don't get the ears of government fully open to listen to issues that we speak to even though we have, you know, we make sure everything that we speak about it evidence-based research. I have some academic background, so I know what's evidence-based research. But still unless you bring a spectrum of stakeholders. So, for example, community support groups, you bring some home care providers, you bring some of the clients themselves and if they all agree to the same thing, then you know,

that kind of raises a flag for the decision-makers that they should address this issue or this matter. [Ahmed]

This presents a paradox of multi-stakeholder advocacy. Ahmed suggests that the QCA was successful at gaining the attention of the government due to the fact that community members advocated loudly alongside large stakeholders like unions. Despite the necessity of their presence, community members were not likely to see gains that satisfy their immediate needs due to the size and pace of the institutions and systems at play.

... Related to 'After Hours' Advocacy.

Another challenge that surfaced was connected to the limitations of doing advocacy work "after hours and on weekends", the reality for many community participants (Parvati). One individual stretched themselves beyond this, stating "it was a lot of time off of work, but it was an important issue". Another touched on the familial impacts of the work.

> We're a community group we have to meet on our own time and that was hard with family. I would be on an 8 o'clock call when I'm trying to organize my family. So it would be nice if we had this as our job. So if it was 9 to 5, I have a secretary, and an office. [Anonymous]

Further, there is potential conflict with employers when after hours advocates choose to engage in causes that take a critical position on systems or institutions. One participant commented that they "have to be careful. This job doesn't allow me to be political. So this was all - it's volunteer" (Anonymous). Although I was not able to include the voices of PSWs in this research, one participant alluded to the particular risks that this group faced when speaking out about the issues they face in the workplace, as home care providers (employers) were sometimes present at QCA events.

There were also practical challenges in having community members take key roles in leadership and organizing, over and above their other responsibilities as mothers, fathers, daughters, and employees. It appeared difficult to sustain the momentum of the group over time. There were suggestions put forward by participants as to how this could be overcome.

> In order to keep the momentum going you would have to somehow... Keeping just interest wouldn't be enough. You have to sort of recognize people as something. Maybe give them some stipend, maybe like a board member or anything... you know. [Anonymous].

It is unclear to me whether this suggestion highlights the importance of financial compensation or recognition of work accomplished, or perhaps both.

... Related to organizational structure.

The final sub-theme relates to particular struggles around the organizational structure of QCA. Some felt that it did not develop into the formal organization it needed to become in order to remain sustainable.

> Some of the challenges were the lack of formal organization. It started as a grassroot, and we stayed as a grassroot. But in any grassroot, the model... The moment comes that you have to formalize your linkages. [Anonymous]

And, also this:

> So we learned a lesson obviously from that, as an organization that you have to make institutional- You kind of have to institutionalize the loose alliance so that it doesn't fall down by the departure of one person. [Anonymous]

The issue was framed as a conflict between a 'grassroots' style and an 'institutional' style of organization, previously touched on in the third theme, *Group Processes*. While some group members were wary of an institutional style of organization, with its frequent meetings and defined roles, others saw how this could help sustain the Alliance's efforts.

Others reasoned that a grassroots approach was necessary in the initial stages of QCA's work, as those involved could not have anticipated their future success in attracting the attention of stakeholders and establishing far-reaching connections between cities.

> I had no idea how quickly this would explode into an organization - it's not an organization, but like people would be calling and asking what they can do. And we didn't have the structure to tell them what they could do in that moment. We don't have a secretary where we could go back to. It was whatever was at top of my head. Do you want to come to our meeting, do you want to come to our Town Hall? And the reason was because we didn't think it was going to get big so fast. (pause) It was great. Yeah it was really great. And the reason it got big so fast, I believe, and this is big lesson for me, is because I stepped back and let them lead the conversation. And they took it back to their communities. [Anonymous]

Here we see that the grassroots nature of the Alliance potentially stopped the group from being more organized, but it allowed community members to feel that their contributions were heard. There are definite tensions between participants' opinions of the QCA's structure, which relate to group sustainability and commitment to community.

Findings around the issue of organizational process and structure seem to be linked with the paradigms underpinning the work. Some participants felt strongly that a grassroots model was most suitable, and appeared to distance themselves from more structured methods. Other felt that a more institutionalized structure would be best to help maintain momentum. Where an institutional approach was favoured, its preference appeared to be tied both with a desire to establish legitimacy, and with the efficiency that can emerge from clearly delegated roles and cohesive planning between cities. These latter reasons for implementing a formalized structure are important, especially considering that, in this context, advocacy work was done outside of community stakeholders' employment, many of whom had have demands on their time, energy and resources connected with their reasons for involvement in the first place.

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Summary of Findings

In summary, all participants tied their decision to become involved in QCA, and in advocacy work more generally, to some element of past experiences, thoughts about the future, and a sense of reciprocity. Participants also theorized around larger issues of public (dis/non)engagement from/in formal political processes. One participant posited that some community stakeholders chose to engage in QCA as they felt threatened, and because previously distant politics had suddenly become close. Another participant noticed that other individuals initially chose not to be involved as they viewed this brand of engagement as "radical". One participant theorized around the importance of speaking and hearing shared experiences, and the value of working collectively to bring about change. Two participants discussed the ability of the group to bridge cultural, religious and ethno-racial communities, and one participant discussed connecting and forming friendships with stakeholders from older generations. Several participants discussed the group's process, with regard to its inclusivity, its leadership by strong voices, and their own struggle to accept chosen processes. Challenges were discussed by all participants, in relation to the diversity of stakeholder needs, advocacy done outside of other commitments, and tensions between the ideologies that underpin a choice of organizational structure.

CHAPTER 6. DISCUSSION

As indicated in the title of this research, I conceptualize QCA's alternative ways of engaging individuals and groups as a form of resistance to larger systems and their underpinning ideologies. It is important to note that I hesitate to limit resistance as only 'counting' when it is accomplished through collective action. As touched on in the findings, there are legitimate reasons that stand behind why some people choose to disengage from formal political processes. Choosing not to vote, for example, is an legitimate reaction to concerns around representation, its limited diversity and lack of public access to political positions and power. Given this, we can and should conceptualize more broadly *what* typically counts as resistance (Thomas & Davies, 2005).

We should also open up to imagining new perspectives on *when* resistance counts (Thomas & Davies, 2005). The literature around home care in Ontario has recognized workers' and service users' creative, 'everyday' micro-processes of resistance to issues they encounter, such as reduction in service hours available to clients, as well as reduced meaning derived from the work and job instability of workers (Aronson, 2002; Aronson & Neysmith, 2006). These problems in home care, initially written about in the literature over a decade ago, persisted into the time of QCA's operation. As uncovered in the findings, some of these issues and small-scale resistance to them, propelled some research participants to become involved in QCA. We see that everyday efforts to resist should not be discounted.

However, in light of the overwhelming nature and size of home care and health care systems, collective resistance, in this case, was necessary. In their investigation of experiences of displaced home care workers affected by impacts of managed competition, Aronson and

Neysmith (2006) point to labour unions as possible sites of resistance for workers. They suggest that work is required to bridge a gap between "institutional inertia" within the union and a potential for change voiced in their research. They asserted that it is important for space to be provided for workers to gather and identify collectively (Aronson & Neysmith 2006, p. 24).

It seems that QCA and its affiliated organizations felt similarly to Aronson and Neysmith (2006), who counseled that conventional union initiatives need to be broadened to further worker self-interest and client welfare (p. 42). In looking at the Alliance's processes, which involved sharing and recognizing personal narratives and building upon these experiences to set the agenda and group goals, the study shows that micro-emotional processes were connected to macro institutional, systemic and political processes (Summers-Effler, 2002)[2]. The considerable skill of QCA organizers also contributed toward the Alliance's success in recruiting diverse stakeholders, as they had the ability to form and maintain meaningful relationships.

I was never able to fully uncover the precise story of QCA's beginnings during the three interviews, likely due to the fact that I spoke with only a small number of participants, and as four years have passed since the group initiated its work. Regardless, support of the Alliance by labour unions was made clear by two participants. I think QCA, which includes the particular efforts of one union, was successful in bringing together "everybody who never sits together to the same table", even if it its cohesion as a group was not sustainable in the long-term. In terms of concrete outcomes, the group managed to garner the attention of various provincial-level politicians to establish a PSW registry, which is no small feat. QCA also "laid the groundwork and provided the kind of legitimacy for [the five priorities] by having diverse stakeholders from

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[2] The narrative analytical framework employed, which examined stories for (intra/inter)personal experiences, and for cultural and structural elements of stories, helped uncover links between micro and macro levels (Fraser, 2004).

all spectrum of care involved" and solidified "the ground for the rest of the advocacy that [one labour union] has taken since then" (Ahmed).

I am quite uncertain of how I feel about the above quotations, considering the finding that QCA's community participants, like service users, their family members and PSWs, may not have benefitted directly or immediately from changes made, beyond the creation of the PSWs registry, in the years after the group dissolved. It is clear from the findings that larger organizations involved in advocacy needed the support of the community members, and vice versa, in order to be heard by those with political power. It is also clear that some community members benefited from the "uplifting", collective experience of sharing their stories (Yvonne). But still, there is something about the agenda underpinning large organizations' decisions to work with community members that I find disconcerting, perhaps unfairly so.

Separately, I am curious about the findings that explore the perception of QCA's work as "radical", as one participant recounted. From my perspective, this label connects to shifting discourses around citizenship that have changed over past decades. Brodie (1996) describes the contemporary dominance of neoliberal values in Canada as part of a departure from a rights-based citizenship discourse, toward one which emphasizes instead the privileges and duties of citizenship. Making demands to alter the status quo of the public home care system, which was (and continues to be) largely unfair to those providing and receiving services, is an action constructed as "radical" rather than as an assertion of the entitlements of citizenship. When resistance and demands for change are framed as radical, adequate home and health care services and fair working conditions and wages become privileges rather than rights.

Within this context, I think it is important to broaden the concept of participation in political processes as one which moves beyond our infrequent opportunities to vote and beyond 'legitimate' involvement in political parties and riding associations. This meshes with the perspectives of academics who assert that participation should be reconsidered to include a new concept: protagonism (Jupp Kina, 2012). Protagonism connects participation and citizenship, and helps us "shift away from the current focus on political participation and participation in pre-defined ways... and embraces the idea of non-participation... to ensure against the danger of participation becoming a mechanism for reinforcing rather than challenging the status quo" (Jupp Kina, 2012, p. 334; Webhi, 2013). QCA offered opportunities for individuals to frame their personal experiences as part of larger trends, and act on this realization by engaging in new methods of participation/protagonism.

Implications for Social Work and AOP Practice

The findings, uncovered through discussion with participants about the about enabling factors, success, challenges and barriers of multi-stakeholder advocacy efforts, have particular importance for social work, and for resistor and AOP social workers in particular. Social work as a profession has undoubtedly been influenced by the same neoliberal processes impacting the home care system in Ontario. A rise in preference for evidence-based practice, while not without merit, forces social workers to employ a mechanistic and technical rationality in their work, not necessarily a style suited to working with diverse people and groups (Webb, 2001). As Ahmed mused, when discussing how the stakeholders prioritized certain goals:

> It's unclear to me, coming from science background. It's not the same as an equation of physics, you can't get the exact results every time you replicate the experiment. You'll get different results every time if you do something like that

involves humans and what they prioritize, what they envision as more important. [Ahmed]

And yet, in the practice of social work in many settings, quality of service is now equated with standardization and documentation, evidence-based practice is rewarded, and efficiency is frequently taken up as a 'yardstick' over effectiveness (Tsui & Cheung, 2004). Social workers, even those who do not identify as employing an AOP or critical lens, surely feel the limits of such priorities in their practice.

Dominelli (1999) suggests that in order to prevent the angst which accompanies individuals facing globalization and its processes, resistor social workers can form local partnerships with other groups like service users, trade unions and groups pursuing local social movements, to begin collective change at local levels. For social workers who wish to intentionally resist neoliberal practices and policies, it is useful to learn about the work of organizing diverse groups, which includes knowing what factors encourage or inhibit success (Dominelli, 1999, p. 21).

For AOP social workers, work with marginalized communities could include supporting alternative ways to engage politically and socially. Organizing alternative projects with an AOP lens should include practices uncovered in these findings like valuing relationships, sharing struggles, connecting with unlike others, and emphasizing the value of process. Considering the theoretical frameworks in place for this research, elements of QCA's particular approach to multi-stakeholder work could be called 'decolonizing advocacy', as the strategies uncovered in the findings mirror some decolonizing research methodologies (Chilisa, 2012; Reyes Cruz, 2008).

Future Research

Given the dearth of research that reflects stories of resistance within the context of home care, and specifically research processes that are inclusive of service users and workers, there is room for deeper inquiry in this area. Further research could contribute to literature that addresses AOP and decolonizing approaches to advocacy and community organizing, and could attempt to overcome some of this project's limitations by expanding the scope of study to include a larger number of participants, specifically the voices of service users and home support workers. Additionally, limitations around design could be met by employing collaborative and participatory research methodologies, that are inclusive of diverse community stakeholders. Researchers continuing this line of inquiry could also incorporate postcolonial and critical theoretical frameworks in deeper ways than what has been possible here.

Given the distinctiveness of QCA's engagement with community around issues of home care, more research with the Alliance as a focus would be helpful. However, as memories fade over time and as participants become increasingly difficult to reach or pass away, there are significant challenges to undertaking further research on this particular group.

Limitations

There are several limitations present in the research. As I was unable to recruit individuals who identify as current service users or home care workers, there is a considerable gap in perspective offered within the narratives. The use of English in recruitment materials, the requirement of comfort with English in interviews, and the chosen electronic recruitment methods likely restricted the range of participants who were able to respond or participate. The length of time available for data analysis was brief due to difficulties with recruitment and

scheduling interviews, and this is reflected in the depth of data analysis. And finally, there are

limitations inherent in narrative approaches due to a lack of collaboration with participants

around the analysis of their narratives. Although I have attempted to address this limitation in my

design, it is still important to note that my interpretation may unintentionally misconstrue

participants' words, or I may draw political implications from the meaning of stories that are

different than what the narrators may have intended (Fraser, 2004, p. 194).

CHAPTER 7. CONCLUSION

By looking deeply at the narratives of individuals involved with the efforts of a multi-stakeholder advocacy group, details were uncovered about the particular challenges, barriers and successes possible in this kind of work within the context of neoliberalism. What could have entailed dry discussion about the how-to's of organizing, instead revealed deeply personal narratives about reasons for involvement, uncovered stories that described creating, sustaining and losing relationships, and illuminated the impacts of challenges like diverse stakeholder needs and doing advocacy 'after hours', among other findings.

Attempts were made to 'dirty' and decolonize narrative inquiry. Although these endeavours were not always successful and sometimes felt clumsy, I was nonetheless provided with a rich learning experience in the attempt. I learned a lesson about how I can tweak a limiting framework in small but significant ways to better operationalize my own set of critical and AOP values.

Personally, I found deep discussions around the topics addressed in interviews inspiring. In-depth conversations with a range of participants involved in the work of QCA somehow made advocacy work with groups and communities appear more accessible, slightly less intimidating and *possible*. I can see, through the experience of doing research, how narratives of resistance can inspire similar acts. This reiterates the need for more research that explores stories of strength, change, and solidarity across communities within a home care context.

Were you or are you involved with Quality Care Alliance?

Would you like to speak about your experiences?

I would love to hear from you!

Good morning _____,

My name is Amy Connolly, and I am a social work graduate student at Ryerson University.

You are invited to participate in a small study about the experiences of people involved in the advocacy work of Quality Care Alliance (QCA). I am interested in exploring the successes and challenges of advocacy groups that bring together different groups of people, like service users, workers, and community members, by looking at the work of QCA. I hope this research will contribute to knowledge about advocacy work with diverse groups of people.

I am looking to speak with individuals who identify in one of the following ways:
- as a member of one of the QCA committees
- as involved former or current staff of a QCA-affiliated organization
- as a QCA-involved community member, home care worker or service user

I welcome the participation of women, people of colour, those living on low income, immigrants, people with disabilities and other equity-seeking groups.

Participation involves a 30 to 90 minute audio-recorded interview, done in person, by phone or over Skype. Participation is completely voluntary and choosing not to participate will not affect any relationship you may have with Ryerson University, or with QCA and its organizers/affiliated organizations. Participation will be determined on a first-come, first-served basis. **A $20.00 compensation will be given to all participants, in appreciation of their time.**

I received your email address from ▓▓▓▓▓▓▓▓▓▓, who has connected me with QCA-involved people only for the purposes of this study. This research is not an evaluation of the QCA, and is not affiliated with QCA in any way. Your choice to participate (or not) will be kept confidential, if you so choose.

I invite you to forward this email and attached flyer to others who may be interested. I look forward to hearing from you.

Thank you!

Amy Connolly

RYERSON
UNIVERSITY

Were you or are you involved in Quality Care Alliance?

Would you like to speak about your experiences?

I would love to hear from you!

You are invited you to participate in graduate level research about the experiences of people involved in Quality Care Alliance (QCA). The focus of this study is explore the successes and challenges of advocacy groups that bring together different groups of people, such as service users, workers, community groups and family members, by looking at the work of QCA.

What does participation involve?

· You are invited to participate in a **one-on-one interview**, 30 to 90 minutes long.
· An interview can be done by phone, in person or over Skype.
· Participation can be **confidential**.
· A **$20.00 compensation** will be given to all participants of this study, in appreciation of their time.

How do I participate?

· Participants **must identify as <u>one</u> of the following**:
  · member of one of the QCA committees
  · involved former or current staff of a QCA-affiliated organization
  · QCA-involved community member, home care worker or service user

Participation will be decided on a **first-come, first-served** basis. This is an exploratory study. It is not affiliated with QCA, nor is it an evaluation of the efforts of this group. Participation in this study is completely voluntary and choosing NOT to participate will not affect any relationship you may have with Ryerson University, or with QCA and its organizers/affiliated organizations.

To learn more, please contact amy.e.connolly@ryerson.ca.
This study has been reviewed by the Ryerson Research and Ethics Board.

RYERSON UNIVERSITY

Ryerson University
Consent Agreement

Stories and Strategies of Resistance: Multi-Stakeholder Advocacy Efforts in Publicly-Provided Home Support Services in Ontario

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigator: This research is being undertaken by Amy Connolly (BA, BSW, and MSW candidate), a social work graduate student at Ryerson University. The person supervising the research is Dr. Lisa Barnoff (PhD), Director of the School of Social Work at Ryerson University.

Purpose of the Study: This study is an exploration of the experiences of individuals involved in Quality Care Alliance (QCA), a multi-stakeholder advocacy group that advocates around issues affecting publicly-provided home support services in southern Ontario. The focus of this research is to explore the successes and challenges of advocacy groups that bring together different groups of people, such as service users, workers, community groups and family members, by looking at the work of QCA. This research will not attempt to evaluate the efforts of QCA, but instead seeks to look at group members' experiences as a way to explore larger ideas about what helps and hinders groups like this one, during a period of change and restructuring in home care services provided by the government.

Three to five participants will be recruited to discuss their experiences. In order to participate in this study, you must be over 18 years of age, and must have been involved in the QCA for a period no less than one month.

Description of the Study: You are being asked to participate in a one-on-one interview, which will be guided by the Investigator. In the interview you will be asked about the following topics: your reasons for becoming involved; your opinion on the successes, challenges and barriers met by the group; the ability of the group to find common ground; and other memorable experiences with the group.

Please initial here to indicate that you have read this page: _____

Description of the Study (continued): The interview can be completed by phone, Skype or in person in a location of the participants' choosing (in home, at work, or in a private location agreed upon by the participant and investigator). The interview will be audio-taped and will last between 30 and 90 minutes. A transcript of the interview will be provided to participants who wish to review and approve the details of their interview. Your participation can be made confidential - a false name of your choosing (pseudonym) can be used in transcripts and identifying details can be removed from direct quotations. Alternatively, if you do not wish to remain confidential you can waive this by signing a clause in the consent form.

Use of Data: The information which participants share in interviews will be used for two purposes. The first purpose is a supervised Major Research Paper submitted to Ryerson University in partial completion of a Master of Social Work degree. The second purpose will be a subsequent unsupervised manuscript intended for publication in a peer-reviewed journal. Both manuscripts will have the same focus.

Risks or Discomforts: You might feel some discomfort during the interview, due to the length or content of the questions. To address this potential risk of discomfort I will remind you that you only need to participate to the level that you feel comfortable, and that you may discontinue participation at any point, either temporarily or permanently, without consequence. You may also take breaks at any time throughout the interview. I will provide a list of referrals of community resources to all participants. There is also a minimal economic risk associated with participation in this study, for those participants employed by organizations that may not approve of their participation in advocacy around issues within home support services. I will mitigate this risk through confidentiality, anonymity and privacy in regard to the handling of audio recordings, transcripts and other data associated with this research. The level of confidentiality in the final manuscripts will be directed by your comfort level, as indicated on this consent form.

Benefits of the Study: The potential benefits of this study include a better understanding about the multi-stakeholder efforts of QCA and its work in home support advocacy. It is possible that this research could contribute to an understanding about the dynamics of multi-stakeholder advocacy groups that involve service users and workers. I cannot guarantee that you will receive any benefits from participating in this study. However, it may be rewarding or empowering for you to review and assess your previous involvement with QCA and have your experiences heard.

Please initial here to indicate that you have read this page: _____

Confidentiality: Only the student investigator and her supervisor will have access to the data collected. The data from interviews will be audio recorded and transcribed. The audio recordings will be transcribed into written words, which will then be used as data along with field notes taken during the interviews. You are entitled to confidentiality to the extent allowed by law. No identifying information will be included in the transcripts, unless you choose otherwise. A professional transcriber may be used and this individual will sign a confidentiality agreement. All data will be kept confidential on two duplicate, password-protected and encrypted USB keys; each audio file and transcript will be saved in separate password protected folders. These two USB keys, as well as any printed transcripts, will be stored in a locked filing cabinet in the researcher's office. All identifying information will be removed from transcripts and false names (pseudonyms) will be used to ensure confidentiality, unless otherwise indicated on the last page of the consent form. However, the name of the advocacy group, Quality Care Alliance, will be used in documents written about the study. The written and audio data will be kept until August 2019, after which point it will be destroyed and erased.

Incentives to Participate: All participants will receive $20.00 in cash as an incentive for participation. If the interview is completed in person, the incentive will be provided before informed consent is obtained so you do not feel obligated to continue with the interview in order to receive the incentive. If you choose to be interviewed by phone or Skype, a certified cheque will be mailed to an address of your choosing. It will be sent to you after the interview, but it will be sent regardless of whether you complete the interview.

Costs and/or Compensation for Participation: Transportation costs or costs associated with phone or Skype services will not be refunded. There will be no other costs incurred by you.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University, or current relationships with QCA, its organizers or its affiliated organizations. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.   At any point in the study, you may refuse to answer any particular question or stop participation altogether.

Future Contact: If you consent be to contacted for the purpose of sharing the study findings, you will be contacted when the study is complete via email or phone, as you prefer. If you consent to having the incentive mailed to you, you will be required to provide the investigator with an address of your choosing.

Please initial here to indicate that you have read this page: _____

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact:

Principal Investigator/Study Coordinator:
Amy Connolly
amy.e.connolly@ryerson.ca

Study Supervisor:
Lisa Barnoff
(416) 979-5000 (ext. 6243)
lbarnoff@ryerson.ca

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

> Research Ethics Board
> c/o Office of the Vice President, Research and Innovation
> Ryerson University
> 350 Victoria Street
> Toronto, ON M5B 2K3
> 416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

_____
Name of Participant (please print)

_____   _____
Signature of Participant   Date

_____   _____
Signature of Investigator   Date

Please indicate with a signature below if you give your consent to have this interview audio-recorded:

_____

Name of Participant (please print)

_____ _____

Signature of Participant   Date

_____ _____

Signature of Investigator   Date

Please indicate with your signature below if you give your consent to be contacted regarding the study results:

_____

Name of Participant (please print)

_____ _____

Signature of Participant   Date

_____ _____

Signature of Investigator   Date

Please indicate with your signature below if you give your consent to be mailed a certified cheque as an incentive for your participation in this research:

_____
Name of Participant (please print)

_____ _____
Signature of Participant   Date

_____ _____
Signature of Investigator   Date

Please indicate with your signature below if you give your consent to have your name used in the documents produced from your interview and attached to the quotes you provide.

_____
Name of Participant (please print)

_____ _____
Signature of Participant   Date

_____ _____
Signature of Investigator   Date

Please indicate with your signature below if you give your consent to participate in an interview using Skype, and understand the potential for reduced confidentiality due to the privacy policy of this service.

_____
Name of Participant (please print)

_____ _____
Signature of Participant   Date

_____ _____
Signature of Investigator   Date

Interview Guide
Interviewer: Amy Connolly

Thank you for your interest in participating in this research project!
The interview will be loosely structured around the questions below. I am interested in hearing about other related issues or experiences that are important that may not be addressed by these questions. You not need to respond to any questions you do not feel comfortable with.

1. Background:
a) Can you recall and describe a life-event or experience that influenced your decision to become involved with Quality Care Alliance (QCA)?
b) From your experience, can you describe any recent changes to home support services provided in Ontario?
c) What has been the impact of these changes?
d) When did these changes begin to affect you or people you know?
e) What do you see as "big picture" events or issues that created the need for this kind of advocacy?

2. Successes, challenges and barriers:
a) Thinking back to QCA meetings you attended, can you describe an experience of success by the group?
b) What do you think helped achieve this success?
        - What from within the group helped?
        - What from outside the group helped?
c) Can you describe an experience of being challenged, or hitting a "road block", as a group?
d) What do you think caused challenges or "road blocks"?
        - What from within the group was challenging?
        - What from outside the group was challenging?

3. Finding common ground:
a) Can you recall and describe a time when different involved groups (i.e.: workers, service users, family members, community groups) were able to find common ground at QCA meetings?
b) Can you recall and describe a time when it was hard for different groups to find common ground?

4. Experiences of Home Support Workers and Service Users:
a) What is your perspective on the experience of home support service users and/or home support workers' involved in QCA meetings?

b) In what ways did having service users and/or workers at meetings influence the direction of actions taken by QCA?

c) In what ways were service users and/or workers able to participate meaningfully in the meetings?

5. What else?:

a) What advice would you offer to other advocacy alliances like QCA that include many groups of people (i.e.: workers, service users, family members, community groups)?

b) What else do you think is important that we have not discussed yet?

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