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Caring from the Margins:

Community HIV/AIDS Care Work as Social Reproduction in the Era of HIV/AIDS

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signed by candidate

30 May 2012

CANDIDATE'S SIGNATURE

DATE

Abstract

I come to my research interest through experiences as an activist, holding firm to the belief that community HIV/AIDS care work is profoundly deprivational for the women who do it. With a commitment to feminist research, I was interested in exploring what care work meant for gender equality and commensurate development consequences.

Employing the theoretical framework of feminist development economics, I adopted a qualitative methodology to explore my interests in women community HIV/AIDS care workers' experiences. Feminist epistemology holds that all in the study terrain have epistemic agency, and as such I was interested in making meaning of care workers' own representations of their experiences, and what their representations could mean for theorising about care work as a new form of social reproduction, situated in the specific space of the HIV/AIDS epidemic in South Africa. In addition, I was interested in what carers' representations could mean for understanding systems and structures that perpetuate and reproduce gender inequality, and locating this within a discussion of development politics.

I conducted eleven in-depth, dialogic interviews with women community HIV/AIDS care workers located in Nyanga and Tafelsig. Informed by Nussbaum's work (2010), I incorporated the capabilities approach into a feminist content and thematic analysis of the interview material. Nussbaum's capabilities approach to development has had significant influence on feminist thinking: specifically, her approach provides a strategy to distil how the impacts of poverty, combined with gender inequality, leads to an 'acute failure' of women's central human capabilities (Nussbaum, 2010).

From the position as a feminist activist embedded in the world of community HIV/AIDS care worker policy contestation, I was not surprised that carers' representations confirmed the deprivational and often debilitating nature of care work. I did, however, find

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the fact that community HIV/AIDS care work could *create* capabilities significant.

The capabilities approach, applied in the over-arching framework of feminist analyses could distil carers as 'agentic individuals' (Cavalieri, 2011). The discursive nuance of this approach, however, is significant for development considerations: it shows that agency within the context of community-based HIV/AIDS care work, as outlined in this dissertation, is 'adaptive' rather than substantive capability formation (Austen and Leonard, 2008). The capabilities approach is thus able to differentiate between agency which contributes to the quality of life women are able to achieve, and agency which 'de-forms' capabilities. As such, the benefit of this feminist approach is its ability to engage with women's dichotomised experiences; to identify moments of capability formation within deprivational contexts and avoid a narrow focus on victim *or* agent; to surface the nuance incumbent therein which evinces the exploitation of women's adaptive or coping capacity to normalise and re/entrench heteronormative and oppressive ideals about gender and care in the service of neoliberal patriarchal interests; and, to strategic entry points for effective development initiatives, because, when taking the experiences of carers' seriously, we see that their agentic action is often in opposition - and thus points to - the causes of deprivation experienced in their settings. Thus, understanding the experiences of women carers', whether in theoretical or political endeavours related to informing development practice, requires conceptualisations and interventions which interrogate the exercise of agency under extreme constraints.

Not only has feminist scholarship provided a platform from which to articulate the problems incumbent within the current care work context, this articulation is in itself transformative in how it enables those engaged in this work to think about carers differently: agentic women struggling in the face of oppressive realities.

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Dedicated to care workers, of all genders. We are because you are.

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Introduction

This dissertation explores the experiences of women HIV/AIDS community care workers in three community-based organisations located in Cape Town, South Africa.

I have been working with community carers since 2007, engaged in activism for the recognition of informal HIV/AIDS carers, particularly in policy processes. My experience in this location has evinced that care work is a deeply deprivational and contested terrain. As a feminist-activist-scholar, I am interested in the possibilities offered by feminist scholarship to contribute to a contextualised and broad understanding of this complex issue.

Feminist scholarship holds that care work, as social reproduction, perpetuates and reproduces systems of gender inequality (Laslett and Brenner, 1989; Folbre, 2006). Thus, this dissertation explores the meaning of community HIV/AIDS care workers' own representations of their experiences; tries to understand these meanings in the era of HIV/AIDS; and explores what these representations might mean for the goal of substantive, sustainable development which presupposes a commitment to social justice, equity and improved quality of life for all.

The first chapter outlines a theoretical framework based on key debates in social reproduction, care theory, and feminist development economics, noting the feminisation of care work. This discussion presents theories that locate care work within the contexts of poverty, power, and gender. Here I argue that the overarching theoretical framework of feminist development economics identifies the complex and intersecting impacts of care work (Cavalieri, 2011: 1457), and evinces that HIV/AIDS care work is deprivation for women who perform it.

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The second chapter outlines the historical and social context of community care work, and defines community care work in the context of the South African HIV/AIDS epidemic. In this chapter I also summarise recent endeavours around community care work policy.

The third chapter describes my research project. I locate this research in my epistemic stance as a feminist activist, and I describe previous research (as an Honours student) which informed my qualitative research design. Attention is given to my overall feminist approach, the process of conducting in-depth interviews, the way in which I applied content and thematic analyses, and I note the value of facilitating interviews with the assistance of an isiXhosa-speaking translator.

Presentation and analyses of the research findings are presented in two chapters. First, I explore carers' representations vis-à-vis capabilities deprivation through categories delineated by Nussbaum, namely: (1) bodily health, (2) bodily integrity, (3) emotions, and (4) material and political control over one's environment. Second, I wanted to highlight carers' positive representations of their work. To reveal these experiences, I applied the following capability categories: (1) practical reason; (2) emotions; (3) affiliation and (4) sense, imagination and thought (Nussbaum, 2011a: 33-34). By applying these categories, I hoped to reveal ways in which carers articulated capability formation.

In the last chapter I discuss how the meaning of care workers' own representations may influence our notions of social reproduction and how we think about development in the context of poverty, HIV/AIDS, and gender.

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Chapter 1

THEORETICAL FRAMEWORK

Introduction

My interest in exploring the representations of community care workers to produce knowledge about the possible impacts of *doing* care work on women is informed by feminist development politics. I will thus present theories within this overarching framework to locate care work within the contexts of poverty, power, and gender. This chapter will outline a theoretical framework based on key debates in social reproduction, care theory, and feminist development economics, noting discussions around the feminisation of care work.

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Social reproduction

The conceptual foundations of social reproduction with which I work in this thesis lie in feminist economic theory, which 'highlights the importance of reproductive activity for the working of any economy, and argues that this should be central to any analysis of economics' (Ferguson, 2010: 3-4).

Historically, 'social reproduction' has referred to maintaining existing life on a daily basis, and reproducing the next generation (Laslett and Brenner, 1989). This includes procreation and how food, clothing, and shelter are made available for immediate consumption. It has come to include 'the ways in which the care and socialization of children are provided' and 'the care of the infirm and elderly' (Laslett and Brenner, 1989: 382-385). Essentially, social reproduction is a broad reference to the 'process of meeting the needs of individuals and families' in society (Folbre, 1996: 186).

The 'naming' of social reproduction as an economic concept is attributed to

Althusser (1971), the French Marxist philosopher, as part of his critique of 'contemporary capitalist society'. Althusser explained reproductive activity as the process through which 'fundamental structures and relations of society continually recreate the existing mode of production' (Gibson-Graham, 2006: 24). In this way, social reproduction and production are 'mutually constitutive and in tension' (Katz, 2001: 711).

Althusser argued that the structures of gender dominance are thus also recreated and maintained within this 'existing mode of production' (Gibson-Graham, 2006: 24-25). Feminist scholarship has interrogated why this is so by focussing on the 'social organisation' of production and reproduction, that is, 'the set of social relationships through which people act to get it done' (Laslett and Brenner, 1989: 384). This refers to the 'socially constructed division of labour' of which gender is a 'fundamental dimension' (Laslett and Brenner, 1989: 400). Thus, argue Laslett and Brenner, social reproduction creates an 'arena of social conflict' which shapes the 'political, economic and ideological contours of society as a whole' (Laslett and Brenner, 1989: 400). One aspect of the 'division of labour' is the separation of productive paid labour, conducted in the market, from reproductive unpaid labour, performed in the home 'usually by women' (Ferguson, 2010: 3-4). The 'conflict' thus created, argue Razavi and Hassim (2006) is, however, an artifice of neoliberal economic theorists.

Laslett and Brenner, in their complete definition of social reproduction, include the 'mental, manual and emotional' work involved in providing the 'historically and socially, as well as biologically defined *care* to maintain existing life' (1989: 383). Care work is 'part of the infrastructure of jobs involved in running and implementing the global economic system' (Harcourt, 2009: 79) and affects the quantity and quality of the labour force, as well as the pattern and rate of economic development (Razavi, 2007). These formulations highlight the co-constitutive nature of social reproduction and production (Ferguson,

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2010: 3; Katz, 2001), and show how any attempt at division may indeed appear to be 'artifice' (Razavi and Hassim, 2006).

Care work, argues Harcourt, locates women in what Laslett and Brenner call the 'arena of social conflict' (1989). Despite their clearly indivisible nature, women's two roles within production and reproduction are 'rarely considered together' (2009: 71-72). Yet, it is the very duality of women's economic location which has brought about 'long-term change in the domestic sphere' and sees markets today penetrate domains once considered 'the antithesis of market principles: the spheres of family reproduction and the domestic economy' (2009: 72). It can be argued that the rise in the need for and performance of care work is one reason for this change. In the context of the global economy, structural adjustment has irrevocably changed 'state-led nation building processes'; governments must prioritise profit-maximisation and efficient economies, resulting in cuts in social expenditure (Harcourt, 2009: 73).

Lund and Budlender (2009) describe how the HIV/AIDS epidemic, in particular, has introduced new needs for care. They describe the impact of the epidemic as 'shifting how people work, and how people need care, and who provides the care' (Lund and Budlender, 2009: 26). In the country with the largest population of people living with HIV (Avert, 2010) 'a complex and diverse new economy of care' has emerged (Ogden, Esim, & Grown, 2006). This economy of care further blurs the line between the market and the private sphere (Schneider and Lehmann, 2010: 60-61).

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Care theory

Care theory has as a primary concern the idea that 'care work is women's work' (Esplen, 2009: 5). Women continue to provide a larger amount of care than men across *all* societies, especially in respect of unpaid care (Esplen, 2009: 5). In the current public

finance environment, which encourages less social expenditure, (as discussed in the previous section), a 'care gap' has emerged that women frequently subsidise with their own time, energy and resources (Ogden et al, 2006; Esim & Grown, 2006: 334).

There is wide consensus that care work increases the risk of women's impoverishment, especially for those already marginalised by social or historical factors related to race, culture or class (Kang'ethe, 2009; Esplen, 2009; Esim & Grown, 2006; Ogden et al, 2006; Bakare-Yusuf, 2003; McFadden, 2000). Vulnerability is exacerbated by the 'invisible nature of much of their work, which takes place inside private homes' (Esplen, 2009: 25). The work is undervalued and of low status (Budlender, 2002: 7). Working conditions are poor, if not dangerous, and the work is informal and without attachment to labour entitlements or protections. These unfavourable conditions, argues Esplen, are 'the result of gender ideologies which portray care work as something requiring few skills that all women and girls are able to do' (2009: 25).

The politics of care work has been a central feminist concern for decades. Betty Friedan is noted for her criticism of the construction of an 'unrewarding feminine ideal' (Freedman, 2007: 269) rooted in notions of care work. Writing in post-World War II America, Friedan's critique was embedded in a context of post-war affluence and addressed 1960s white, middle-class, educated women. Despite the specificity of her location, Friedan's deconstruction of the 'role of women', told through women's personal stories, remain relevant, not only in the West, but in settings where the expectation of an oppressive 'feminine ideal' persists. Friedan's writing addresses the homogenizing notion of women as caregivers, particularly in the home (Freedman, 2007: 270-271). The burdens of this particular oppression – the oppression of 'women's work', the 'gender role' binary and the expectations incumbent therein – were noted as having very real repercussions for women's well-being (Freedman, 2007: 276-278).

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The gender-division of labour has been historically organised along patriarchal interests in such a way that women were and remain the primary caregivers in society (Bakare-Yusuf, 2003; McFadden, 2000). Women's unpaid labour is seen as the 'product of patriarchal and capitalist systems of production which give men power over women through sexual division of labour' (Freedman, 2001: 51). The role of women in society is therefore 'couched in terms of old relations of power which have defined women as nurturers and care-givers' (McFadden, 2000). These roles have been further entrenched through notions of culture (Gqola, 2008) and tradition (Bennett, 2002), couched in essentialist notions of a natural feminine ideal (Hamington, 2004; Nussbaum, 2000).

In virtually all cultures, it has been women's traditional role to care for the home, the sick, the husband, the children, the family and the elderly (Nussbaum, 2001a: 242). Furthermore, these roles have been associated with some important 'moral virtues' such as altruistic concern, responsiveness to the needs of others, and 'a willingness to sacrifice one's own interests for those of others' (Nussbaum, 2001a). Yet, society as a whole benefits from this 'work' more than women themselves (McFadden, 2000). It has been argued that patriarchal interests have 'mediated' this acquiescence by the ideological claim that the interests of everyone are more important than the individual rights of the one performing the care work (McFadden, 2000). Gqola argues similarly when she says culture positions 'caring for the sick as feminine' and that 'the expectations of women as nurturers' means that their own illnesses and general well-being are 'often not taken seriously' (2008: 44).

While care theory as discussed so far is concerned with care work *as* women's work, the literature also attempts to unravel *how* care work came to be women's work. Hamington (2004) attends to the complex, contextual nature of care work. Gilligan describes it as embedded in the connections between people and the 'entangled web of

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dynamic relationships' thus established. Importantly, Gilligan shows that these relationships, these particular bonds of care, or 'morality' depending on one's approach, are not all freely chosen. Care, as a concept, cannot be removed from the context in which it occurs; care always occurs in a 'network of connection, a web of relationships that is sustained by a process of communication' (Hamington, 2004: 14-16; Gilligan, 1982 [1993]: 24-63). The web of human connectedness intrinsic in care has conjured theoretical debate around care as *moral virtue.* Specifically, ethical gender essentialism pertaining to notions of motherhood (Hamington, 2004: 24-26) contributes to the widely-held belief that care falls on the side of feminine virtues. Hamington writes that the 'issue of the gender connection to care can be seen as a background-foreground concern'; care has been 'in the background of male-dominated approaches to ethics, but it has been in the foreground of women's moral identity' (2004: 19).

Thus, through morality, tradition, culture or religion, women have been portrayed 'as *by nature* dependent and made for obedience, with a primary duty to serve men' (Nussbaum, 2000: 247, 253). If women's 'propensity to care' exists by nature, it can thus be assigned (by 'God', tradition, culture or moral norms) *because* it derives from nature (Nussbaum, 2000: 253). Political arguments which appeal to nature slip between claims of 'biology', 'tradition', 'necessity' and 'norm', which imply respectively that: caring is 'an innate endowment or tendency'; women have *always* been carers - it is the only way we know; things cannot be any other way; and it is right and proper that women are the carers - this is the way things should be (Nussbaum, 2000: 254). Based on any of these notions, care has been 'woman's destiny, and as destiny, requires no return in kind' (Nussbaum, 2000: 264). Thus, care work is embedded in a socially constructed paradigm where it is 'natural' not to attribute monetary (or other) values to the work which women do 'anyway' (Nussbaum, 2000: 264-270, Budlender, 2002: 7).

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Feminist scholars such as Gilligan (1982 [1993]), Noddings (1984), Ruddick (1989) and Bubeck (1995) argue that care has come to be grounded in women's *experiences* rather than in their *biology*; experiences which occur within the a socially constructed role vis-à-vis care rather than because of an 'essential nature' (Hamington, 2004: 18). Nussbaum states that the nature of woman is an 'eminently artificial thing', a social artefact constructed in a 'plurality of complex social structures' (Nussbaum, 2000: 264-270). Care is a practice, rather than a moral orientation (Engster, 2005: 69-70). Hamington argues that practice, or 'the habits of the body' make it seem 'built for care' (2004: 31). She also notes that such 'habits' may be the result of specific decisions which involve 'sacrifice, pain, and great effort of will' (2004: 31-35). Moving further away from the 'naturalistic fallacy' of care as passive, instinctual, and befitting of the constructed 'nurturing character' of the female gender (Hamington, 2004: 35), care is also emphasised as work (Ruddick, 1989: 17; Tronto, 1993: 101-122; Hamington, 2004: 34-35), requiring effort and energy. In this way, feminist conceptions of care ensure that the 'sheer amount of work necessary in many caring relationships' (Hamington, 204: 35) does not go unrecognised.

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Feminisation of care work

The previous discussion helps to delineate care work, especially unpaid care work, as feminised. According to Mohanty (2003: 141) this means that gender, race and class are 'naturalised' through this particular category of 'women's work'. Mohanty moves beyond the actual tasks performed and foregrounds 'the ideological construction of jobs and tasks in terms of notions of appropriate femininity, domesticity, (hetero)sexuality, and racial and cultural stereotypes' (2003: 142). Thus, it is important when theorising care work to locate the analysis in how 'women's work is constitutively defined' through the 'naturalisation of capitalist processes, ideologies and values' (2003: 142). The fact of *being*

women, with particular racial, political, social, ethnic, cultural, sexual, and geographical histories, has everything to do with definitions and identities as workers (2003: 142). Care work, in turn, draws upon and re/constructs notions of masculinity, femininity, and sexuality (2003: 144).

If care work is neither natural to, nor moral duty for women, then what is it? Care work comprises complex patterns of behaviour influenced by 'different axes of domination', such as class, ethnicity, race, politics, histories, able-bodiedness and sexuality, which mutually construct one another and sustain inequalities, which generally 'deprivilege women relative to men in society' (Bredström, 2006: 232 and 237; Kuumba, 2002: 505). Care work is 'forced repression in some directions, unnatural stimulation in others' (Nussbaum, 2000: 265). In the former sense, persistent gender norms reinforce the role of women as carers in the home, done as an extension of their domestic duties. In the latter sense, women may 'choose' care work due to 'the social norms and traditions that form women's preferences, and that influence their aspirations and their effective choices' (Robeyns, 2010: 228).

The point of care work being performed in the *home* as an extension of women's domestic duties needs further unpacking. Home is the private realm where the state rarely intervenes (Waring, 2003). Home is the realm where gender operates (Mohanty, 2003: 141). Home is where the majority of the poor survive, and thus where the new workforce that is the care economy operates, and where 'the embodied lives of women' that comprise this work force remain 'largely invisible in mainstream analysis of the global market economy' (Harcourt, 2009: 70-71). Feminist scholars view the home as 'a, if not the, major site of oppression of women', in no small measure attributed to the oppression engendered by social reproduction (Nussbaum, 2000: 243; see also Harcourt, 2009; Mohanty, 2003; Narayan, 1997). The state has so often failed marginalised members of

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families in this 'space' when it enforces particular laws, such as unequal property rights for girls, or when it fails to enforce laws, such as domestic violence laws; laws which require a type of 'meddling' in the private realm (Nussbaum, 2000: 261). In other ways, the state rewards the normative family structure through economic incentives or protections. The home, as fundamental to the reproduction of the economy, is thus reinforced and protected (Nussbaum, 2000: 265-270). As a critical space, home is where the gender power differentials that maintain capitalocentric and heteronormative economic policies are re/produced, thus maintaining the status quo (Harcourt, 2009: 74). With the state reluctant to 'meddle' in private affairs - in the dominion of private patriarchy - care work, those who perform it, the value of it, and its repercussions, remain outside of public purview. Thus, care work is invisible.

To be invisible as a worker, or as Waring writes, a 'producer', means that you are invisible in the state's allocation of economic benefits and protections (2003). Therefore, care work is unregulated, unprotected and unremunerated. Despite large numbers of women entering the global market, 'new jobs for women are in the unregulated informal economy' (Harcourt, 2009: 74). The feminisation of labour is less about the economic empowerment of women and more about informalisation and 'a plentiful supply of cheap labour' (Harcourt, 2009: 73). Feminisation of care work 'is about sub-contracted supply chains operating outside of the formal sector' (Harcourt, 2009: 74). The concept of value will be expanded upon in the next section. But first, the increasing need for care requires interrogation.

Popke (2006: 504) suggests the increased need for care is borne out of the context of neoliberal economics as exacerbated by the HIV/AIDS epidemic. Razavi and Hassim (2006) argue that state withdrawal, at the time of increased social need (during the AIDS crisis in particular), shows the limits of this economic paradigm: it assumes unlimited

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coping capacities among families and communities, an assumption which re-entrenches gender inequalities (Razavi and Hassim, 2006). In addition, informed by gender norms as discussed previously, the burgeoning informal welfare sector, in the form of informal community-based and non-profit organisations, considers it acceptable and appropriate for women to provide care services in their communities. Patel argues that the informal HIV/AIDS care sector reinforces the neoliberal economic project 'because it mimics and does not distinguish itself from the trend of unequal gender relations and power inequalities between men and women in the society at large' (Patel, 2009: 6-7).

Feminist Development Theory

The discussion so far points to the conceptual gaps in mainstream economic analyses of feminised social reproduction, gaps which are implicated in 'informing gender and development policy' (Harcourt, 2009: 70-71). Recognising that care work is a form of social reproduction, a biological, political and sociological phenomenon, and 'part of the fabric of society and integral to social development' (Razavi, 2007) means that it is of concern for feminist scholarship. Thus, contemporary feminist theorists have identified the concept of 'social reproduction' as a central challenge to gender equality and development (Kabeer, Magnus and Stark, 2008: 5). Women's responsibility for social reproduction, argue materialist feminists, is illustrative of the inherent inequality within the social and economic organisation of society (Raaber, 2010). In the 'feminist quest' of encompassing care into economic and development analyses (Razavi, 2007), social reproduction provides the 'starting point' from which to explore gender inequality in global production and brings to the fore 'the degrees of unfreedom' incumbent therein (Ferguson, 2010: 9). The following discussion outlines some of the feminist development debates relevant to this dissertation, which specifically confront social reproduction as

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fundamental to impeding women's substantive development (Jackson, 2001; Nussbaum, 2000).

Since Boserup's watershed work on women's productive and reproductive roles in the context of Africa's development, feminist development discourse has focused on showing 'women's important contribution to economic production', 'how women are critical to economic development', and how they have, literally, borne the burden of economic growth (Harcourt, 2009: 69). Evolving through the discourses related to 'women in development', 'women and development' and 'gender and development', contemporary feminist interrogations draw on radical politics and Marxist analysis to 'wrest "development" from its traditional moorings in liberalism and discourses of modernisation' (Lewis, 2002: 42).

The idea of a people-centred approach to development emerged. Informed by Sen's view of 'development as freedom' which argues for conceptions of economic development to move beyond economic growth and market efficiency to considering the consequences of economic and market forces on people (1999: 6-8), Benería denounces the patriarchal, 'economistic bias' of development approaches and (2003: 1) proposes strategies that 'begin and end with the dignity of each human being' (2003: 2; 23; 32). She advocates for a gendered approach to economic development which emphasises 'human' rather than solely 'economic' development (2003: 18). In her book *Gender, Development and Globalisation: Economics as if all people mattered*, Benería envisions development as 'an intuitive idea of a life that is worthy of the dignity of the human being … for each and every person' and, argues Benería, is 'much in tune with the basic objectives of feminist economics' (2003: 21). This again echoes Sen's approach in which economic growth is but a means to pursue a life of value, not an end (1999: 10).

This people-centred response, or 'the return to the social' in development policy, as

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outlined in Razavi's work, is a critique of twenty years of steadfast commitment to 'abstracting the economic from the social' (2007: 377). The latter is responsible for social degradation across the African continent through adjustment and stabilisation policies which called for dramatic reductions in social expenditure (Razavi, 2007: 378). This is because, central to neoliberalism, is an efficient national machinery which contends that 'social security should no longer reside solely with the state' (Razavi, 2007: 378). In this way, social needs are sublimated to principles of neoliberal globalisation. Thus, social safety nets are increasingly being left to market forces; on the ground, this means that communities have to fend for themselves (Jenson and Saint-Martin 2003:81 as cited in Razavi, 2007: 20; Razavi, 2007: 378).

A particular area of state withdrawal is in public health services; when these are not adequately financed to cater to the needs of all citizens, the message is that other institutions must fill the gap. In many poorer countries, private small-scale and largely unregulated provision has come to play an important role in urban primary health care as a result of under-investment in public services (Razavi, 2007: 20). One manifestation of 'fending for themselves' in this regard is the emergence of unpaid care work as 'the bedrock of social protection and provisioning' (Razavi, 2007: 378).

The dilemma, as Razavi puts it, is 'how to respond to social needs while remaining within the constraints of macroeconomic stabilisation' and without 'abandoning neoliberal basics' (2007: 378). The tension is irreconcilable - as neoliberalism is solely focused on producing people to serve the (global) economy: a neoliberal economy by its nature is not geared to serve the needs of people. It fosters 'fiscal restraint and a nimble state that facilitates the integration of people into the market' (Razavi, 2007: 378). This discussion outlines how care work proliferated as a response to contemporary economic policies.

Benería describes how the economic realm encompassing care work is gendered

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(2003: 35). From pre-World War II to women's increased participation in the labour force in the 1950s, Benería describes how the 'androcentric' and 'essentialist' assumptions within economic theory came to be applied as a way of understanding the sphere of the 'household' (2003: 14 and 34). 'New Household Economics' emerged in the 1960s, a concept painfully blind to gender discrimination and power differentials between men and women in the domestic sphere. Nonetheless, the 'hegemony of New Household Economics' predicated on sociobiological explanations for women's place in the household and labour markets held sway until the 1980s (2003: 35-36). Feminist critique emphasised constructivist approaches to understanding unequal divisions of labour, resources and opportunities, largely ignored in dominant economic theory to date. This made way for feminist thought to expand economic analysis to encompass a more holistic approach, such as the work of Friedan which showed the value of non-economic factors in assessing unequal divisions vis-à-vis power, autonomy and male-domination (2003: 36). This emergent gendered approach showed that economic theories, such as New Household Economics, were not interrogating *why* gender divisions and inequalities existed and persisted in the household and in labour markets (2003: 37-38).

These questions, notes Benería (2003), saw gender emerge as a category of economic analysis in the late 1980s and early 1990s (2003: 32). For example, Sen's 'cooperative conflict' theory of household economics proposed a valuable alternative methodology for analysing the 'factors behind women's subordination, powerlessness and low bargaining power' and captured household dynamics in a much more realistic way, unlike the notions put forth by Becker such as the 'harmonious rational choice model' (2003: 37-39). Understanding the household 'as a locus of conflict' allowed for a feminist critique of neoclassical models; it interrogated the systematically inferior position of women in society (2003: 39). Furthermore, the 'household' could now be seen as a critical

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site for analysing the nexus between finance, production and social reproduction (Elson, 2004: 5). Thus, feminist economic analysis highlighted the 'social' (Razavi, 2007); it could *see* activities which provided for people's needs, 'rather than being oriented to making money' (Elson, 2004: 6). In so doing, the artificial divide between that which 'counts' and that which does not is evinced. Feminist economic theory also articulates that social reproduction 'is disproportionately reliant on the unpaid work of women and girls in the family and community' (2004: 6). As such, feminist development economics calls into question the assumption that women's unpaid work will be done regardless of economic vagaries and 'can be relied upon to act as a safety net of last resort in times of economic crisis' (Elson, 2004: 6).

Through a feminist lens, the critical level of non-monetary investment in maintaining the economy is surfaced (2004: 6). Feminist economics interrogates the notion of 'value'. Tripp argues for alternative 'units' of production, consumption and investment beyond the household and for recognising 'the role of women as independent economic actors' (1992: 169). Çağatay challenges macro-economic notions of value through the concept of 'gender budget analysis' (2003: 15). Budlender calls this 'gender responsive budgeting'. It reflects the 'values of a country – who it values, whose work it values and who it rewards … and who and what and whose work it doesn't' (Budlender, 2003: 6 citing Govender). This in turn resonates with Waring's argument for assessing 'where value lies in society' (2003: 37). Waring uses a gendered analysis to show how conventional measures of economic development have rendered large amounts of labour invisible (2003: 35). As noted earlier, Waring equates the central problem of recognising social reproduction to its invisibility: 'if you are invisible as a producer in a nation's economy, you are invisible in the distribution of benefits' (2003: 35).

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Capabilities approach

With respect to care work, it is necessary to adopt a broad, holistic approach to development that interrogates the consequences of economic and market forces on people, specific to this thesis, women.

Sen's people-centred approach to development is relevant. In dominant development discourse, the 'market' is seen as a source of material growth and individual freedom. However, as argued by Sen (1999: 7) it cannot ensure this for everyone. If the market cannot provide for everyone, then what is the true purpose of modern economics? Is it a mechanism for organising society around the process of exchange dictated by 'rational choices', or is it the means by which society provides for human life? (Benería, 2003: 42-43).

Sen does not denounce the relevance of markets, instead his focus shifts to the 'primacy of individual freedoms' to participate in economic activity within the market (1999: 6). For Sen, 'free and sustainable agency' emerges as a major 'engine of development' (1999: 4) and 'viewing development in terms of expanding substantive freedoms directs attention to the ends that make development important' rather than merely to some of the means that comprise only part of the process (1999: 3). This agent-oriented approach has several promising corollaries.

Development as freedom requires the 'removal of major sources of unfreedoms' such as poverty, poor economic opportunities, systematic social deprivation and neglect of public facilities, to name a few (1999: 3). A shift in focus to the 'ends' which 'advance the general capabilities of people to lead the kind of lives they have reason to value' allows for a broader notion of development (1999: 10-11; 88), one which includes a contextual understanding of poverty and its related 'deprivations' (1999: 88-89). For instance, deprivations related to gender, resource allocation, or, what Sen calls the 'epidemiological

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atmosphere', are not revealed in income analysis alone. Understanding the *ways* in which people are deprived allows us to understand how income alone cannot serve to change the capabilities or living circumstances of the working poor (Sen, 1999). One can have an income, but live a survivalist existence. Sen's agent-oriented approach attempts to surface the social, economic and political deprivations which may limit one's capabilities (1999: 91).

Nussbaum is able to expand on Sen's capabilities approach by focusing on his formulation of 'complementarity', or intersectionality in feminist theory. Davis (2008: 71) argues that intersectionality provides a 'joint nodal point', a platform which enables multiple theories and approaches to be incorporated within feminist scholarship. This is important in building a theoretical framework which aims to understand the multiple ways in which women are socially constructed as carers. An intersectional approach shows how the 'different axes of domination', such as class, ethnicity, race, politics, histories, able-bodiedness and sexuality, mutually construct one another and sustain inequalities between women and between men (Bredström, 2006: 232 and 237). An intersectional approach to theory-building highlights the multiple and interacting systems of inequality which 'deprivilege women relative to men in society' (Kuumba, 2002: 505). As such, Nussbaum is able to propose a comprehensive assessment of how personal, social, environmental, political and economic factors act with, and not independent of each other to limit capabilities (Giullari and Lewis, 2005: 15; hooks 1984 [2000]; Sen, 1999).

One of the underlying assumptions of this research, as evidenced in the literature (Condon, 2010; Esplen, 2009; Van Dyk, 2007; Freedman, 2007; Ogden, Esim and Grown, 2006: 336; WHO, 2003) is that a major impact of care work is the deprivation of women's capabilities (Sen, 1999; Nussbaum, 2010). This is premised on the idea that 'poverty combined with gender inequality leads to the acute failure of central human capabilities'

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(Harcourt, 2001: 3).

Failure of human capabilities, or the deprivation of capabilities, arise from the 'enormous time-tax' imposed by care work, the limits on other aspects of social engagement or income-generating market participation (Antonopoulos, 2008: 16). It also may limit one's time to spend on self-care, to engage in political process which may secure one's rights (especially important as a vulnerable worker located in the informal sector) or to attend school or other career development opportunities (2008: 16). Nussbaum defines her approach using central human functional capabilities as 'an approach to comparative quality-of-life assessment and to theorising about basic social justice' which holds that when assessing societies for their basic decency or justice, the question to ask is 'What is each person able to do and to be?' (2010: 18-19). This approach takes each person as and end, 'asking not just about the total or average well-being … the approach is concerned with entrenched social injustice and inequality, especially capability failures that are the result of discrimination or marginalisation' (2010: 18-19).

Nussbaum applies Sen's notion of deprivation to care work specifically; referring not only to 'income deprivation', it infers 'deprivation' as any damage, dispossession, divestment, or denial (1999: 88-89). In the context of care work, deprivation can thus be seen as not only experiencing lack of payment. The performance of care work can dispossess or divest the carer of her material means of existence, it can cause her physical or psychic damage, or it can deny her rights as a full and equal citizen, say, through her lack of rights as a worker. It is not enough to acknowledge women's greater burden of care (Giullari and Lewis, 2005). The capabilities approach provides a mechanism for distilling the broader, multi-faceted nature of their burden.

Robeyns agrees that the capability approach is 'a promising evaluative framework for gender inequalities' (2004: 1). It is a useful way of illuminating how social structures,

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institutions and human relationships affect women's well-being (2004: 2). Harcourt has also found the capabilities approach to be a good analytic tool to understand the economic and politically 'disabling environment', especially how poverty combines with gender inequality to lead to the 'acute failure of central human capabilities' (2001: 1-3). The usefulness of the approach lies in the analytic possibilities it presents by looking at women's lives, looking at what women do, what they are in a position to do, and how resources and opportunities which are present work or do not work toward enabling women to function (Nussbaum, 2001b: 52).

Nussbaum argues that the capabilities approach, which treats each individual as an end, as a political subject in her own right separate from the 'organic entity' of family or community, 'provides the best framework within which both to value care and to give it the necessary critical scrutiny' (2000: 244).

Critical scrutiny surfaces the overall effect of care work on carers' 'capability set', whether in terms of deprivation *or* formation. This fits into the underlying theme of emancipatory politics and transformation; it is an approach which sees beyond only lack, disempowerment, absence and victimhood, it also sees opportunity and agency (Sen, 1999; Giullari and Lewis, 2005). In this way, capability is linked to human rights: what rights are carers actually able to realise? Freedom is 'not just a matter of having rights on paper, it requires being in a material position to exercise those rights' (Nussbaum, 2001: 49). Being capable of realising one's rights, and being able to form these requisite capabilities, comprise the capabilities approach.

My approach to research subscribes to Hill's contention that feminist scholars are to 'act as catalysts for the creation of knowledge that effectively advances the goal of human freedom' (2003: 131). I understand this to mean exploring my topic in a way which recognises the existence of 'capability spaces' (2003: 131), and that the operation of power

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and freedom in such spaces can both (not either) deprive and promote capability formation. Recognising the latter requires an approach which strives to be cognisant of dominant binaries which locate institutions in society as *either* depriving or emancipatory. The capabilities approach provides a potentially transformative mechanism to see the opportunities arising out of the phenomenon of community care work, not only the more immediately apparent exploitative, impoverishing and deprivational nature. Hill writes: 'the capability approach provides not only a framework for evaluating human welfare, but a tool for advancing it' (2003: 119). Sen (1999) argues that the capability approach provides an understanding of economic development that gives a firmer foundation to those working towards its achievement (Hill, 2003: 119).

An underlying assumption of this research, as evidenced in the literature, is that one of the many impacts of care work is the deprivation of women's capabilities, as defined by Sen (1999) and expanded on by Nussbaum (2000; 2001a and b). Thus, a capabilities approach would assist in contextualising the experiences of care workers in terms of specific impacts vis-à-vis gender equity, social justice and development generally. It also provides for action in that it is 'a more grounded analysis of the problems women face because of their gender … [and] looks at what is needed to enable poor women to function fully within society' (Harcourt, 2001: 4).

Thus, in this study, the capabilities approach is a valuable way of understanding 'how to build the capabilities of carers to function in a fully empowered way' (Harcourt, 2001: 8). It could potentially provide the argument that women carers' realities require more substantive assessment, because it is 'profoundly wrong to subordinate the ends of some individuals to those of others' (Harcourt, 2001: 8). That is at the core of what exploitation is, to treat a person as a mere object for the use of others (Nussbaum, 2001b: 53).

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The current plight of care workers is intolerable, yet, an approach exists which, in its illumination of deprivation, points to the exact entry points for a response which enables 'people everywhere to live full and creative lives' (Nussbaum, 2010).

Conclusion

The theoretical approach described in this chapter is informed by my location as an advocate for the rights and representation of community care workers in policy processes. I chose theoretical concepts which would frame my interest in: exploring the experiences of women HIV/AIDS community care workers; making meaning out of care workers' own representations of their experiences; understanding these meanings in the era of HIV/AIDS; and exploring what these representations might mean for the goal of substantive, sustainable development predicated on a commitment to social justice, equity and improved quality of life for all. Ultimately, I am concerned with understanding and theorising about the impact of doing community care work on women, to inform a more responsive activism able to make relevant, meaningful and substantive claims on policy development.

Feminist scholarship holds that care work, as social reproduction, perpetuates and reproduces systems of gender inequality (Laslett and Brenner, 1989; Folbre, 2006). The global distribution of care work and the corresponding patterns of gender and racial inequality, as well as the under-provision of care and resources for care raise questions about the deployment of care work and the meaning of gender equality. In addition, these questions continually fuel theoretical debates on the conceptualisation of development within cycles of poverty, inequality and social injustice on a global scale (Robinson, 2006: 5-25).

My experience in the field, especially as witness to the exponential nature of the

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multiple impacts on women carers, leads me to ask how care work can be imagined within the politics of development. To explore this, I analyse interview material from eleven HIV/AIDS community care workers gendered as women through notions of capabilities, using Nussbaum's ideas to develop themes for understanding 'the material possibilities offered' (De Beauvoir, 1949 [1991]: 91). In this way, I explored the meaning of carers' experiences vis-à-vis how capabilities are – or are not – generated by options for labour in under-resourced and poor contexts. My question focuses on how to understand capability within the day-to-day processes of creating 'caretakers'.

I approached my analysis thinking about how doing care work affected carers' agency, rights, and their ability to 'lead the kind of lives they have reason to value' (Sen, 1999: 10-11). Given the rapid escalation of care work within the HIV/AIDS economy in South Africa (to be discussed in the next chapter), it is critical to research the experiences of those materially involved as care workers. These experiences are embedded within a nexus of policy, HIV treatment, gender and labour. They also arise in a context where care workers' labour is positioned as a 'central plank of government policy' dealing with HIV treatment and care (Lund and Budlender, 2009). This highlights that community development is core to the prevention and management of the epidemic.

As an overarching theoretical framework, feminist development economics identifies the complex and intersecting impacts of care work (Cavalieri, 2011: 1457). This evinces HIV/AIDS care work as capability deprivation for the women who perform it, in that care work re/produces the socially constructed gender division of labour which has historically served patriarchal interests and the 'deprivileging of women relative to men in society' (Kuumba, 2002: 505; Nussbaum, 2000: 265; Laslett and Brenner, 1989). In its invisibility, care work's implications for development and the perpetuation of the existing global economic system makes it more insidious.

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The next chapter will contextualise the meaning of community HIV/AIDS care work and locate the debates outlined thus far in the South African context.

Chapter 2

THE CONTEXT OF COMMUNITY HIV/AIDS CARE WORK IN SOUTH AFRICA

Introduction

This chapter outlines the historical and social context of community care work, and focuses the theoretical debates discussed thus far on the context of this dissertation: community HIV/AIDS care work in South Africa. I will describe the attempts to define community care work in the context of the South African HIV/AIDS epidemic as well as discuss the ideological significance of the emergent local care economy.

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HIV/AIDS Care Work

Schneider and Lehmann have conducted considerable work focusing on community care work in South Africa. They describe care work in this context to represent 'an informalisation of essential health care delivery in South Africa's public health system, consequent on reduced state expenditure and the devastating impact of the HIV epidemic' (2010: 65). The notion of care work blurs the boundaries between 'home' and 'work', between the public sphere and the private domain, between household caring, volunteerism and 'regular labour' (Ferguson, 2010: 9), and may be unpaid or 'underpaid' (Budlender, 2002).

Lund and Budlender (2009) describe care work as encompassing 'counselling and spiritual support, training household members in simple nursing tasks, hands-on treatment such as bed sores, surveillance of medication, and provision of resources such as nutrition', following up on patients who have been discharged from health facilities, as well as palliative care in the later stages of AIDS (2009: 9). Carers also undertake

household chores which may assist their clients, especially those who are immobile and have no other carers within their own households. These can include cleaning and cooking (Lund and Budlender, 2009: 9). Care work also refers to a range of social services and home-visiting programmes with respect to support for children and other vulnerable children. Carers are also engaged in supporting households to get access to pensions and grants, 'inter alia the pensions for elderly people, and people with disabilities, and children in poor households' (Lund, 2008). As such, there is an overlap between health-related care work and care work which is related to social development. As Lund describes, this often causes confusion vis-à-vis funding and supervisory boundaries, and carers themselves often do not know which government agency oversees their area of care work (Lund, 2008).

Due to task-shifting (discussed later in this chapter) and economic expediency (Schneider and Lehmann, 2010), care work has emerged as a response to the extraordinary needs of the HIV/AIDS epidemic, in a 'fuzzy domain' in which the status of work is at best 'ambiguous' and where even the most basic workers' rights are not invigilated (Lund and Budlender, 2009: 25); care work is a 'fragmented, 'precariously located' (Schneider, Hlope and van Rensburg, 2008: 184) and 'vulnerable' sector (Lund and Budlender, 2009: 5, 11; Schneider and Lehmann, 2010: 65; Munakamwe, 2010: 33).

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Community Care Workers

While the conventional home-based carer is often a family member, friend or connected to the HIV/AIDS patient in some other extended familial way, Lund and Budlender specify that a *community care worker* is 'clearly distinguishable from the household caregiver, the resident family member who cares for a sick person in that household' (2009: 5). The World Health Organisation specifies: 'community care workers

are not formally trained aides, assistants, paraprofessionals or auxiliary personnel engaged in the formal health or social development sectors. Traditional, faith and complementary healers as well as traditional birth attendants also are not included in this definition' (2007: 2)

Personal engagement in the field suggests that, in reality, a uniform description of care work, or care worker, is complex. Furthermore, 'formal' universalising definitions could exclude tranches of people who consider themselves community care workers; people who react to the needs and contexts of the HIV/AIDS epidemic in diverse communities. Such nuance is reflected in the varieties of self-description among community care workers. For instance, at the time of this study, I facilitated a series of 7 workshops in the Cape Town metro area between June and November 2010. This process reached 118 carers in 32 community-based organisations. The question 'what work do you do?' was posed. Twenty-five different and definitive job descriptions were given. In her study, Schneider found that among 1,435 study participants, community care workers enumerated 87 distinct role descriptions (Schneider, 2010).

In this thesis, I approach the definition of community care worker as a person who provides care to people with HIV or AIDS in their home (Tarimo et al, 2009: 62). To broaden this definition, I refer to Razavi's description of the 'heterogeneous cluster of care providers that is variously referred to as the "community", "voluntary", "non-market" or "non-profit sector"' (2007: 20-21). The term 'community care worker' is also in keeping with current discourse: while there is by no means consensus on the term, there is informal agreement amongst the carers worked with in this study that it is, for the moment, the most broadly encompassing and fitting name in use. It notes that care is *work*, and locates this specific form of care at the community level, outside of formal state structures: it acknowledges that the community care worker operates at the periphery of

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the formal health and social welfare systems (Schneider and Lehmann, 2010; Lund and Budlender, 2009; Tarimo et al., 2009; Razavi, 2007). In addition, it is the name used in current policy development, and to avoid confusion - while acknowledging that naming is important and vested with power and implied meaning - this study will proceed with the term 'community care worker'.

The Alma Ata Declaration and beyond

The 1978 Alma Ata Declaration on Primary Health Care spurred the promotion of 'community health workers' in developing countries as a way of increasing access to health care (Schneider and Lehmann, 2010: 61). Before HIV/AIDS became a central consideration in every aspect of development in South Africa, researchers estimate that community care workers approximated 5,600 in number, were located in community health programmes across the country, and were 'anchored within the formal health system' (Schneider and Lehmann, 2010: 62). During the political transition of the early 1990s, community care was no longer prioritised (Lund and Budlender, 2009; Friedman, 2005). Schneider and Lehmann (2010) describe how community health worker programmes fell out of favour in the rest of the developing world, largely due to unrealistic expectations and lack of adequate planning, management and reliable funding (2010: 61).

As the HIV epidemic emerged in devastating ways in South Africa, however, civil society revived the notion of community care in the form of 'home-based care' projects to address the immediate crisis: providing palliative care to HIV-infected people and supporting children orphaned by the epidemic (Schneider and Lehmann, 2010: 62). As HIV/AIDS programme budgets increased, community care workers were described by the national Department of Health as 'indispensable' to the roll-out of HIV/AIDS treatment services (Schneider et al, 2008: 180). Community care workers were seen as a pragmatic

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solution to the 'crippling health worker shortages ... hampering national scale-up' of HIV/AIDS services (Schneider at al, 2008: 180). However, community care worker programmes were 'introduced in an overly hasty and top-down manner with little planning', thus the opportunity was missed to introduce a transformative approach into an ailing healthcare system (Schneider at al, 2008: 180). The result was a poorly resourced and undervalued 'extension' of existing health services (Schneider et al, 2008: 180).

As community care workers proliferated in South Africa, the World Health Organisation (WHO) proposed 'task shifting' (discussed in the next section) from primary health workers to community care workers as a global priority. Promoted as 'a coping mechanism' for human resource shortages, task shifting is intended as a stop-measure for over-stretched public health systems globally (Zachariah et al, 2009: 550). It was also touted as a 'quick win for achieving the Millennium Development Goals' in developing countries (Schneider et al., 2008: 180). However, lack of political will, poor planning, unrealistic expectations, little or no supervision, inadequate training and conflict within the health professions did not translate into the WHO vision of quality, cost-effective support for an over-burdened health system (Schneider at al, 2008: 180). Schneider and Lehmann describe the reality thus: 'Couched in a language of a seamless "continuum of care" between health system, community and home, and drawing on "communitarian" ideas of reciprocity and caring in African culture, its [community care work] more "profane" or real role was to legitimate the widespread practice of turning people with end stage AIDS away from over-burdened health facilities' (2010: 63).

Task shifting in the South African context, and the concomitant evolution of home and community based care has been taken as signalling 'a limit to claims on the health system' with a 'growing dependence on the labour of lay health workers for the every day functioning of the health system' (Schneider and Lehmann, 2010: 64).

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The primary health care model and task shifting

A central feature of the primary health care model as adopted by South Africa is that, as much as possible, services are nurse-driven (Lehmann, 2008). Yet, nurses function in circumstances characterised by staff-shortages, excessive over-time demands, low staff morale, lack of equipment and functioning facilities, stressful private lives and an ever burgeoning demand for health services (Pillay, 2009). In South Africa there is a substantial maldistribution of health personnel across the private-public divide: about 60% of nurses are engaged in the public sector, but serve 85% of the population. The profession also has high attrition levels and the nursing workforce is ageing: about two-thirds of nurses are over the age of 40 (Breier et al., 2009). A Human Sciences Research Council report concluded that while South Africa has a favourable nurse to patient ratio when compared to other developing nations, overall, considering the need, emigration of professional health workers, the challenge of integrating a highly dysfunctional health system, and the high burden of chronic diseases, such as HIV/AIDS, combines to constitute a human resource crisis. The public health sector is thus characterised by a shortage and maldistribution of nurses (Breier et al, 2009: 28; Zachariah et al, 2009).

The HIV/AIDS epidemic in particular, and ironically, the consequent success of AIDS campaigns to secure national access to ARV treatment, has placed enormous pressure on a strained health service (Zachariah et al, 2009). Beier et al. (2009) further note that the HIV and AIDS and STI Strategic Plan for South Africa, 2007–2011 (NSP), acknowledges these shortages while suggesting community care as an 'innovative' way of resolving this crisis. Human resource shortages should not be 'a justification for paralysis' because 'local communities' have been mobilised to provide the requisite services (Beier et al. 2009: 30 referring to DOH, 2007: 121).

The NSP supports 'task shifting', that is, the delegation of activities to less qualified

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staff, as a means of addressing this crisis (Breier et al, 2009: 30). Sanctioned by the WHO through specific guidelines and recommendations, task shifting is considered an appropriate and practicable response (Zachariah et al, 2009). Task shifting is 'the delegation of medical and health service duties from higher to lower cadres or new cadres' (Zachariah et al, 2009: 550). In the context of care work, task shifting is 'the extension of the scope of practice of community health workers or lay providers in order to enable them to assume some tasks previously undertaken by more senior cadres' such as nurses and midwives, non-physician clinicians or doctors (Zachariah et al, 2009: 550-551). Lund and Budlender expand this definition by specifying the delegation of tasks between levels of skill or qualification, allowing 'less formally skilled people to do a broader variety of activities' (2009: 23). Task-shifting fits within the ideological tenets of the South African public health care model in that 'health promotion and prevention is best done by people from "the community"' (Lund and Budlender, 2009: 24).

Under task-shifting, nurses, rather than doctors, can initiate antiretroviral therapy; lay counsellors, rather than nurses, can carry out HIV tests, as well as provide support for orphans usually done by social workers; and pharmacy assistants, rather than pharmacists themselves, can prescribe ARV drugs. It is argued that task-shifting vastly increases the access points to treatment and care by reducing the 'bottlenecks' in the system created by a lack of staff able to perform certain tasks. While unofficially implemented, Health Minister Motsoaledi approved formal task-shifting regulations in May 2010, a strategy upon which the success of the ambitious South African HIV counselling and testing campaign was pegged (Avert, 2010).

Lund and Budlender (2009) describe the reality of task-shifting in our current context as a coping mechanism; an expedient solution which has displaced the responsibility for care 'downward and outward onto un-resourced communities' (2009:

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24). The international guidelines stress the importance of an approach which is well-resourced and includes proper training. In reality, however, as is the case in South Africa, 'task-shifting is often resorted to in situations of stress and scarcity, to solve a resource problem, as is happening in the face of the HIV/AIDS crisis at present (Lund and Budlender, 2009: 24). They argue that task shifting onto communities means shifting the responsibility of care onto 'volunteers' - who are in fact unpaid workers, and mostly women. Schneider and Lehmann's study (2010: 62) found that 93% of community care workers were female, reflecting patterns elsewhere in the country (Akintola, 2006; Friedman et al, 2007) while 90% of AIDS care now takes place in the home (GCWA, 2006; South African AIDS Conference, 2007).

The scale of the burden notwithstanding, community health workers have had a significant positive impact on HIV care including uptake of HIV testing, ART delivery and the critical function of adherence support, improved health-seeking behaviour amongst HIV-positive community-members and community activism to reduce stigma and discrimination (Zachariah et al, 2009). While community-based volunteers have become the backbone of many care and support activities linked to HIV/AIDS, the voluntary or inadequately remunerated positions make the long-term provision of care at this level unsustainable. A threshold is likely to be reached and there is virtually no evidence to show that volunteerism can be sustained for long periods (Zachariah et al, 2009: 55; Avert, 2010).

The South African context therefore evinces task-shifting as an ad hoc, informal response to need. As a strategy, it lacks structure and policy frameworks, this results in 'the proliferation of new cadres with vague or overlapping responsibilities' (Zachariah et al, 2009: 554), 'cadres' which have little recourse to addressing these shortcomings, or protecting their own rights as workers. Task-shifting represents a move from the health

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sector to the 'community' or domestic domain in which volunteers and home-based carers work (Lund and Budlender, 2009: 25). Thus, tasks are shifted downward into a space where 'even the legislated basic conditions of employment are not monitored': a 'fuzzy domain' in which the status of work is at best ambiguous' (Lund and Budlender, 2009: 25). Despite formal acceptance of the need for, and benefits of, shifting care to community workers (Avert, 2010; Zachariah et al. 2009), and the 'numerically significant presence relative to professional health workers' (Schneider and Lehmann, 2010: 62), community care workers continue to operate at the periphery of the formal health and social welfare systems (Schneider and Lehmann, 2010; Lund and Budlender, 2009; Tarimo et al., 2009; Razavi, 2007).

Task-shifting means that community care workers have become the 'backbone' of HIV care and support in our communities; however, our dependence on their volunteerism makes it an entirely unsustainable strategy.

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Care work in context

Notions of care, the nature of the health system and the very determinants of health in South Africa are deeply influenced by the historical dimensions of 'colonial subjugation and apartheid dispossession'. This historical context, in turn, informs how racial and gender inequality, poverty and violence, fragmented communal and family arrangements as well as macroeconomic policies impact on health (Coovadia et al, 2009: 817, 825). The crises of communicable and non-communicable diseases, and the complexities of poverty-related illness collide in a dysfunction health system - further complicated by post-apartheid and transitional challenges.

This historical legacy remains visible in the geography of our existence: where health services are located, how people access such services, and the health of

communities are all products of the political organisation of social life geared toward generating affluence and privilege for a minority (Coovadia et al, 2009). The cost of such skewed distribution created impoverished black communities: low wages, overcrowding, inadequate sanitation, malnutrition, and stress caused the ill-health and intergenerational deterioration of many communities (Coovadia et al, 2009: 825). Specifically, the need to separate people so completely resulted in the fragmentation of health services - segregated along racial lines with divisions between curative and preventive services. Coovadia et al. describe that, at the end of apartheid, the South African health system comprised fourteen separate health departments, and, with a focus on the hospital sector, underdeveloped and under-resourced primary level services (2009: 825).

Non-profit organisations and missionary-run hospitals proliferated in under-served areas, although these were ill-equipped to deal with the high burden of poverty-related diseases (Coovadia et al., 2009: 826). In response, community members took on the care of their family and neighbours, and the care worker operating outside the formal health sector emerged. It is this 'layer' of care worker that was engaged in responses to emerging health crises, such as the community TB DOTS supporters (Directly Observed Treatment Short-Course), then lay counsellors recruited by organisations such as the AIDS Training, Information and Counselling Centres (ATTICs) as peer educators. This was an initial response to the emerging epidemic, and foundational for a new generation of lay health workers in South Africa (Lehmann and Schneider, 2010).

As the epidemic exploded, a crippled public health sector shifted the responsibility of care onto communities (Razavi, 2007: 20). Hospital beds filled up, and despite the clear need for hospital or specialist care, limited resources meant that the state 'shifted the burdens of care, particularly terminal care, from the formal health system to semi-formal agents of care in private, non-governmental organisations and to households' (Schneider

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and Lehmann, 2010: 63). Government rhetoric couched this shift as 'a seamless continuum of care between health system, community, and home', drawing on 'communitarian ideas of reciprocity and caring in African culture' (Schneider and Lehmann, 2010: 63). This approach is also central to the states' public health care model, which argues that 'health promotion and prevention is best done by people from "the community"' (Lund and Budlender, 2009: 24). An over-stretched health system subscribed to a neoliberal economic paradigm, this rhetoric can only be seen as an attempt to legitimate the widespread practice of delegating the responsibility for HIV/AIDS related care, death and dying to household members, generally women, who face this potentially debilitating and stressful challenge with little support (Schneider and Lehmann, 2010: 63).

The informal carer was now the HIV/AIDS 'home-based carer' (HBC), emerging as a response to the enormous demands for care which could not be met by state health services (Tarimo et al, 2009: 61). Razavi also argues that, when public health services are not adequately financed to cater to the needs of all citizens, then the message being sent is that other institutions or mechanisms must fill the gap. In this way, the care of our communities has been 'left to markets, families and communities' (Jenson and Saint-Martin 2003:81 as cited in Razavi, 2007: 20). Therefore, private, small-scale, and largely unregulated provision has come to play an important role in urban primary health care as a result of under-investment in public services (Razavi, 2007: 20). The number of informal health facilities responding to HIV/AIDS, as well as the numbers of volunteers doing care work has increased exponentially over time. The epidemic has changed 'how people work, how people need care, and who provides the care' (Lund and Budlender, 2009: 26). Poor political leadership on HIV/AIDS has delayed the availability, and access, to appropriate treatment; political rhetoric around 'AIDS denialism', which, at times, likened AIDS treatment to poison, caused many to abandon treatment regimes which were available.

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This meant that thousands of South Africans died, in their homes, needing intensive levels of care (Lund and Budlender, 2009: 26).

In light of the enormous need, since 2000, community care work has steadily emerged as an established part of district health systems (Schneider and Lehmann, 2010: 60-61), in some instances, attracting ring-fenced State grants 'to expand home and community-based care' (Hickey & Whelan, 2001). From then on there was a rapid growth in state supported non-profit organisations (NPOs) employing 'community care givers' in both health and social development sectors. By 2002, a national audit counted a total of 31,565 carers in both sectors (noting the pre-1990 estimate of around 5,600) (Schneider and Lehmann, 2010: 62). In 2008, approximately 65,000 'work opportunities' as community care work were reportedly provided through NPOs in the health sector alone (Schneider and Lehmann, 2010).

A mapping exercise conducted at the end of 2008 sought to establish more precisely the numbers and roles of lay workers engaged on a regular basis in the public health system (Lehmann et al., 2009). This inventory identified a total of 1,636 NPOs funded by contracts with provincial health departments, employing close to 40,000 lay workers. This excludes many, difficult to quantify, workers in initiatives funded through a sizable donor presence in HIV/AIDS and TB care, or completely 'unlinked' volunteers in small community-based organisations. To place the numbers in perspective, in 2008, the public health sector employed 48,000 professional nurses and 10,700 medical practitioners (Day & Gray, 2008), only a proportion of who work in the primary health care system. Lay workers are thus now as numerically significant, if not more so, as other categories of health professionals (Schneider and Lehmann, 2010: 62). Schneider (2010) notes that, despite the 'large and rapid increase in community care worker numbers over the last decade' (from 5,600 in 1997, to 65,000 in 2009), the limited amount of data and

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research on care work implies that these numbers are an underestimation.

An informative study by Schneider et al. (2010) focused on care work in Khayelitsha, South Africa. The study was conducted from 5 February to 8 March 2010, and forms part of a broader process being undertaken at the national level to 'identify community care worker numbers, roles, and non-profit organisation institutional arrangements in two sub-districts (1 urban, 1 rural)'.

NPO proliferation was found to follow the trajectory of the HIV/AIDS epidemic. As the first table below shows, community care NPOs in Khayelitsha increased dramatically between the years 1998 through 2006 - the time when the epidemic seemed almost out of control, with little guidance from the state during the period of 'AIDS denialism'. In the second table, it can be seen that the rise in NPOs in Khayelitsha also closely follows the rapid increase and peak of new HIV infections, and the increase in AIDS deaths. Palliative caring for those dying of AIDS in the home was, of course, where the type of 'home-based care', as discussed in this thesis, arose.

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Table 1: *Annual AIDS deaths, non-AIDS deaths and new HIV infections 1985-2009 (DOH)*

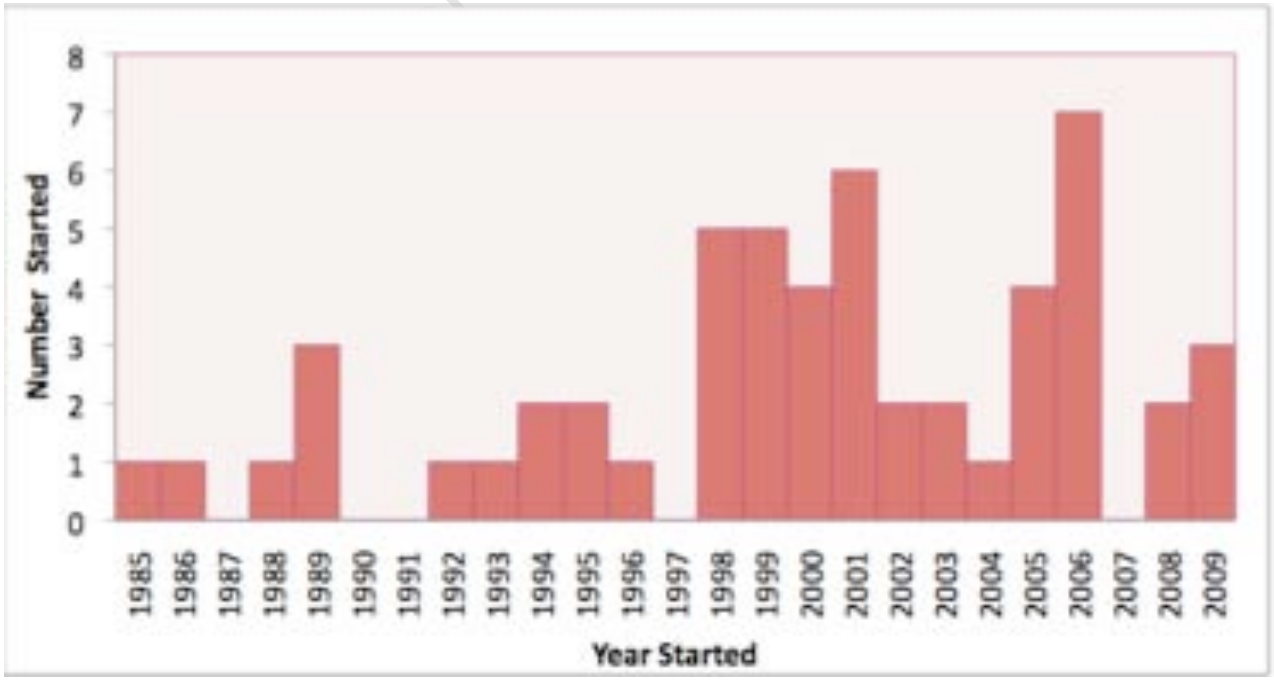
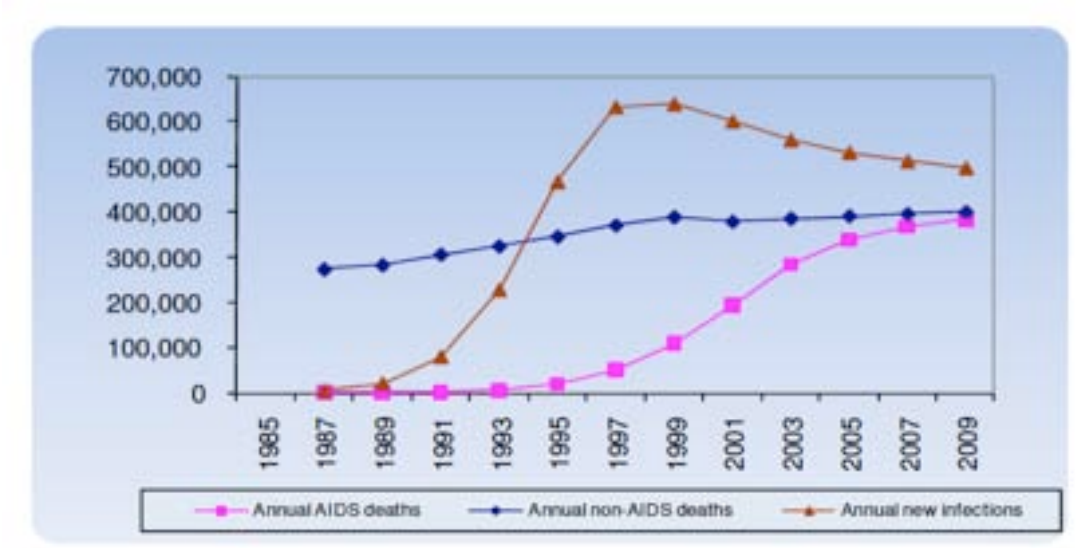


Image 2: *Number of NPOs in Khayelitsha 1985 to 2009 (Schneider et al, 2010)*



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The Care Economy

In the country with the largest population of people living with HIV (Avert, 2010), in the context explained so far, 'a complex and diverse new economy of care' has emerged (Ogden, Esim, & Grown, 2006).

The most recent data available from UNAIDS shows that South Africa has approximately 5.7 million people living with HIV - the largest population of people living with HIV in the world (UNAIDS, 2009: 27). The epidemic has engendered a complex and diverse new ''economy of care'' (Ogden, Esim, & Grown, 2006) Community-based services are now an established and growing part of district health system budgets. Health care, most specifically TB and HIV care, would simply be unimaginable without the services of lay health workers. Activities such as counselling and home-based care have become routine functions within the health system and the exclusive preserve of lay health workers, who increasingly occupy a front-line service provision role. Collectively, lay workers represent a new mediating layer between the formal health system and citizens (Schneider and Lehmann, 2010: 60-61).

This mediating layer, however, 'straddles the boundary between paid and unpaid workers, between real volunteers and ambiguous 'volunteers' (Lund and Budlender, 2009: 26). Informal HIV/AIDS care work is a form of unpaid and/or underpaid labour. The bulk of the home-based carers work on a 'voluntary' basis, that is, without pay or for very little pay, and often even without the most basic equipment that is needed to safely perform their tasks. For example, studies in Khayelitsha found that 51% of community care workers received stipends while 19% received no compensation at all (Schneider and Lehmann, 2010; Schneider et al., 2010). In addition, anecdotal evidence and findings from this thesis show that community care workers often contribute from their own resources to meet the nutritional, and other, requirements of the households where they provide care.

With respect to volunteerism, work by Swartz (2010) and Schneider et al (2010) is illuminating. In these studies, most community care workers referred to themselves as 'volunteers', yet 73% of those surveyed said they worked full-time, and despite noting their work as 'fulltime' only 30% considered themselves formally employed.

In the era of HIV/AIDS, the need to shift care to the communities, as described by Lehmann and Schneider earlier in this chapter, resulted in a sort of 'out-sourcing' whereby the Departments of Health and Social Development fund community organisations to manage community care workers. This funding is to provide stipends for care workers.

A stipend is not a 'wage' and thus is not subject to a sectoral determination as to minimum wages. In this sense, a stipend also assumes informal or semi-formal labour, or labour performed over less time, such as on a voluntary basis. It is a payment to 'offset or defray expenses'. It is not a salary nor a wage, but rather a token amount given to cover expenses in the execution of services. As noted above, the reality is that current stipend allowances may not sufficiently defray care-related expenses. Stipends are set low

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(CCWPF, 2009). There is little regulation or oversight regarding what an organisation chooses to pay a care worker (Schneider and Lehmann, 2010).

Budlender (2002) discusses the difference between 'unpaid' and 'underpaid.' 'Unpaid' care work as the provision of services within the household or by community members to individuals or households in communities. Specifically, 'unpaid' refers to the fact that the person doing the activity does not receive a wage for the work; 'care' means that the activity serves people and their well-being; and 'work' means that the activity has a cost in terms of time and energy and arises out of a social or contractual obligation (Budlender 2002: 6, 9). As a stipend is not a wage, and noting that stipends rarely cover the expenses incurred through performing care work, the current reality leaves no doubt that community care work is undervalued. Therefore, the categorisation of community care work as discussed in this thesis falls clearly into the realm of 'unpaid' labour.

Community care workers are acknowledged as 'a central plank in the government strategy to combat HIV/AIDS' and 'are implementing government policy' (Lund and Budlender, 2009). It is therefore necessary to explicitly acknowledge the position of community care workers in the labour market, not only to meet the state's own agenda of 'motivating NGOs and CBOs to be better able to assist informal workers to find pathways into more secure and more formal work' but also to ensure the 'systematic engendering of the analysis of home-based and community-based care and its implications for women' and others precariously 'employed' in this sector (Lund and Budlender, 2009; Schneider and Lehmann, 2010).

Without acknowledging the nature and implications of this 'care economy' with commensurate policy frameworks and labour regulations, the 'massive displacement of the burden of care onto ambiguously employed female home-based carers' will continue (Lund and Budlender, 2009: 26). By ignoring who cares, that the volunteers are women,

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unpaid, from poor households, 'ungendered notions of "community" and "volunteerism" have dangerous implications" for women, especially poor women' (Lund and Budlender, 2009: 26). Lund and Budlender describe women's employment status within this 'care economy' as 'precarious' and 'ambiguous', with the line between 'employee' and 'volunteer' being, at best, 'very fuzzy' (Lund and Budlender, 2009: 5-7).

A further point should be raised as to the character of this 'care economy'. As noted earlier, the tasks and roles of community care workers can vary considerably, despite all being engaged in community care work focused on the impacts of the HIV/AIDS epidemic. While care work is often considered to be located in health care, in this setting, it is clear that community care worker services cannot be strictly confined to 'health care'. A recent audit of the range of services provided in Khayelitsha and Bushbuckridge (Schneider et al, 2010) indicate clearly that the impact and needs arising from the HIV/AIDS epidemic blur any attempt to distinguish what is 'social' and what is 'health'. In a developing country (if not all countries) the line between 'health' and 'social' is fine, if not entirely artificial. As one colleague notes: 'If people are poor, how can they be well?' (Helen Lieberman, Director, Ikamva Labantu, 2010). Put more substantively, poverty and ill-health are intertwined. Wagstaff (2002) argues that this can be seen in the fact that poor countries tend to have worse health outcomes than better-off countries, and that within countries poor people have worse health outcomes than their better-off counterparts. This association, continues Wagstaff, reflects causality in both directions: 'poverty breeds ill-health, and ill-health keeps poor people poor' (Wagstaff, 2002: 97).

The difficult distinction between that which is 'social' and that which is 'health' is made explicit when auditing care organisations and carers themselves. An audit by Schneider et al (2010) showed that HIV/AIDS carers described their tasks as monitoring treatment adherence, providing palliative home-based care for terminal clients, providing

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meals, bathing and feeding clients, cleaning clients' homes, and facilitating access to psychosocial support services.

In relation to the previous chapter, the idea of a 'care economy' can be seen to highlight the location of care work in the private sphere; the 'economy of care' has lead to 'privatised' care, consigning it to the sphere of the home, while at the same time gendering care. Work in the home is considered domestic, and part of 'women's work' as related to their domestic duties, and thus undervalued in economic terms. The 'privatisation' of care has reinforced the feminisation of care work, entrenching the role of women in society in terms of existing relations of power which homogenise women as nurturers and care givers (Bakare-Yusuf, 2003; McFadden, 2000). By extension, we see neoliberal discourse operationalise gendered power differences to successfully shift responsibility for care, and in so doing, re-entrenching gender divisions (Schneider and Lehmann, 2010: 65).

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Policy considerations

I will end this discussion by noting recent policy deliberations with respect to community care work. Although initially premised on a model of voluntary contribution, a growing dependence on the labour of lay health workers for the every day functioning of the health system led to a series of shifts in the policy environment (Schneider and Lehmann, 2010). Policy initiatives concerning lay workers have been launched from several government agencies, such as the Departments of Health and Social Development and the Expanded Public Works Programme

In 2003, the Department of Health launched the Community Health Worker Policy Framework (CHWPF). This plan was to meet the human resource requirements laid out by the South African Health Act (2003) through collaboration with the national Expanded Public Works Programme (NSP, 2007: 48). The CHWPF was also an articulation of National

Strategic Plan for HIV and AIDS & STIs for 2007-2011 (NSP) recommendations which envisioned home and community-based carers as a means 'to avert the inpatient care costs that would have been incurred for patients in the absence of these interventions' (NSP, 2007: 142).

Parallel processes initiated by the Department of Social Development and the Expanded Public Works Programme created confusion, requiring a revision of the framework (AIDS Response, 2009; SANAC Treatment Care and Support Technical Task Team, 2009). Thus, a review process was initiated, resulting in the current Community Care Worker Management Policy Framework (CCWMPF), which was in its sixth draft in 2009 (AIDS Response, 2009; SANAC Treatment Care and Support Technical Task Team, 2009).

An enduring outcome of the initial 2003 process was the initiation of stipends for volunteers, and setting a stipend level of R1000 per month (DOH, 2003). The 'stipended' volunteer reinforced the strong move to 'sharpen the distinction between "lay" and other work, and consolidate the community "care economy" outside of the formal health system' which was criticised at the time for being at odds with HIV initiatives that had 'as a core objective improving access to antiretroviral treatment and other care services *within* the formal health system' (Schneider and Lehmann, 2010: 64 emphasis added).

By locating community care workers firmly outside of the boundaries of the formal health system, a state of marginalisation is enforced, despite their acknowledged centrality to the functioning of the primary health care system. Other factors compounding community care workers' peripheral existence are: exclusion from formal health sector human resource and service planning frameworks; the lack of standardised training programmes; limited opportunities for career-pathing; their semi-formal identity; and the fact that this marginalised sector is the first to be cut from budget considerations when

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local governments experience financial crises (Schneider and Lehmann, 2010: 65; Lehmann, 2008).

To provide a more complete picture of how care work is conceived from a policy and development point of view, I will briefly examine the last (known) public draft of the CCWMPF (Version 6, 2009). Care workers are described as being central to the implementation of the Department of Health's public health care model (DOH, 2009: 27). Noted as a 'formal resource' that facilitates 'services reaching homes', this policy document envisions care workers' management and coordination within Department of Health structures (2009: 30). Carers are also described as a critical strategy 'to expand community-based services beyond the capacity of the public health service' (2009: 30-31). Taken together, these comments acknowledge the importance of the care worker to state strategy, and the original vision that they should be situated within formal state structures (as opposed to civil society structures). These stipulations did not materialise, and as will be discussed later in this section, the status of this policy is currently unknown.

A second comment which must be made is that this policy seems uninformed as to the realities of community-based care work. In describing the nature of care work, the policy does not acknowledge the burden currently experienced by community-based care workers. The policy delineates a range of activities for which carers should take responsibility - across a range of social welfare programmes related to health, social development, early childhood development, education, maternal and child health, to name a few. In addition, an overview of other sector-specific policies reveals the promotion of task-shifting to community care workers. For example, the recent draft Mental Health Policy (2009) stipulates a substantial work load be shifted to care workers, including screening for mental illness in addition to providing basic counselling support. While a necessary intervention, screening alone is a time-consuming process. The trend to allocate

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that which cannot be allocated anywhere else to care workers renders the sustainability of the community care worker impossible (if it in fact is sustainable). Policies which attempt to collapse all community needs onto all carers will not succeed, least of all because carers will burnout from the unrealistic load envisioned by a range of sectors' uncoordinated recommendations to task-shift with abandon. Considering what is known about the realities of care work, such as the time spent doing care work (Budlender, 2002: 21), the time, workload and performance indicators as stipulated in the CCWPMF cannot realistically be informed by actual data on care work (2009: 81-82).

While the status of the CCWPMF is currently unknown, the recent consultation process on drafting the next National Strategic Plan for HIV and AIDS, STIs and TB 2012-2016 produced a first draft (5 August 2011) which outlines strategies which may draw similar criticism as noted above. It calls for 'large cadres' of community health workers to be deployed to take care of community needs, and stipulates an extensive list of new responsibilities to be taken on by carers, such as providing comprehensive health screening (2011: 41) and working in a range of new settings; in addition to home-based care, there are suggestions of deploying community carers to schools and at other strategic 'nodal' points within communities (2011: 41).

The most recent policy development with respect to community-based care workers is the Minister of Health's 'vision for the re-engineering of primary health care' (Pillay and Barron, 2011). When first put forward, this vision, frequently referred to as 'the Brazilian model'[1], was applauded for its acknowledgement that 'home and community based health services … are critical to good health outcomes' and for proposing to 'correct' the current situation vis-à-vis community care work. If community care workers were part

1 In order to learn lessons the Minister and MECs visited Brazil in 2010 and came back with a vision for the re-engineering of primary health care (PHC). Brazil was able to improve health outcomes by inter alia expanding the role of community agents working in teams with health professionals in designated catchment areas. Upon returning home the Minister established a small team to elaborate a South African model to strengthen PHC.

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of a well-supported team, suggests the Minister of Health's strategy, and if they were well trained and supported, with a clear mandate, many of the 'limitations in the way community-based health services are currently provided in the country' could be addressed (2009: 2-3). The 'team' is called a ward-based primary health care outreach team, and will comprise a professional nurse, environmental health and health promotion practitioners as well as six community carers. Each team will be linked to a public health care facility, and thus formally connected to the health system infrastructure. The overall vision is that each ward within each district will be 'covered with a primary health care outreach team' (there are 4,277 electoral wards in South Africa) (2009: 3). Toward the end of 2011, five-thousand community care workers were 're-oriented' to be the first 'tranche' of carers to be deployed according to this strategy (2011: 4).

While this strategy sounds like a positive shift in terms of how we think about care workers in South Africa, I would argue that it is poorly conceived on several grounds. First, in personal communications with participants responsible for training the first five-thousand carers in Pretoria last year, the process was described as hurried, haphazard and poorly conceived. Second, peers doing activist work are of the opinion that this strategy has been imposed to appease critics of the CCWPMF. However, the implementation of this strategy has usurped the public consultation process underway around the CCWPMF; this strategy has not been put out for public consultation through the channels created during the (lengthy) CCWPMF consultation process. Third, a concern in terms of fairness exists around processes for deciding which carers will be included in this strategy. As it stands, the Western Cape has been excluded from the national recruitment of care workers into this formal structure. Reasons are not yet clear as to why this decision has been taken. In addition, age has been noted as a delimiting factor. What of the women who have been carers since the epidemic first blighted our country? I would argue that their experiential

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knowledge is vast, and that those capable of meeting the physical requirements of the work should not be excluded based on age. Knowledge presents another problematic selection category: will formal training receive preference over experiential knowledge?

As a feminist-activist-scholar, I would argue that it is imperative to create relevant knowledge about community HIV/AIDS care work in South Africa. Uniformed, uncontested and non-transparent policy development is always problematic, however, in the case of HIV/AIDS community care, the process of shifting responsibility onto communities and absolving the state of responsibility disguises the fact that it is typically women who are providing this care (Esplen, 2009: 30). Considering that the women providing this care are an already marginalised group, the unconscious and uninformed promotion of community-based care may amount to societal exploitation (Kang'ethe, 2009: 84).

In the next chapter I explore an approach to feminist research which enables theorisation about the impact of doing community care work on women. The goal is to suggest an argument for responsive activism able to make relevant, meaningful and substantive claims on policy development.

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Chapter 3

RESEARCH DESIGN

Introduction

This chapter outlines the design of my research. I explain my epistemic stance as an activist-feminist researcher and lessons learned from research as an Honours student. These lessons inform the qualitative methodology adopted in this dissertation, the methods used, and my approach to analysis.

Epistemology

Epistemology provides a connection between research practice and formal theories of knowledge (Carter and Little, 2007: 1324). In my Honours thesis I explored the idea of 'knowledge creation' in the context of HIV/AIDS. I described how our historic engagement with the epidemic, due in large part to androcentric bias[2], has focused on the biomedical and public health aspects of HIV/AIDS. This means that most research interventions have not questioned social hierarchies related to gender, race and class and have ignored how these relationships mediate individuals; power, agency, and choices in the myriad contextual circumstances pertaining to HIV/AIDS (Inhorn and Whittle, 2001: 554). Research and policy have not considered sufficiently the impact of HIV/AIDS beyond the biomedical, particularly with respect to gender. Roy, in her excellent piece on feminist theory in science, puts it thus: 'what distinguishes what feminist researchers "do" from what non-feminist researchers "do" involves analysing gender critically, taking women's

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2 As noted in my Honours thesis: The HIV/AIDS pandemic is a quintessential example of the problem of androcentric knowledge creation. What McFadden calls the 'medicalisation' of HIV/AIDS resulted in a poor understanding of the 'socio-cultural characteristics of HIV transmission and its life-threatening implications' (1992: 159). Inhorn and Whittle argue that this is because 'malestream' epidemiology 'leaves off' at the point where a relationship between risk factor and disease outcome is discovered, an approach which ignored, for decades the structural drivers – social, cultural, political and economic – of the pandemic (2001: 562). Viewing HIV/AIDS as merely a health issue ignored the very vectors of vulnerability for women, with gender differences at their root (UNAIDS, 2008; Epstein *et al*, 2004; Eldis, 2003).

experiences into account and including them as valid scientific evidence, and identifying the complex subjectivities in ... what we observe (2004: 260-261).

Therefore, this dissertation articulates women community care workers' epistemic agency and foregrounds their own representations (Biseswar, 2008; Power, 2004: 11, Narayan, 2003; Taylor, 1998) as sources of knowledge (Acker et al, 1996). A feminist approach holds that social scientists can contribute to the 'end of social and economic conditions that oppress women' by analysing how the personal is political, and by pushing the analysis beyond individual experiences to understanding them as determinant factors in the larger socio-economic structure (Acker et al, 1996: 61). An emancipatory social science makes meaning of how women's everyday experiences are generated by the larger social structure (Acker et al, 1996: 61-62). The epistemological philosophy adopted here, (as in my Honours thesis, 2008[3]), is that of an emancipatory and transformative feminism: a desire to produce feminist research. It tries to be transparent about how the research is done, what informs the research, who is involved in the research, and what their location is to the research. It acknowledges that the data produced is a situated, co-constructed truth. It is subjective. It tries to attend to the dynamic, organic nature of how this particular knowledge was produced. It argues for the value of this knowledge by distilling the impact of structural factors on individuals' lives; value vesting in its specificity, not in its generalisability. It is about research that respects the agency of research participants, their experiences; their 'power' to name phenomena and make 'meaning' of their experiences (May, 2010).

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3 Meintjes, I (2008) *Women AIDS Activists' Experiences as Leaders in the Treatment Action Campaign 2005-2007. A case study.* Dissertation submitted in partial fulfillment of BSocSc Honours Degree in Gender and Transformation. African Gender Institute. University of Cape Town [Hereafter referred to as 'Honours thesis'.]

A feminist approach

Producing feminist research is less about following a particular method than about taking a particular approach, a 'pro-feminist approach' (Harding, 1987: 9; Letherby, 2003: 5-6). In her thesis on 'constructing feminist topographies' Pratt's summary of a feminist approach resonates:

> *Feminists argue that conventional methodology, which is rooted in positivist empiricism and focused on the search for universal truths through logical, value-free research, is consistent with a male, androcentric point of view. Conversely, feminist methodologies challenge researchers to recognize the gendered basis of all social life and to rethink concepts concerning gender and other social relations and their connections to broader structures. They forward women's 'ways of knowing' by advocating a feminist value position and perspective and challenge conventional notions of objectivity, rationality, and truth. In addition, feminist methodological approaches are often action-oriented and working for social change (2006: 151).*

I adopt a feminist framework which tackles the issue of HIV/AIDS community care work, as a form of social reproduction, from the perspective that gender is a political force, a factor central to the way in which societies organise themselves (Coleman, 2005: 337; English, 2005). By using gender as an analytic category, this kind of analysis seeks to understand how gender differences and gender inequalities are constructed and perpetuated. A feminist analysis helps to illuminate gendered power differentials in everyday social relations (English, 2004). It helps to highlight dominant, gendered scripts and how these are ascribed to bodies sexed as male and female; how these scripts 'denote masculine and feminine attributes and characteristics and how these are ascribed to ideas and beliefs'; how these attributions are never neutral; and how these attributes attach to and operate in women's lives (Adam, 1998: 18).

African feminist approaches include a focus on theories of culture and race, as well as colonial, capitalist and democratization processes. This 'intersectionality' distils the multiple ways in which power is 'deployed and resisted' in society, the diverse factors which combine to entrench oppression (Oberhauser and Pratt, 2004: 211). As a process,

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Davis (2008: 71) explains that it ‘takes up the political project of making the social and material consequences of the categories of gender/race/class visible, but does so by employing methodologies compatible with the poststructuralist project of deconstructing categories, unmasking universalism, and exploring the dynamic and contradictory workings of power’. In addition, ‘new sites of investigation, such as the individual, home, community, and workplace, are advanced and attention is paid to how socioeconomic relations of gender and power permeate all spheres of social life, including the research process (2008: 71).

Pereira speaks of an African feminism which strives to 'transform the ways in which African realities are understood, with attendant implications for progressive social change' (Pereira, 2002). It is the notion of transforming what is observed, not only explaining or understanding what is observed. The aim of 'building theory' on my observations is to challenge and contribute to transforming existing notions predicated on (mostly) positivistic, universalising and gendered knowledge creation and theory (Mbilinyi, 1992: 55; Taylor, 1998: 374). This is critical research geared toward 'social relevance, individual empowerment and, ultimately, political emancipation' (Babbie and Mouton, 2007: 39). I am interested in principles of African feminism, which I strive to reflect in my approach to this research in a way that ‘acknowledges the inequality of social relations between the sexes and from there analyses the degree, forms and consequences the inequality takes in order to transform them’ (Sow, 1997: 45).

In a section titled 'An African AIDS feminism?' in my Honours thesis, I explored my personal location as feminist, and the consequent feminist approach I hoped to take to my research. I wrote: ‘in the context of the epidemic, a post-structuralist approach is taken whereby aspects of feminist thought most relevant to the struggle against HIV/AIDS and the present analysis will be noted’ (2008: 80). This approach remains relevant to me, as

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my understanding of feminism is that it is not universal, static, or singular. It makes sense to adopt an approach which acknowledges that not all women have the same concerns or political interests. It follows that more than one form of feminism can emerge (Hassim, 1991: 71-73). Feminism is not 'one unitary concept, but instead a diverse and multi-faceted grouping of ideas, and indeed actions' (Freedman, 2001: 1). In addition, HIV/AIDS cannot be approached, nor understood, unless a multi-dimensional 'lens' is applied. The intersectional nature of the feminist approach adopted here, I believe, is able to provide insights into the epidemic, because it 'intertwines with issues of rights (reproductive, sexual and human), conditions of production and reproduction, economic status and social class, and is irrevocably enmeshed with the power dynamics of male oppression (Honours thesis, 2008: 81).

My meaning of an 'African AIDS feminism' is acknowledging that the African continent is especially affected by the myriad consequences of the HIV/AIDS epidemic. It foregrounds a critical feminism that focuses on the 'forms and consequences' of gender oppression (Sow, 1997). I acknowledge, as I did in my Honours work, that the term 'AIDS feminism' is inspired by Richter's plea to 'cultivate a new form of AIDS activism', and that AIDS is an imperative for feminists located on the African continent (2005). This approach is also informed by Pratt's conceptualisation of 'materialist feminism' which analyses 'material manifestations of power' as they are grounded in everyday life, and as such, interrogates 'women's material realities and economic identities within their everyday lives and their connections to the broader workings of capitalism, colonialism, and patriarchy' (2006: 4-5). Analytic approaches attempting this project have been called socialist feminism, womanism, materialist feminism, and feminist materialism, but, notes Pratt, it is really 'internationalist, antiracists, antiheterosexist feminism' (2006: 30).

To conclude, while my epistemic stance is one which is informed by tenets of

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materialist feminism, it retains the aspects of radical feminism. This is a fitting approach to a study which takes the HIV/AIDS epidemic to be a phenomenon through which many forms of oppression – such as economic, social, cultural, political, racial, patriarchal – are manifest in the lives of women; which takes the epidemic to be the 'common cause' which necessitates our 'blazing, outspoken feminist response' (Richter, 2005). It is the approach I want to take to a critical examination of HIV/AIDS community care work, which is committed to 'feminism's transformative vision', which allows me to produce research in a way that can 'imagine the social world as radically other than it is' (Jackson, 2001: 291). To attempt this 'imaginative leap', argues Jackson, requires us to think critically about the social order we inhabit. If this is achieved, 'we may recover feminism's transformative vision and restore our ability to imagine the unimaginable: not only a world without gender, but also a world without the myriad inequalities and injustices that constrain women's lives today' (Jackson, 2001: 291).

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Positionality

I would argue that one of the triumphs of feminist scholarship is the deconstruction of universal truths, essentialising generalisations, the all-knowing scholar; and, reconstructing her within her location, context, politics, and all that may influence and inform what she seeks to know and the meaning she makes of the knowledge sought. Narayan writes that 'the project of giving an account of oneself - of one's specific location as speaker and thinker; of the complex experiences and perceptions and sense of life that fuel one's concerns; of the reasons, feelings, and anxieties that texture one's position on an issue; of the values that inform one's considered judgement of things' and to be self-aware during the research process is 'an inherent good' (1997: 9-10).

The researcher's positionality shapes the observations, interpretations and

outcomes of research (Taylor, 1998: 369; Bhavnani, 1994; Harding, 1987). It is a central focus of feminist scholarship to challenge the notion that there is "an independent reality to be known separate from the subjective knower" and thus the "reflexivity of social science", that is every aspect of our position, social location and standpoint, is incorporated into all aspects of the research endeavour (Taylor, 1998: 368; Harding, 1987: 9). Illuminating the linkages between this research project, who I am, who the study participants are, how we are all located, and what we claim to know is a method of 'authorising' our speech (and opening up the nature of this 'authority' to evaluation and interrogation (Walker, 1991; Narayan, 1997: 3). Part of the feminist endeavour is making connections between our political experiences within the constructs of 'home', 'family', 'culture' and 'community', and the systematic way in which these experiences construct, reconstruct, entrench and reify the script of gender roles in women's lives (Narayan, 1997: 10). In this way, these experiences may be lifted out of the isolating frame of 'personal problem', to a wider social and material problem, with public and political implications, and possibly solutions (Narayan, 1997).

Positionality requires one to be attentive to one's own interaction and positioning within one's research endeavour and how this could affect that which is being researched. Harding writes: 'observation cannot be separated from its social consequences … in social inquiry, observation changes the field observed' (1991: 161). How I interpret the data in this study, how I go about finding it and why I want to find it, are all considerations in the reflexivity incumbent within a feminist approach. For example, my interest in this study is informed by my activism toward realising the rights and representation of community HIV/AIDS care workers. As such, my observations are informed by my opinion that carers are profoundly exploited, and that remedy is necessary. Reflecting on my feminist practice as a researcher, however, was a constant process: it was important for me, despite the

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very stark hardships I witnessed - not only in the interview settings, but in my ongoing work with community carers - to remain cognisant of producing research which did not cast women carers as victims.

In the next section, I would like to reflect on two specific ways in which positionality informs my research.

The politics of 'home'

Narayan writes that the feminist endeavour is not merely the exercise of noting women's experiences, but that it requires 'political connections to other women and their experiences, political analyses of women's problems, and attempts to construct political solutions for them, to make women into feminists in any full-blooded sense, as the history of women's movements in various parts of the world shows us' (Narayan, 1997: 9-11).

Central to my positionality is my experience of 'home', and subsequent political connections with other women in the HIV/AIDS struggle. As explored in my Honours thesis, my experience of 'home' was of a place of hidden, silenced terror. It was a space of disempowerment. It was abusive. It was formative in my understanding of 'man' and 'woman', the inequities, the silent and automatic cultivation of oppression. Here I also learned about HIV-as-always-possible in the context of violation and oppression. It is where I watched women work, and men exploit.

It is ironic that it is in the context of the HIV/AIDS epidemic that I experienced political (emotional, psychic, spiritual) liberation from 'home'. HIV-as-always-possible became a political consciousness. It led me to the Treatment Action Campaign (TAC)[4],

4 I worked at the Treatment Action Campaign (TAC) from 2005 through 2007. TAC is a South African non-government and membership organisation - also acknowledged as a social movement - lobbying for treatment for people with HIV and for the protection and safeguarding of the rights of those affected and infected by HIV. TAC is focused on reducing new HIV infections and engages in active 'treatment literacy' programmes to ensure sustained treatment adherence and access to antiretroviral treatment. At the time of my employment, the organisation comprised a membership of 16,000, 80% of which were women. TAC has a global reputation, and has been acknowledged as a significant force in realising universal access (notwithstanding the challenges in ensuring access) to HIV/AIDS treatment in the public health sector.

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where I became an activist and employee. It is where I first heard the expression 'the personal is political' from then General Secretary (at the time) Siphokazi Mthathi. This statement, and movement, became my new 'home'. It was immanently logical. My own experience validated it utterly.

My feminist consciousness evolved concurrently with my trajectory as an AIDS activist in TAC. Increasingly, I was able to identify the oppression and inequities in this organisation, this 'home' to 16,000 people, mostly women. I recognised ways of being: the role of women, the rights of men. This informed my Honours thesis: I needed to interrogate why certain injustices transpired in a space reputed for its contribution to social justice. I came to see that some of the answers could be found in understanding and making meaning of how gender operated in this organisation. This became a broader awareness: a consciousness of not only how gender operates, but that gender scripts took on new meanings, and consequences, in the context of HIV/AIDS.

My interest in the 'politics of home' took on a deeper, broader meaning as I started to unravel the impacts of HIV on women: women were affected in particular ways, not because of being women, but because of being 'constructed' women, within the particularities of the social, political and historic processes attributed to the space we call 'South Africa'. Connected to my own experiences of 'home', the site where my own being was re/produced, formed and informed, contested and negotiated, a space that would forever defy its assumed denotation as 'safe', I could make sense of Mohanty's description of the 'psychic economy of *home* and of *work* [which] has always been the space of contradiction and struggle' (2003: 141). I conceive of 'home' as a space of gender operation, a space in which exploitation, un-safeness, care, resilience and resistance can exist simultaneously; 'home' is very much the terrain of struggle, and survival. It is also a site where much of the impacts of HIV are being felt, experienced and resisted, an invisible

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space (almost) beyond the reach of state protections (in preservation and deference of the masculinity at the helm), the invisibility of which has precluded us from accessing some of the most important lessons about the HIV/AIDS epidemic. Community care work has, however, blurred the line between 'home' and 'state', between private and public, with attendant consequences, which are worth exploring.

The 'world' of community care work

A discussion on positionality requires a description of my embeddedness in the world of community care work. With specific reference to the context of this study, I have been engaged within the community care worker milieu for several years. After being engaged with activist activities in AIDS Response since 2007, I was formally employed by the organisation to assist in the development of community care worker advocacy strategies.

AIDS Response is a non-governmental organisation which works to improve service delivery in the HIV/AIDS sector through (a) capacity building for care workers in order to provide them with respite and equip them with tools for self-care and (b) supporting the overall sustainability of the sector by providing for CCWs' emotional and physical well-being. In addition, the organisation advocates actively for policy change related to CCWs.

I engaged with community care workers and community-based care organisations in mobilising activities and I was, and continue to be, active in the community care worker policy process. I was fortunate to give input at the Community Care Worker Symposium (29 April to 1 May 2010). I was tasked to write up the technical report emerging from the Symposium, outlining recommendations for the re-drafting of the community care worker policy. This report was presented to the South African National AIDS Council (SANAC)

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Treatment, Care and Support Technical Task Team. Review, debate and contestation continues.[5]

My location as an advocate for the rights and representation of community care workers in policy processes informs many aspects of this thesis, such as my interest in making meaning of community care workers' experiences, of understanding these meanings in the era of HIV/AIDS, and of locating such meaning in the overall context of social justice: ultimately, I am concerned with the impact of doing community care work on women, and of ensuring that these experiences inform State responses.

Ethics

I am familiar with the complex nature of research related to HIV/AIDS. Experience as a former employee in the Treatment Action Campaign, as an HIV/AIDS activist, and as a student researching gender and HIV/AIDS for my Honours thesis, I am concerned with designing research which ensures 'that people are not made more vulnerable by [my] research or its products' (Anthropology Southern Africa, 2005: 142). I have to acknowledge, being close to the research site, embedded within it, and committed to a cause within which I frame my research, means that the risk exists of being too comfortable or over-confident in assuming that what I do is 'right' or 'good for the cause'. Good intentions can be as destructive as bad ones. To this end, I have located myself within an organisation which advocates for the rights of care workers. The Director and the Care for the Caregiver programme coordinator at AIDS Response reviewed my study protocol, and ensured that informed consent was received from all study participants. Care for Caregiver workshop facilitators were informed of my study, and spent time discussing this

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5 At the time of writing, the next stage of policy development around community care work was scheduled for 20-22 September 2011, as a Symposium hosted by the South African National AIDS Council entitled 'Building partnerships to implement community-based health services in PrimaryHealth Care'. All previous stakeholders in the policy process have been invited to attend this 'working' symposium, where key elements of the policy will be re-drafted.

research project with CCW workshop beneficiaries. All study participants had access to contact details of the organisation, and space within workshops to ask questions or raise concerns (without my being present). In this way, volunteers were sought rather than participants selected.

I re-visited the ethical research guidelines adopted in my Honours study (Anthropology Southern Africa, 2005: 142-143). All participants participated under confidential disclosure. All participants were provided with a detailed consent form. To ensure informed consent, the form was translated into the three primary languages spoken by participants, namely isiXhosa, English and Afrikaans.

The consent form stipulated the aims and objectives of my research. Participants were assured of their 'right to withhold their support for the research, to refuse to participate or to withdraw their consent at any time in the research process'.

Upon completion, I plan to produce a 'popular' version of my findings and to share these with the study participants. This will be done in partnership with AIDS Response, and will form part of the political education and public participation process under the helm of the Linking, Learning and Lobbying programme.

A critical lesson learned in my Honours pilot study was that I must, at all times, be 'attentive to the moral dimension of interviewing' (Anderson and Jack, 1991:25). For me, this goes beyond obtaining permissions and clearly explaining the purpose of my research. It includes considerations about the 'up close and personal style' of feminist research (Heyl, 2001:374), about carefully considering the responsibilities and expectations set up in the research relationship, and about feeding back the research findings to the participants who gave of their time and energy to participate in this study. Another important consideration emerged: translation was key to this entire project. The difference between my engagement with CCWs at the pilot stage and during the actual

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interviews is marked: I learned that participants took the presence of a translator as a sign of respect. The importance of speaking in their home language was visible. One CCW quoted former president Nelson Mandela, 'If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart.' Translation is also important in ensuring that all parties are informed, at ease, and understood as accurately as possible.

Ethical considerations in a study which claims to be 'feminist', and begins and ends with the interests of women foremost, and which aspires to be transformative, must be careful of placing the 'cause' embedded within the research project before the rights of the individual participants. I hope that my engagement with AIDS Response, in addition to my academic supervision, has ensured the latter.

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Methodology

While epistemology can be thought of as 'the justification of knowledge' (2007: 1317), methodology is the justification of the methods used in the research project: 'the description, the explanation and the justification of methods, not the methods themselves' (Harding, 1987:2; Carter and Little, 2007: 1317). Methodology also attends to how we describe, and how we talk about the research being done; it is not the product of the research, it is the process by which research is conducted (Carter and Little, 2007: 1317-1318). Methods, in turn, are the means to pursuing the 'action' of research, the 'procedures, tools and techniques' employed in the study Carter and Little, 2007: 1317). Methods produce the data, and knowledge is created from analysis of the data. Thus, there should be a logical flow from the data produced, the methods used to produce the data, and the knowledge created from the analysis of such data (Carter and Little, 2007).

With this in mind, I have chosen qualitative methodology, which is, according to

Carter and Little 'social research in which the researcher relies on text data rather than numerical data, analyses those data in their textual form rather than converting them to numbers for analysis, aims to understand the meaning of human action … and asks open questions about phenomena as they occur in context rather than setting out to test predetermined hypotheses' (2007: 1316).

Little and Carter outline an approach to qualitative research which allows for an holistic, systematic assessment of the rigour of the research, while allowing the flexibility and diversity which facilitates the innovation for which qualitative research has become known (2007: 1316).

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Lessons learned

My Honours study, which piloted most of the methodology adopted in the present study, drew strongly from Harding's work: I took the research problem from 'the perspective of women's experiences' (1987: 7). However, a valuable lesson learned in my Honours work was that being too close to one's field of study, or too embedded, can pose challenges. The challenge was linked to what Bhavnani explains as: 'the micro-political processes which are in play during the conduct of the research' (1994: 30). The 'camp' I had been in while employed at the TAC implied a certain relationship with leaders within the organisation. This implied relationship posed a threat to interview participants who continued to be located within the organisation; specifically, associating with me could send a message to leaders implying disloyalty. This resulted in one study participant withdrawing. As I noted in the thesis: 'Had I been a stranger I suspect I would have been more successful: speaking to me would have seemed less threatening, it would have been easier to believe that I was 'just' doing research, that I had no ulterior motives. Instead, speaking to me could have repercussions in their lives' (2008: 125).

This lesson informed the process of identifying participants in the current study. To ameliorate my embeddedness in the 'critical plane' of enquiry (Harding, 1987), I did not recruit interview participants whom I knew. AIDS Response sent out a request to organisations in their member database for volunteers to participate in my study. The organisations in turn sent out a notice to their community care workers. Individuals contacted me independently. At this stage of sample selection, I focused on volunteers from 3 community organisations for comparative purposes.

In addition, I have learned the value of credibility, specifically, the credibility of my own politics. Despite the challenges noted above, and those which may be associated with my location as a middle-class, white South African woman, located within academia, outside of the social, political and economic contexts of the study participants, I feel privileged to have accessed informative, generous and rich narratives. After several years as an activist within AIDS Response, the organisation endorsed my study. My experiences as a TAC activist, in turn, contributed to my credibility within AIDS Response. Consequently, the respect which AIDS Response has earned as an authentic force fighting for the rights of community care workers endorsed my entrance into the 'critical plane' of enquiry.

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Qualitative methodology

Identifying methods suitable for studying community care workers 'doing' care work is informed by my Honours thesis of women HIV/AIDS activists located in the Treatment Action Campaign. The task of listening to activists using open-ended, dialogic interview methods proved useful for distilling aspects of women's lived experiences as HIV/AIDS activists and leaders.

It is of interest to me that quantitative researchers have highlighted the need for

qualitative, experiential data to contribute to and expand on existing quantitative data. Lehmann (2008) has highlighted the 'limited body of qualitative data on community HIV/AIDS care work' and Budlender (2002) notes that qualitative data has the potential to inform more nuanced quantitative survey questionnaires.

Budlender has conducted studies on unpaid care work, extrapolating quantitative data from time-use surveys (2002). This method is 'most commonly used to measure unpaid care work because of the difficulties of measuring this activity in any other way' (2002: 21): 'There is no obvious measure of what is produced, because unpaid care work produces intangible services. The main available option is to find out (a) whether people did any unpaid care work; and (b) how much unpaid care work they did' (Budlender, 2002: 21).

Thus, according to Budlender, time use surveys of different kinds are the most common way of implementing research on unpaid care work. However, the data produced shows the types of activities done, and how much time is spent on them (2002: 27). The actual impact, experiences and consequences of care work remain less explicit. The feminist ambition of this study is thus served by a qualitative methodology. What 'doing care work' looks like, and what 'doing care work' means would contribute to our understanding of community care work, and of interest to me, would contribute to a more holistic approach to activism and policy development which serves the needs and rights of care workers. Budlender points this out, stating that quantitative time use studies 'say little about the social and cultural conditions that determine why people do what they do, or why the gender division of labour is the way it is' (Budlender, 2002). Again, I refer to Budlender: 'Small studies allow for more qualitative insights. These insights add to our understanding of what the numbers from the bigger studies mean. Often NGOs or academic researchers are better placed to do the qualitative studies, while government

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statistical agencies are better placed to produce the big numbers' (2002: 27).

My study thus takes its inspiration from Budlender's work, not in opposition to her quantitative methodology, but in support of it; quantifying care work is critical in making it count. Sketching the contours of the 'doing' of care work, what it looks like, what it 'is', what it 'does', and what impacts it has on a range of levels, is critical for making the argument of why care work should count. Further, Budlender goes on to say that a qualitative approach can be beneficial 'if we are interested in changing current patterns of unpaid care work' (2002: 27). In her 2009 study for the Huairou Commission, covering care workers in 6 countries (Cameroon, Kenya, Malawi, Nigeria, South Africa and Uganda), focus group discussions and in-depth interviews were used to generate data. The data was analysed numerically, with the overall research focus being to calculate the minimum monetary value that community carers should be paid. Budlender explains it as follows: [W]e calculate the monetary value of the work done by taking a minimum wage that is paid in each country and multiplying it by the average number of hours worked per week by the volunteers who were interviewed in that country. This shows the minimum amount that government or the organisation with which the volunteer works would need to pay the volunteer if she or he was paid a wage (2009: 20).

The purpose of this exercise was to inform advocacy for the fair (albeit minimum) compensation care workers should be paid 'in return for both the services delivered and the 'saving' that the volunteers are achieving for government … by working on an unpaid basis' (Budlender, 2009: 20). While this research is able to quantify the value of care work, qualitative data can complement this exercise (Fossey et al, 2002: 717) by showing the necessity for quantifying care work, and by drawing attention to the consequences of **not** valuing care work - not only fiscally, but developmentally.

The strength of qualitative research is that it can 'draw from different perspectives,

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methodologies and techniques to generate breadth of knowledge and depth of understanding' which are appropriate for describing and explaining people's 'experiences, behaviours, interactions and social contexts' (Fossey et al, 2002: 718). Quantification can, at times, be 'ill-equipped to develop an understanding of subjective experience, meaning and intersubjective interaction [and] within a positivist paradigm it is assumed that an objective reality, or truth, exists independent of those undertaking the inquiry and the inquiry context' (Fossey et al, 2002: 718).

It is the contextual elaboration, and the focus on particularity rather than generalisability which makes this a popular (but not the sole) methodology in feminist research. It is the interpretive and critical research paradigms which underpin qualitative methodology which contribute to its relevance for feminist scholarship (Fossey et al, 2002). These paradigms 'place emphasis on seeking understanding of the meanings of human actions and experiences, and on generating accounts of their meaning from the viewpoints of those involved' (2002: 719-720).

Through a qualitative methodology, I can adopt a critical feminist 'lens' which focuses on issues of power, illuminates how this research context (and all within it, including the researcher) is socially and historically constructed, promotes self-reflection, mutual learning, participation, empowerment and creates knowledge of social relevance (Fossey et al, 2002: 720-723).

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Methods

Methods speak to the range of actions in doing research. I will outline how I went about sampling, participating in interviews with community care workers, and reporting on my findings. The methods selected will determine the final research product (Little and Carter, 2007: 1325), therefore careful and purposeful selection of method is necessary.

Interviews

This study built on the interview techniques and style piloted in my Honours study. In addition, possible interview questions were piloted in June 2009 with a group of four community HIV/AIDS carers. This pilot revealed that language barriers posed a critical obstacle to my listening to interview participants. Thus, the assistance of a first-language isiXhosa speaker was arranged. Interviews could thus be conducted in the three languages spoken by participants: isiXhosa, English and Afrikaans. This was a critical intervention in my study. I believe it assisted in a more authentic listening and hearing on my part, while promoting the authentic and active engagement of participants in the research experience, and in the data generated - all important tenets of feminist research (Harding, 1997; Letherby, 2003; Roy, 2004; Mbilinyi, 1992; Acker et al, 1996: 75). The pilot questionnaire suggested that depth of meaning could be achieved better if participants were able to communicate in their first language. Concern about being understood, or misunderstood, or expressing oneself accurately, could make it difficult to follow the logic of a narrative, and possibly preclude nuanced, spontaneous meta-statements - both of which add to the richness of the data created, as suggested by Anderson and Jack: 'listening' means listening to a person's 'moral language', taking note of a person's 'meta-statements' where the interviewee is 'watching their own thinking' and being attentive to the 'logic of the narrative' (1991: 19-22)

It is a way of exploring and describing core ideas, themes and issues of a phenomenon. Interview procedures were replicated for each case. Creswell et al (2007: 247) would describe my method as a collective, instrumental case study. Collective refers to multiple cases and instrumental refers to the fact that I identified cases (purposive sampling) to help explicate the problem I intended to investigate.

Data was gathered through eleven interviews with woman community care

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workers. Using dialogical, open-ended, semi-formal interviews with women identified through purposive sampling (Hsieh and Shannon, 2005: 1280), I hoped to explore the lived experiences of community care workers (Chisholm, 2008; Levy and Storeng, 2007; Hsieh and Shannon, 2005; Fraser, 2004; Butler, 1998; Stevens and Doerr, 1997; Langellier, 1994). The findings of this research is therefore limited, however, this method can contribute toward understanding the complexity of the issue; it is not intended to be exhaustive or generalisable across the field of 'community care work' (Lincoln and Guba, 1985; Sinclair, 1998).

In his analysis of texts in qualitative research, Rapley concludes that 'interviewing is the central resource through which contemporary social science (and society) engages with issues that concern it' (2001: 304). However, researchers cannot 'rely ‘unproblematically’ on interview data as a transparent window on life beyond the interview' (Rapley, 2001: 305). Rather, critical and feminist theory have deconstructed interview data as 'reflecting a reality jointly constructed by the interviewee and interviewer' (Rapley, 2001: 305). Because 'a context of discursive control shapes the accounts that [interviewees] give', themes of power, positionality and the context in which interviews are conducted must be acknowledged, accounted for and analysed as part of the research process (Rapley, 2001: 305; Presser, 2005: 2067). In addition, the narrative created to express an experience is always situated (Presser, 2005: 2070). That means, for instance, that accounts are situated within the particular power relations of the research, shaped by class, race and gender, while 'the interview provides participants with certain resources for presenting themselves' in a particular way (Presser, 2005: 2086). In sum, 'stories are constructed situationally' and quite possibly in reaction or response to the positionality of the interviewer. Further, the interview provides an opportunity to behave consequent to one’s narrative of self (Presser, 2005: 2087). Thus, Presser advises

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researchers to assimilate into their observations the research participants' current social situation, which necessarily includes the present research interaction (2005: 2068).

A feminist approach to research encourages reflexivity. I understand this to mean continuously being aware of and analysing the situated, collaborative negotiation of narrated identities in research interviews and the dynamic relations of power within the research setting (Presser, 2005: 2070). In order to achieve this, Rapley suggests that a sensitivity to the interview context be central in the analysis of interview data whatever analytic framework is adopted, particularly the interviewer's role in producing both the form and content of the interview (2001: 304-305).

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Questions

Guiding questions were loosely structured along three themes: 1) recognition and remuneration, 2) working conditions and 3) institutional influences. The guiding questions were informed by the literature and my own experience as an active participant in the field. Despite a guiding structure, interviews remained flexible, as the transcripts show, in order to respond to the particularities of each participant's case (Skjelsbæk, 2006: 378). Simple follow-up questions such as 'Can you tell me more about that?', 'How does that work?' or 'And then what happened?' were posed to expand upon responses in a non-directive manner (Hsieh and Shannon, 2005: 1279; Fraser, 2004: 185). My previous experience showed the value of being prepared for a reciprocal exchange of information, of encouraging a conversational, informal interview style, and of discussing my own investment in the research by way of contextualising the research endeavour (Fraser, 2004: 184). The questions used to guide interviews are listed below, according to three themes:

Recognition and remuneration

- How long have you been a care worker?
- Why did you become a care worker?
- Feelings about being a care worker? Others' feelings?
- What do you call yourself?
- Do you get paid? (salary or stipend)
- If yes, how much do you get paid?

Working conditions

- What do you need to do your work?
- Do you have what you need?
- When do you work?
- Where do you work?
- Tell me about your day: What do you do? How do you feel?
- What do you worry about?

Institutional issues

- Have you received any training?
- Tell me about your organisation?
- Do you know about the community care worker policy?
- What would you like to add?
- What would you like to ask me?

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Sampling

Interviews were conducted with eleven participants. The type of sampling employed could be described as community-based purposive sampling (Stevens and Doerr, 1997: 524). Sampling was purposive and theoretical, as one of the main objectives of this study was to interrogate and explain the phenomenon of community care work (White and Marsh, 2006: 36-37).

AIDS Response facilitated the recruitment of community care workers from community-based organisations. Of the organisations which showed interest in participating, I selected three for the following reasons (a) one was located in an area of great need and well-resourced, (b) the other was located in an area of great need but extremely under-resourced and (c) the third organisation was situated in an area of comparatively different demographics. Four community care workers from each

organisation volunteered to be interviewed.

Of the original twelve, eleven participated in the study. One participants withdrew owing to scheduling difficulties. More than half of the interviewees were black, isiXhosa-speaking women (64%), with 36% self-identifying as coloured, with Afrikaans as their first language.

The organisations noted in (a) and (b) above were both in Nyanga, Cape Town. I thought it would be interesting, for comparative purposes, to explore the experiences of community care workers 'located differently' in the same community. The organisation noted in (c) is based in Tafelsig, Cape Town. Due to demographic differences, again, I thought this would allow for a small degree of comparative data to emerge, while allowing the possibility of different issues to emerge.

Thus, the analysis will allow for description and comparison of the following sub-groups of community care workers: (a) community care workers in well-resourced and under-resourced organisations; (b) community care workers in Nyanga (demographically black with high levels of poverty) and community care workers in Tafelsig (demographically coloured with high levels of poverty). The descriptions below are taken from my research notes, written at the start of the interview phase (2009):

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> *Organisation (a) is well-resourced and is a respected institution in the community. It runs many different programmes, from day care for working, single mothers, to nutrition programmes. There is also an income-generating programme. The organisation sits in a lovely, landscapes space. There are 4 stand alone buildings. They are simply constructed but pleasant, airy, with a lot of light. The grounds are filled with well-kept vegetable patches. Everything is clean and neat. It feels like a sanctuary, an oasis in the middle of the hustle of Nyanga. Everyone greets me. The mood is relaxed. The women in the sewing room are singing, and I can hear children's voices laughing and carrying on upstairs in the day care centre.*
>
> *Organisation (b) operates from the backyard of the Director's home. The home itself is dilapidated. The ceiling is water-damaged. The coordinator sits at a desk in what looks like a combined kitchen-bathroom. There seem to be many people living on the premises. The garage seems to be divided into three sections, with about 3 or 4 people in each section - I assume they are families. It seems chaotic. There is a huge dog covered in sores. Dog faeces everywhere. Lots of flies. It smells really bad. When the care workers arrived, they took me to a broken down caravan in the front garden. I'd*

walked past it on my way in and just assumed it was scrap. We enter the musty caravan from the side which is titling severely. I'm not sure if it's strong enough to hold all five of us. But I follow everyone in. It seems like a storage area, various rusted garden tools, plastic sheeting, and so on. It smells really bad in here too. One care worker tells me this is where they have their meetings. It seems that whatever funding there is, its not going to the carers, or to the organisation per se. I feel a sense of tension among the carers. They are not very talkative. They seem guarded, cautious, and in a hurry to leave.

Organisation (c): There are many people sitting on the sidewalk, most of them seem young, teenagers. The organisation's office has security gates and burglar bars. The perimeter wall is topped with barbed wire. The office is an old house. It has 4 large rooms, and a big kitchen. Despite being old, it is immaculately clean. There is a bustle of activity throughout the house. I'm told they're preparing the food for the soup kitchen. I can smell 'mielie pap'. The furniture seems brittle and broken, like old school desks and such. There is a fifth room which is used for counselling patients and treating wounds, applying dressings and so on. This is the room where we conduct the interviews. It's a little cramped, but it's cheerful. There is a bed with bright blankets and pillows, and a few stuffed toys. The walls are bright yellow and appear freshly painted. There are lots of HIV, TB and general health awareness posters. It seems like someone took great pride in fixing up this room.

Nyanga is one of the poorer townships in Cape Town, with extremely high homicide rates (Norman et al, 2007). A socio-economic profile collated by the City of Cape Town in 2006 shows that 56% of the community is unemployed, and about 80% of earners earn less than R1600 per month. The population is 99% black African, with 97% speaking isiXhosa as a first language. In terms of housing, Nyanga is almost split down the middle, with just over 40% of residents live in informal dwellings (e.g. shacks or backyard dwellings) and just under 40% live in brick structures.

Tafelsig forms part of Mitchells Plain. This community is 89% coloured with 57% speaking Afrikaans. Only half of the population is economically active (City of Cape Town, 2006). About 40% of earners earn under R1600 per month. With respect to housing, 67% of the population live in brick structures, with only about 4% living in informal structures (City of Cape Town, 2006). The following table summarises the demographic data pertaining to carers' communities. The map indicates the geographic location of these communities relative to central business district of Cape Town.

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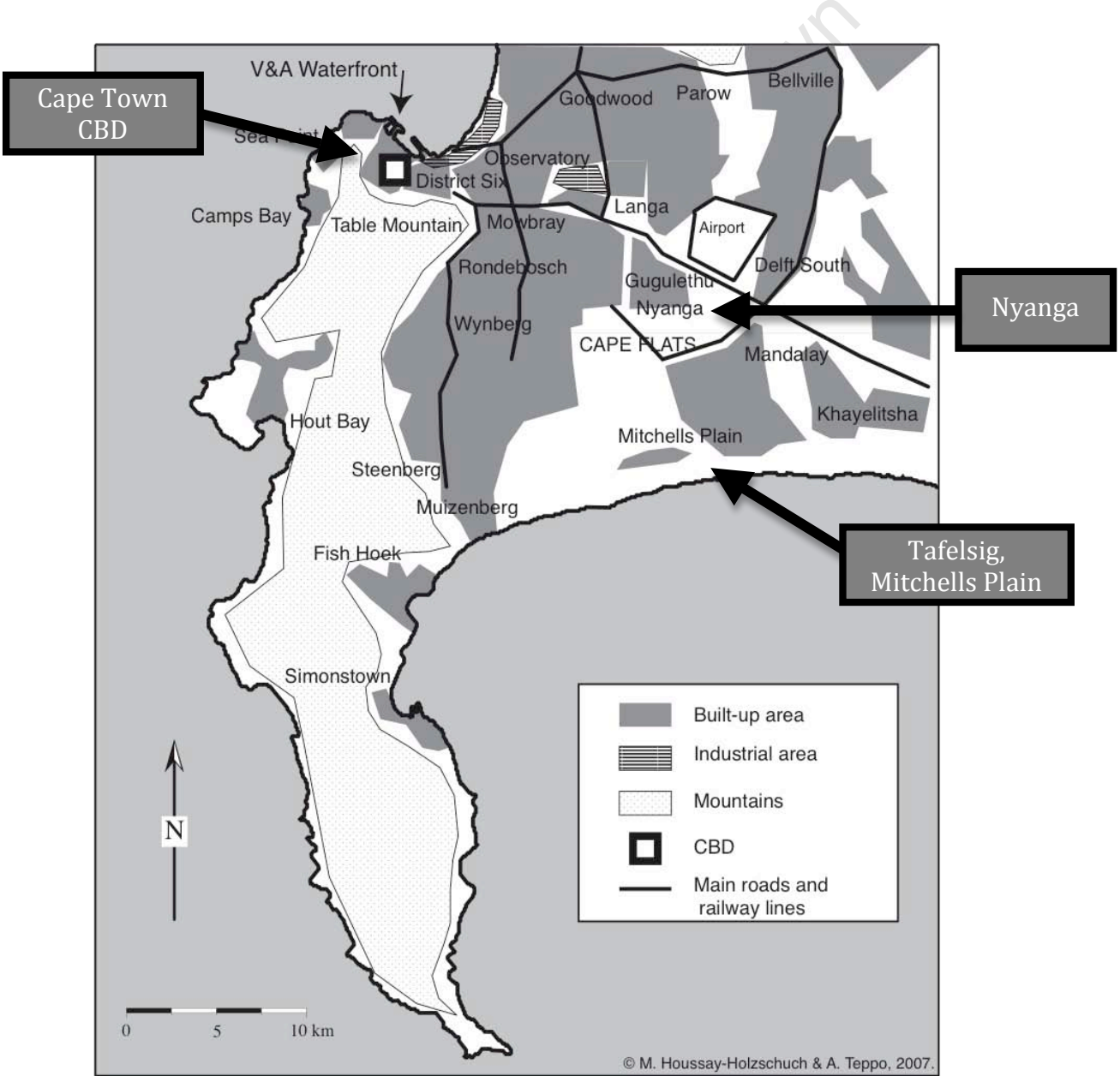
Table: *Comparative indicators for Nyanga and Tafelsig, (Statistics South Africa, Census Data 2001)*

Indicator	*Nyanga*	*Tafelsig*
Unemployed	*56%*	*50%*
Race	*99% black*	*89% coloured*
Language	*97% isiXhosa*	*57% Afrikaans*
Informal dwellings	*40%*	*4%*
Brick structures/houses	*40%*	*67%*
Earn less than R1600pm	*80%*	*40%*

Image: *Map of Cape Town showing Nyanga and Mitchells Plain (Statistics South Africa, Census Data 2001)*



Translation

Feminist scholarship on translation theory again emphasises the need for reflexivity. Issues of power, difference, and culture, of representation and de/re/construction of meaning, and the situated nature of knowledge and its creation must be interrogated (Wallmach, 2006; Twinn, 1997; Drennan, Levett and Swarz, 1991). The translation process is a specific example of how research methods can 'bind the knower and the known together in social relationships of domination and subordination typical of the race, class, and gender-stratified society in which science is produced' (McDowell, 1992: 407).

The meaning I create, that the translator creates, that the interviewee creates, comes from somewhere, it 'cannot be unplaced, it cannot be un-positioned, it is always positioned in a discourse' (McDowell, 1992: 408). Shread refers to a 'politics of translation' (2011) and asks:

> *Is feminism simply a politics that informs, acting through textual representations, or does it go deeper, working at a formative level that is constitutive of the translation? … I have come to see feminism … as a formative influence that inflects the translation process. Making the distinction between formative and informative aspects of translation allows me to untangle the ways in which feminism is not just a politics seeking to inform representations but also a critical disposition that impacts the art and practice of translation … part of the 'becoming' of translation (Shread, 2011: 283).*

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Critical feminist theory calls for researchers to 'recognise and take account of our positions, as well as that of our research participants, including translators, and write this into our research practice' (McDowell, 1992: 408-409). Furthermore, our own interests, dispositions and politics must be visible in the 'becoming of translation' (Shread, 2011). This is more effective and honest than claiming 'some idealised equality' between all engaged in the interview process (McDowell, 1992: 409). To this end, I attempt to describe my method here.

Twinn (1997) suggests conducting the interviews in the language of the

participants. Issues of clarity are also best addressed at the time of the interview. This is important because translation adds another interpretive layer to the 'making of meaning' and could potentially complicate ambiguous statements at the analysis stage (Anderson and Jack, 1991). Thus, the interviews were conducted in a 'triadic' conversational style. I posed the interview questions. The translator translated as and when requested by the interviewee. Some participants chose to respond to the translator, who translated responses back to me in English. These response were recorded as part of the overall interview transcript. In this way, both interviewer and interviewee, facilitated by the translator when necessary, could discuss and clarify meanings and interpretations. Furthermore, the same translator facilitated all interviews, an important aspect for maximising the reliability of the study, as argued by Twinn (1997: 423).

Researchers have acknowledged the significance of what I refer to as the 'translation moment' in qualitative data: 'translation [is] neither a nuisance value nor strictly a technical problem but the very essence of ethnographic research' (Twinn, 1997: 419).

Another point worth noting is that the translator was not familiar with the subject of the interview. I selected the translator deliberately to meet specific criteria I hoped would enhance my research (Skjelsbæk, 2006: 378). I sought a woman who identified as black South Africa, who spoke isiXhosa as a first language, and who was also comfortable in English. I was fortunate to engage the support of Weziwe Buti, a translator who identified herself as a black woman, 'born and raised in Gugulethu'. She is a teacher in a local primary school, and is an adult language teacher: she teaches English speakers isiXhosa, and isiXhosa speakers English. Her location as a woman 'from the townships' located her closer to the interview participants, racially, culturally, economically and geographically. Her language skills, I hoped, would limit interpretation difficulties for both

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myself as interviewer, and the interviewee. The translator's ability to connect as a peer, as more similarly located than myself, the interviewer, was evident. Research participants seemed immediately at ease with Weziwe, and the interactions between them made the research 'setting' a much more interactive exchange. This seemed appropriate as most interview participants experienced a range of emotions while telling their stories and Weziwe was able to provide comfort as a peer. I also felt that Weziwe's presence validated my position and mediated my identity as 'white', 'outsider' and 'researcher' in the township. In comparison with the isiXhosa pilot interviews conducted without the translator, these interviews were more conversational, longer in length, evinced greater detail with less occurrence of ambiguous answers. Weziwe was the only translator engaged in this study to enhance consistency. As noted by Skjelsbæk, my interviews are a construction of three voices: the translator, the care worker, and myself, the researcher (2006: 378).

The Afrikaans interviews require some consideration. I am bilingual in English and Afrikaans and did not use a translator in the four Afrikaans interviews. As Afrikaans is my first language, translation happened almost unconsciously during transcription. It was only after the fact that I realised this, and this is important to note. When it caught my attention I returned to the interview recordings to assess if I could identify any differences between the Afrikaans interviews and the English and isiXhosa interviews. I did notice that the Afrikaans interviews were much more conversational, that both the interviewee and myself mixed English and Afrikaans throughout our conversations and that a higher degree of personal detail was accessed. This may confirm Twinn's (1997) argument for conducting interviews in the first language of the interviewees, and I would add, that this experience, coupled with the experience of having a translator present, adds to a more relaxed exchange and enhances opportunities for accessing in-depth 'stories'.

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Analysis

Content analysis, under the broad rubric of 'textual analysis' is concerned with 'meanings, intentions, consequences and context' (Elo and Kyngäs, 2008: 109; White and Marsh, 2006: 23), this making it suitable for a feminist approach (Sow, 1997). According to Hsieh and Shannon, the goal of content analysis is 'to provide knowledge and understanding of the phenomenon under study' (2005: 1278). Adopting the conventional approach to qualitative content analysis, the overall study design is aimed at identifying a problem, describing a phenomenon and 'concept development' (Hsieh and Shannon, 2005: 1279-1281). White and Marsh describe this as a method to generate 'a composite picture of the phenomenon being studied [which] carefully incorporates the context, including the population, the situation(s), and the theoretical construct' (2006: 39). The goal is to depict the 'big picture' of a given subject, showing 'conceptual depth through thoughtful arrangement of a wealth of detailed observation' (2006: 39).

Content analysis is a research method for making replicable and valid inferences from data (inductive content analysis) to the contexts of their use, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action (Elo and Kyngäs, 2008: 107-108; White and Marsh, 2006: 23-27). The method practically involves identifying patterns, trends and themes (White and Marsh, 2006: 34) in the interview transcripts, observation notes and selected texts.

It is thus a useful method when data on the phenomenon is limited (Hsieh and Shannon, 2005: 1279), as it is in this case (Lehmann, 2008: 165). Content analysis facilitates the generating of knowledge based on participants' own, unique experiences and perspectives, grounded in the actual data (Hsieh and Shannon, 2005: 1280). Content analysis can assist in capturing the complexities of these experiences (Hsieh and Shannon, 2005: 1279) while distilling the multi-faceted phenomena characteristic of care work (Elo

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and Kyngäs, 2008: 113). The literature also shows that inductive content analysis, for these reasons, is a frequently used method in public health studies (Elo and Kyngäs, 2008: 107).

Hsieh and Shannon note that one of the challenges in using content analysis is that misinterpretation and inaccurate data can arise if one does not pay attention to context (2005: 1280). In addition to incorporating methods of data creation which are attentive to the complexities of contexts, Hsieh and Shannon advise that complementary methods of analysis be adopted to ensure internal validity of the research (2005: 1280). Being attentive to what Marsh and White refer to as the 'hermeneutic loop' (2006: 35) is another mechanism toward creating accurate data. This means understanding content analysis as an iterative process of 'recontextualising, reinterpreting, and redefining the research until a satisfactory and logical interpretation is reached, embedded within the data' (2006: 34-35).

White and Marsh (2006) outline the steps of content analysis: a) sample text, in the sense of selecting what is relevant; b) unitize text, in the sense of distinguishing words or propositions and using quotes or examples; c) contextualise the text in what I know about the circumstances surrounding the text; and d) have specific research questions in mind. An inductive approach is necessary because this research is not concerned with testing hypotheses; rather, foreshadowing questions guide the research and influence the data gathered (White and Marsh, 2006: 34).

Qualitative content analysis involves a process designed to condense raw data into categories or themes based on valid inference and interpretation. Inductive reasoning is used when studying the text, and is focused on themes and categories which emerge from the data through constant comparison. But qualitative content analysis does not need to exclude deductive reasoning. Generating concepts or variables from theory or previous

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studies is also very useful for qualitative research, especially at the inception of data analysis (2009: 309).

Zhang and Wildemuth note that meaningful analysis strives for a 'balance between description and interpretation', providing quotes and other data to provide 'adequate representation of the constructions of the social world under study' (2009: 12-13). In addition, 'prolonged engagement in the field, [and] persistent observation' contributes to the credibility of one's study.

Identifying themes and patterns is central to content analysis. Braun and Clarke (2006) offer guidelines to thematic analysis, which are applied across methods of qualitative analysis rather than as a 'stand alone' method (2006: 78). It is a method 'that works both to reflect reality and to unpick or unravel the surface of reality' (2006: 81). Acknowledging the process of thematic analysis is critical as it is the foundation of content analysis. A theme, according to Braun and Clarke (2006) 'captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set ... the 'keyness' of a theme is not necessarily dependent on quantifiable measures – but rather on whether it captures something important in relation to the overall research question' (2006: 82).

Braun and Clarke (2006) raise an interesting point in the previous quote, the importance of a theme, or the justification of foregrounding a theme, is not predicated on the number of times it occurs in the text. As a qualitative researcher, I am not bound to limiting my themes based on the frequency with which they occur. Thus, a community care worker's experience is not validated by its commonality; its individuality is as relevant to the interrogation of carers' experiences. In this way, I am able to work within a feminist theoretical framework which takes the individual, the subjective, and the specific to be of value in understanding a social phenomenon.

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Thematic analysis also enhances the gender analysis of this research in that it takes a constructivist perspective. Analysis is not merely descriptive, but also theorises as it takes meaning and experience to be socially constructed (Braun and Clarke, 2006: 84). As a whole, thematic analysis considers the broader social context when making meaning of people's experiences and when attempting to understand how people make meaning of their own experiences (Braun and Clarke, 2006: 81). In this study, content analysis involves

> *'Coding' or 'scoring' verbal material for content and style for the purpose of making inferences about, or assessing, the characteristics or experiences of persons, social groups, or historical periods (Smith, 1992: 4).*

Conclusion

Through this research design, I hope to explore the experiences of women HIV/AIDS community care workers and make meaning out of their own representation of their experiences; understanding these meanings in the era of HIV/AIDS. In an attempt to produce feminist research on a topic of feminist concern, I have tried to delineate a feminist approach to knowledge creation. Most importantly, I have chosen approaches and methods which take seriously the day-to-day realities of community HIV/AIDS carers and which can incorporate feminist strategies such as Nussbaum's (2000) capabilities approach. How this is realised will be the purview of the next two analytical chapters.

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Chapter 4

ANALYSIS I

Capability Deprivation

Introduction

My analysis applied Nussbaum's notion of the capabilities approach (Nussbaum 2000; 2001; 2010) to the research data. Interview data was categorised according to themes purposively chosen to surface the experiences of women community care workers through their own representations. I categorised their responses to interview questions according to four of Nussbaum's ten 'central human functional capabilities' (2000; 78–80).

The capabilities approach is described by Nussbaum as 'an approach to comparative quality-of-life assessment and to theorising about basic social justice' (2010: 18). Thus, I adopt elements of this approach in an attempt to reveal how doing care work may affect carers' agency, rights, and their ability to 'lead the kind of lives they have reason to value' (Sen, 1999: 10-11). The capability-categories applied are: (1) bodily health, (2) bodily integrity, (3) emotions, and (4) material and political control over one's environment.

The categories were chosen with the intention of accessing an analysis of carers' representations which could reveal the impacts of doing care work. Taking into account the literature and carers' concerns as shared with me over the last five years of my activist work, the capabilities approach appeals to me as a way of exploring these concerns. I propose that the capabilities approach to development may be able to frame and articulate carers' representations in a way that provides an argument for re-engaging with existing theory. The feminist development framework in which Nussbaum's capabilities approach is grounded contextualises this argument, providing evidence that care work in the era of HIV/AIDS is especially shaped by poverty, power and gender.

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Bodily health

Care work represents a complex web of risk to those undertaking it. From the data, we learn that carers feel 'exposed in many ways'.

> *We are exposed in many ways. Like TB. If there is a client lying down, and you don't know which sickness that client has, and then you go there without wearing anything. That can lead you to also be sick. We are exposed to those things. (C)*

Perhaps the most obvious precaution required in HIV settings is gloves. Only one organisation supplied gloves to carers, and this was only when supplies were available, so thus, not routinely. The other two organisations did not supply gloves, or other basic equipment.

> *What kind of equipment do you get?*
> *Everyday, you must use gloves. But at [organisation] eish, there is a shortage of equipment. Sometimes, hey! – you're using the plastic bag over your hands. If you are lucky, you use those small plastic bags, that they put the meat in at Shoprite, and you put the elastic around your wrist. And then the dressings, sometimes there are no bandages. You have to ask the patient to wash their bandages so they can use it again. (D)*
>
> *We need masks too, but we don't get masks all the time. (G)*
>
> *Do you feel that you are protected when you do this work?*
> *No gloves. No nothing here. They don't give us. Maybe we don't ask, so I don't know. But I have no materials, or gloves, here. (B)*

The data confirms the lack of basic protective equipment, such as gloves and masks. One carer's account tells of a colleague contracting TB:

> *There is one care worker here who was infected with TB ... I asked her what is going on, because I've noticed some difference. I told her, the reason I am saying this, is because I had my sister who had TB. The care worker cried to me, and said she was afraid. (C)*

An earlier quote states: 'Maybe we don't ask, so I don't know. But I have no materials, or gloves, here' (B). Here the carer expresses a need to request essential equipment. There does not seem to be an expectation of the right to protection which a formal employee would take for granted, such as a nurse.

All carers in this study reported taking care of clients' wounds. It is clear how

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working with infectious clients' open wounds may expose carers to infection. In a context where carers may be HIV-positive themselves, re-infection and increased viral load for the client is also a concern. While HIV transmission through exposure to wounds is not as likely as a direct exchange of bodily fluids, the severity of the wounds cause carers concern.

> *I hear a lot about wounds. What kind of wounds do your patients have?*
>
> *They get deep deep deep wounds. If they are not taken care of they get infected. And when they are infected its not easy to wash them. Their wounds are not always taken care of. It's mostly from the bedsores. And sores from stage 3 and 4 [of AIDS]... but we get a very minimal amount of equipment from [our organisation]. There are very little bandages. Gauze is scarce too. And it's first come first serve for equipment. Sometimes we work for 2 months without gloves. The bandages we cut up to use as gauze to treat the wounds. (F)*
>
> *The clients with bedsores, those holes get bigger and bigger … I could fit my whole face into one of his holes. (H)*

Carers also reported that bathing their clients is a routine part of their work.

> *If your client is lying down. You first help her. You wash her. You make the bed nicely. Then you put your client in bed. Then you clean the house. (A)*

Some carers are of the opinion that, because clients are alone and often immobile, their hygienic care is limited. Physical proximity to unhygienic conditions, open wounds, excrement, and the small, confined spaces in which carers work, all contribute to an environment in which risk of infection is high.

> *The children don't look after their parents. For us, it's very hard to see that. How can you…its your mother? The patient lies in shit the whole weekend, and when we come on Monday, we have to deal with that mess. They don't care. And if we don't care, who's going to care for them? (H)*
>
> *It was very bad in the house, a new client. It smelt bad. I said 'oh my god'. It was a grandmother … That house was so small. Small. So small. There is no window. No light from outside. The small house, with the father, mother, the grandson, they are 4 in this small house. The bed is terrible, its is dirty. It's got a bad smell. They can't look after the grandmother there (A).*

The physically taxing nature of care work may cause additional challenges to physical health. As discussed by participant A and B, carers walk from client to client, noting the

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additional expense of paying for public transport as prohibitive.

> *How do you get to your client?*
> *Like how do you mean?*
> *How do you go there?*
> *I walk.*
> *And are all your clients in Nyanga?*
> *Some are in Polar Park, and Gugulethu. There are 3 not in Nyanga. I have to use the money from my own pocket if I want to catch a taxi.*
> *Do you use transport?*
> *Only to Polar Park – it's a bit far. But in Nyanga, I walk, whether is raining or not. I walk. (A)*

> *Where are your patients?*
> *They're in KTC. And some in Nyanga.*
> *How do you get around?*
> *Hayi, I walk.*
> *All the time?*
> *Every time. It is part of the work (laughs). Raining or what, it is the work. The whole year. (B)*

Participant D spends up to 4 hours with a client, while having others to see in the same day to meet targets. The work includes lifting, bathing and assisting the client with physiotherapy. Participant H said: 'We do physiotherapy, everything. That is all in our job.' Participant K confirms this in our exchange:

> *So the work is quite physical?*
> *Yes. And lifting the clients, and bathing them. It's very tiring. (K)*

Ensuring that the necessities are in place for 'doing' care work pose additional physical burdens.

> *Water is a main issue. Sometimes the taps are far, or sometimes there is no water in the taps … I must find the tap, and walk far, with the 25 litre bucket. Hey, it is difficult … (D: 150-154).*

Nussbaum defines 'bodily health' as a central human functional capability, as 'being able to have good health' (2000: 78). In the broad context of HIV and poverty, and the specific context of care work, it would not be inappropriate to extend health to include the overarching central capability of 'life', defined by Nussbaum as 'being able to live to the end of a human life of normal length, not dying prematurely, or before one's life is so reduced as to be not worth living' (2000: 78).

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Yet, the data reveals a range of inter-weaving factors which have bearing on a carer's ability to remain healthy. The most obvious is the risk to health posed by infections: the data shows that carers are at risk of HIV and TB infection and being susceptible to illnesses which could compromise already weakened immune systems. This risk is compounded by a lack of resources in the poor communities where carers work. A lack of basic protective devices and supplies (such as gloves, masks and disinfectant) and poor service delivery (a lack or running water and sanitation, over-crowded homes with poor ventilation and poor hygiene) constitutes a hazardous working environment. The data reveals that many carers may be sick themselves. The physically demanding nature of care work can pose an additional challenge to good health. Whether bathing or lifting clients, providing physiotherapy and cleaning, or walking extensively owing to the prohibitive costs of transport for a stipended carer (carers may walk up to 2 hours per client), or because of poor service delivery (carers often have to collect water from communal taps and carry buckets of water to the client's home), carers are fatigued. 'We are also hungry people' notes participant B, which implies that fatigue is exacerbated by a lack of nutrition due to carers' own financial precariousness. Thus emerges a complex picture of carer's ability to remain in good health.

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Bodily integrity

Bodily health is closely related to the capability Nussbaum calls 'bodily integrity', defined as: 'being able to move freely from place to place; having one's bodily boundaries treated as sovereign' that is, 'being able to be secure against assault, including sexual assault' (2000: 78).

Common to all interviewed carers' work experience is that they walk from client to client, from house to house. One carer sums up this experience: 'because we are walking,

we are not safe' (G).

A complex web of historical, political and socio-economic factors combine violently within the context of care work. Carers frequently confront the high rates of crime in their communities, as the following statements show:

> *We need to be safe. We are not safe. We get mugged. Because we are walking. People notice us. They think we have money. That is why we stopped wearing the uniform, because they think we are nurses, which means that we have a lot of money. (E).*
>
> *The walking. It is far. It is not safe. You don't feel safe. You get robbed by the skollies [gangster, hoodlum] (G).*
>
> *Do you experience any violence?*
> *Its just sometimes…if I know someone is on drugs, you know, they can get crazy. So I'll just keep my mouth and walk past the person. And that's why we don't go alone. We go two-together. Because in the morning, its very quiet. You get scared sometimes. You don't know if someone can come up behind you. That's why we go with someone.*
> *So it's good that you don't walk alone?*
> *You can't walk alone. It's too dangerous.*
> *Have you experienced any violence?*
> *No. Luckily not me. But there are times when I feel really scared. I was walking from my client, and I was walking with another care worker, and I saw a guy with a gun. So I said [to my colleague] 'let's walk fast' and she asked what was going on. When we got to the office I told her, and my heart was going so fast. (I)*

In the above responses we see the complicated nature of violence, threat of violence and fear. The surveillance and recognition of care workers is a manifestation of 'threat'. Poverty is the vehicle through which this surveillance operates: 'they think we have money'. Being safe means being invisible. I am reminded of the major challenge in achieving recognition for carers, namely, the invisibility of their work. Increased visibility could be undesirable, and unsafe, in this context. Safety also means never being alone, 'that's why you go with someone…you can't walk alone. It's too dangerous' (I). Substance misuse is articulated as a major factor in the existence and experience of violence: if 'someone is on drugs, you know, they can get crazy'. Here violence is experienced as random. It is also pervasive: 'skollies' abound; and inevitable: 'we are getting used to it…what else can we do?' In another interview, a carer responds to the question 'Are you

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safe?'

> *No. Not at all. That's why we go in twos. But we have to leave our earrings, cell phones, everything at work. (K)*

Here being safe means downplaying the performance of gender. If one way of performing gender is 'through the stylization of the body' (Butler, 1988: 519), carers have to remove, or hide this particular part of their identity to be safe: again, the notion of invisibility comes to the fore. In a country with high levels of gender-based violence, fear of violence includes fear of sexual violence. Carers face the risk of assault and rape while walking from home to home. In some communities, care workers reported that they are not safe when visiting in a client's home:

> *You are never safe at a client's house...it is not so good here...it's the community itself. It's very hard sometimes. (H)*

Violence or the threats of violence are challenges to carers' bodily integrity. Movement is not free, nor are bodily boundaries treated as sovereign. It can be seen, in many ways, how carers may not necessarily have the wherewithal to secure their own bodily integrity. While carers are predominantly women, marginalisation and high rates of gender-based violence conspire in particular vulnerabilities and threats to their bodily integrity.

Participant J reflects on the nexus of violence and gender in another way: unsafeness is interpreted through her identity as a mother.

> *It is not good, this job. Because I'm not secured in those places I have to walk. Like Gugulethu, New Cross. Sometimes you get attacked. Who will take care of my child? (D)*

This echoes previous statements where carers reflect on the risk to their health through a concern for family: what will happen to my family if I am attacked, become sick or die (most carers in this study were breadwinners and single mothers), what will happen to the family if I cannot afford a funeral policy or if I default on my funeral policy because my

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stipend was not paid on time, or I was ill and was unable to work? There is great anxiety that the cost of their care work will manifest in being unable to fulfil their roles as mothers; safety is being able to be a mother.

Carer J highlights the degree to which violence is normalised in many South African communities, especially where people live in already adverse circumstances. In a previous quote she said 'we are getting used' to violence. Not only is the overall context of care work disabling, it constitutes 'structural violence' as described in the literature. The fact that one has to 'get used to violence' as a daily reality is in itself a form of violence. Violence is normalised and pervasive. Carers are not safe around people, on the street or in a client's home, nor are they safe in the absence of people: whether they are watched (E), or find themselves in quiet spaces, carers 'get scared' (I).

Carers do, however, view safety as a 'right', albeit a right they are not always able to realise.

> *We do have rights also. It's not just 'you must do this and that'. They must …support us. They must give us transport. And our safety, that is important. (H)*

In the quote above, lack of safety can be seen as a manifestation of carers' exploitation: 'its not just "you must do this and that"…our safety, that is important.' The lack of transport, the fact that carers walk from client to client, is perceived throughout carers' responses as a key, but not sole, source of their lack of safety.

Participant D also articulates safety as a client's right.

> *What will the uniform mean?*
>
> *The reason we need a uniform is that the people [pause] I'll make an example. Like the police, you know when you see a policeman. You can identify them. I think there could be problems. Maybe someone can go into a house and say they are a caregiver, to see if the patient is alone, then they steal everything. But if we have to have a name badge, the uniform, if we need to be registered, then we can't do funny things to the patient. You know, the people who are not the volunteer care giver, their hearts are not the same. It is better for the patient if we have uniforms. (D)*

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In this, the complexity of 'rights' emerges. A uniform, as an above quote by participant E indicated, is an identifier, something which makes carers more visible, and according to participant E, less safe. However, the uniform protects the client, and prevents people from 'doing funny things to the patient' (D). The complexity of safety in the context of poverty and lack presents a dilemma: whose rights matter, or matter more? Considering the feminisation of care work, and pervasive gender inequality, whose rights are more likely to be compromised?

Emotions

The discussion of violence as it pertains to bodily integrity revealed the high degree of fear in which many carers operate. In addition, the discussion on 'bodily health' revealed experiences of stress and anxiety, mental anguish and fatigue. Nussbaum lists 'emotions' as a central human functional capability, noting that one should 'not have one's emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect' (2000: 79). The context of HIV/AIDS care revealed thus far, compounded by poverty, inequality and violence, depicts care work as emotionally distressing.

Caring for stage 3 and 4 AIDS clients, as well as a range of chronic illnesses, means that death is a daily reality for care workers. Grief and bereavement are routine, as participant A's moving account reveals:

> *Sometimes it's very painful. You make a relationship with the client. Then they get used to you. The most difficult part [pause] you go to the client everyday, and you see the client is getting weaker and weaker. And then you go there, and your client is getting better and better and better. Then after that, you think to go check again, and I find out that the patient died the day before. It's too hard. You cry. You cry and cry.*

Participant J shares a similarly evocative experience of grief:

> *It's very hard. When you get attached to your clients, its very hard. You know, when they've been terminally ill for a long time, its very hard too.*

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> *And this morning, I was at a funeral. I buried a patient, she was just 22 years old. (J)*

There is an added element to carers' grief: all carers were mothers, and the experience of burying the younger generation, a phenomenon now all too familiar in the era of HIV/AIDS, is particularly traumatic: 'she was *just* 22 years old'.

Most carers face competing burdens, in the home, in the community, with their clients – all in myriad adverse contexts. The literature on emotional stress and burnout within the caring professions is extensive (Condon, 2010; Van Dyk, 2007). This is exacerbated by the psychological repercussions of assault and violence, or the threat of living in fear thereof. Safety emerged in the section on 'bodily integrity', revealing the almost constant fear, and expectation, of violence. Safety, or lack thereof, is also reflected through being a witness to violence.

> *What are the main issues you see?*
> *I see a lot of domestic violence going on. Basically, it's the drugs.*
> *And alcohol?*
> *It's more drugs than alcohol. And the poverty. It goes hand-in-hand.*
> *Can you tell me about the domestic violence?*
> *Its mostly men abusing women. But also, children are abusing the parents. This is because of tik, mostly. (I)*

Participant G's experience reflects how violence impacts on her emotional state, and in turn, impacts on her ability to provide 'proper' care.

> *…because we are walking, we are not safe. At times, when you see bad things happening, it hurts you. And that makes you stressed. And you don't do your work properly because you are thinking about what you saw. (Gτ)*

The exchanges above interpret the emotional experience of violence, or being unsafe, as impacting negatively on one's ability to care. Participant E also reflects on an experience which impacted on her ability to care, an experience which articulates the nexus of insecurity, poverty, failures in state responsibility, and the simultaneous emotions attached to experiencing trauma:

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> *… you get to a house, where someone must take ARVs. But you find out there is no food in the home. In the past, social services used to give us food parcels to take with to these houses, so when they have to take medication, we can give them food. But this stopped, because the money got stolen. [Our organisation] got robbed, at gunpoint. (E)*

The significance of the emotional repercussions connected to care work is amplified when learning that many carers come to care work through personal experiences of HIV/AIDS. The following excerpt is an example:

> *She first experienced this with her own husband. Her husband got sick for 3 years and she had to take care of him. For three years. Until he died. And he died in her hands. (Gτ)*

Complicating emotional stress is the issue of relative poverty. In addition to the concern expressed about their own economic precariousness, carers also expressed concern about the extreme impecuniosity of their clients. Poor themselves, most carers in this study earned a stipend of R750 a month (considerably below other low wage incomes); carers' clients had even less. Participant K notes: 'You have your own problems, and now you face a client in need, so it's hard.'

Participant D reflected on the negligible compensation for her work, and the deeper implications of her economic vulnerability.

> *It is not enough. Because, I'm using a taxi, a 'cockroach'. A week is R50 to get to [my organization]. So R200 a month. So now, that is R550 for the month. So R50 rand goes to my insurance, for when I die, it helps to bury me. My rent is R260. Sometimes you don't want to stay with a boyfriend, you want to be independent, you want to be on your own. But you can't afford it.*

The way in which participant D articulates her desire to be on her own, to be 'independent', illuminates the gendered ripple effect of doing care work. We see the reality of a woman engaged in care work, the low economic value attributed to her work, and we see how her economic participation yields little financial reward or opportunity to realise that which is of value to her: her independence. Her work is fulltime. She does not have time to generate additional income. One of the few survival options open to her is to 'stay

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with her boyfriend'. For D, her independence, her ability to fully realize her agency in a way which is of value to her, is unaffordable.

Participant B states clearly that her financial situation is a 'worry'. As noted earlier, there is a connection between bodily integrity, through insecurity, and motherhood. In the quote below, carer B links her health *and* her lack of income to a sense of familial responsibility: if she gets ill, if she dies, she cannot afford to make the necessary provisions which will alleviate her family of the financial burden of a funeral.

> *My worry is that we care about the people, give hope, love, but one of the days, it will be you. Who is going to care for you? I don't have a salary. It's a stipend. We don't have benefits. How can you afford a policy if you've got R750? Because you're hungry. You don't even have a policy. You will die, and you will have no policy. No burial policy.*[6] *These are the worries.*

It is interesting to note that participant B phrases her concern as 'one of the days, it will be you'. Her concern is not about the risk of getting sick, her concern is for *when* she gets sick. In hindsight, it would have been of interest to explore further her articulation of the inevitability of becoming ill. Is she currently ill? Or are there more complex contextual factors which may inform a person's state of mind vis-à-vis her longevity? The distress caused by financial insecurity, thwarted desires and a lack of hope adds complexity to the notion of emotional well-being.

Despite this reality, carers reflect that their clients think that they, the carers, are 'better than them'.

> *We sometimes take money from our own pocket. They see us as hope. They see us as better than them – even when we only get R750. They don't know we only get R750. They think we are a better person, with more money. They don't know that we are hungry people. So we must get them something to eat. You must take out of your pocket and get them something to eat (B).*

[6] Participant B is an isiXhosa woman who is concerned about the cultural expectations and norms connected to funeral rites. Usually lasting several days and involving gatherings of extended kin and community, many want to contribute to the considerable financial outlay they know their funeral ceremony will incur on their family. As the quote above reflects, not being able to make such provisions can be a cause of distress. The issue of funeral policies came up frequently in my discussions with care workers. Participant D notes it as one of the three items she spends her stipend on: rent, transport to her work, and her funeral policy.

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Participant D also notes:

> *...it is difficult, because sometimes, even me, maybe I have no money to buy paraffin. And you need paraffin to boil the water. This situation is not alright. It is difficult…I use the green soap, the Sunlight. Everywhere I go, I need to take the soap. I cut up the bar, into small slices, and I take a slice everywhere I go.*
> *Do you buy the soap yourself?*
> *Yes. All these things, we must buy them, because we need them.*
> *From your R750?*
> *Yes, it is not enough.*

Participant H witnesses that her client 'is not living in the right environment'.

> *When you come to a house, and see the environment is not right … our patients are poor. They don't have food. (H)*

Emotions of guilt and desperation are clearly present. The dilemma of not having enough, but having more than one's clients, contribute to a carer's emotional state as reflected in participant G's comment: 'You hear about people with more difficulties than you…It's hard. It is stressful.' (Gτ) What adds to this stress is the carer's financial precariousness. Participant C told the story of her colleague who contracted TB from a client: 'she was afraid they'd stop her stipend if she was not working'. Here we see a situation where a carer was afraid to disclose her condition, and continue to care for clients, because of the stipend system. Carers, in this interview, all reported that if they do not work the standard hours as set by their organisation, they do not get their stipend for the month. Without sick leave, and dependent on their stipend, carers may be unlikely to disclose their own health status. The carer states that 'it's a big problem' and tells how her colleague 'was afraid, she didn't know what would happen to her'. Both carer and client are compromised by the almost punitive way in which care work is administered. The time specifications, on which a carer's stipend is paid out, is influenced by the organisation's 'concern about the stats' (E). She elaborates:

> *We get threatened … if we don't see enough patients, because the department [of health] is concerned with stats, they [the organisation] gets into trouble if they don't have enough patients. They want us to see 10 patients a day. That is impossible.*

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In this exchange it is clear that participant E feels a profound unfairness: her meagre earnings subsidise community health needs - buying necessary items such as soap, disinfectant, paraffin to warm water for bathing and sterilizing used bandages, or food - yet these earnings are withheld if carers cannot meet the unrealistic expectations of an uninformed government agency.

Faced with limited resources, care work takes on a survivalist nature. Carers describe activities akin to begging for the resources they need to provide care. This comes with its own emotional cost as participant D explains:

> *Sometimes the taps are far, or sometimes there is no water in the taps. So sometimes I have to go to the patient's neighbour and fill up a bottle. But people fight with you, because they say they rent this water.*

In addition to creating conflict, competition for scarce resources contributes to stressful, highly emotional communal relationships. This interview also broadens the context of community care. As mentioned previously, communities are subsidizing the safety nets which have been relegated to market forces.

Carers are not only faced by the extreme impecuniosity of their clients, but also by the disintegration of kinship and cultural ways of being and caring which used to provide some succour to the marginalised of a community. While this point is elaborated on in the next section, participant D's experience noted below shows how this may cause additional distress:

> *That old woman, she is alone, her daughter has passed away a long time ago. So maybe she phoned someone outside to come to help. But no-one comes. She wants bread, but there is no bread. And she can't get anyone to go buy her bread. So she is desperate, and angry. So that anger, that anger goes to the first person that comes inside her house. (D).*

Here we see client reactions to being ill, poor and alone. Another example shows how the client's emotional response to being sick can elevate to physical aggression toward the carer: 'One woman kicked me. She didn't want to wash. I had to talk to her for a long time

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before I could wash her.' (H)

A discussion on emotion surfaces a sort of meta-data emerging from the translator's response to interview G. She cried openly when the carer explained *why* she did care work. After reflecting on the extensive, physical nature of her duties for her clients, participant G explained:

> *We feel the pain of the person. Maybe there are no relatives in Cape Town, or they are just alone, so you must put yourself in that person's shoes, because that could be me one day. So it's like that.*

The carer also described her previous job.

> *I was making more money at Hope Africa. What was nice was that I would work from home. When I make 50 badges, like South Africa badges or the AIDS ribbon badges, then I would receive R1000 for 50 badges. So I was making more money.*

The translator, a Xhosa woman living in Gugulethu, explained her feelings thus:

> *I'm just amazed [pause - crying]. She says she loves it. She sees the little money. She doesn't mind that. She's very grateful that she's doing this. And she knows that it's very important. She has so many certificates for this. When she goes back home, to the rural area, she will be proud to tell the people what she did, and she'll be able to help the people who are sick out there. [Weziwe continues to cry].*

A visceral response is understandable. Not only does the translator share her astonishment at the realities faced by the carer, but we were both attentive to another detail. In participant G's articulation, we learn that care work, or the care of those sick with HIV/AIDS, is of less value than a beaded AIDS badge: the symbol of African victimhood yields greater economic value than the care which would raise the client out of a state of victimhood. The carer's representation provides an articulation of an economic paradigm which does not value people. Her client's health and well-being is worth less than a beaded badge, the symbol of his plight. Her articulation poses a critical question to development politics: whose interests are really being served?

The complexity of a carer's emotional state emerges from this data. Concern for

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one's own financial security juxtaposed against the plight of one's clients, fear of punitive monitoring and remuneration practices and self-care are all implicated in a carer's ability to remain emotionally well. It makes sense to assume that the fear and anxiety attached to health risks and to the pervasive 'un-safeness' of carers on the street or in a client's home - anywhere (we recall the statement by participant H: 'the environment is not so good, its no good here. It's the community itself') will be constitutive of carers' emotional deprivation.

Control over one's environment

Closely related to emotional stress and anxiety is the carer's ability to take meaningful control of her future. Nussbaum describes this capability as the ability to have control over one's environment, in material and political ways (2000: 80).

In identifying instances where carers' reflect on material control over their environment, deprivations with regard to financial and job insecurity as well as loss of investment opportunity surfaced. All interview participants experienced profound financial insecurity amplified by precarious employment. The most significant reflection of this point is carers' reflections on remuneration. In the interviews, carers noted that their stipends are too little to make any material difference to their living conditions or quality of life.

> *My worry is that we care about the people, give hope, love, but one of these days, it will be you. Who is going to care for you? I don't have a salary. It's a stipend. We don't have benefits. How can you afford a policy if you've got R750. Because you're hungry. You don't even have a policy. You will die, and you will have no policy. No burial policy. These are the worries … And medical aid. I'm helping somebody now. But at the end, what or who is going to help me. Nobody will look after me. I will sit there at the day hospital, sit there in the chair the whole day. I was a caregiver, but now I can't go to the front of the queue for me, but I do it for the client now. I will sit there, there, the whole day. (B)*

When revisiting participant B's interview, it is clear that she is assessing her financial future, and concluding that there is a profound unfairness (as echoed in the literature) at

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play: carers are expected to care without consideration for their own well-being, now or in the future. She points to the potentially intergenerational aspect of this particular deprivation (as well as emotional, as discussed in the previous section): her next of kin will carry the financial burden of her ill-health and/or funeral. Participant B is also aware that she is not guaranteed health care. She says: 'at the end, what or who is going to help me. Nobody will look after me.' She clearly implicates the Department of Health (the 'what'): while noting, but not belabouring the lack of salary, it could be an understandable assumption that the very system she is subsidising would acknowledge her and provide her the same courtesy, when she one day requires it. Participant H's reflection on this point is simple but stark:

> *If I get HIV/AIDS there is no plan B. There is nothing to look after me. But I do the work. (H)*

Financial insecurity as emotional deprivation was discussed in the previous section. However, it deserves elaboration under material deprivation. The data shows that the earning potential of carers is very low, and that the nature of care does not allow time for additional income-generating opportunities. Seven of the eleven participants (64%) earned exactly R750 per month. Eight (73%) earned under R1000 per month, and two (18%) earned over R1000 per month. The average monthly income (including the significantly high outliers) was R915.

I asked carers if there was additional income in their homes. Only three out of the eleven carers reported additional income. One participant noted that her husband worked as a gardener three days per week, but that she was not always sure what he earned (B: 152). The other care worker with a spouse reported his income, from a carpentry job, to be R800 per month. The last care worker who reported additional income received child support grants for her two children. This amounted to R240 per month per child. Her total

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income was thus R1,380. Only two carers therefore reported actual additional income. If included in the household income, the average income in carers' homes rises from R915 to R1,031.

Thus, eight of the eleven women (73%) interviewed were the sole breadwinners for their households. If the average income is R915, and the average number of people to sustain in the household is six (five plus the care worker), then, in this study, the average person in a care worker's household lived on R152.50 per month.

Participant D's description of her living expenses cited earlier reflects the reality of this situation: she earns R750 per month, yet her expenses for travel, rent and her funeral policy add up to R510. She reflects on her reality with outrage, and the simple but profound awareness that her work is not valued. Her ire is aimed at a government that thinks this is an acceptable status quo:

> *[T]his is not enough, this 750. They must cancel this policy, if they say it is right!*

The result of this financially precarious situation is that many carers have limited material control over their environment. Earlier, for example, participant D reflected on how her ability to realise her full agency and independence is thwarted:

> *Sometimes you don't want to stay with a boyfriend, you want to be independent, you want to be on your own. But you can't afford it.*

The interviews also showed that carers do not have the resources they need to do care work, and note that much of what they need they purchase themselves, out of their stipend. They noted multiple levels of lack. Carers do not having basic equipment such as gloves or masks, which could result in negative consequences for their own health (as discussed previously). They also do not have basic supplies such as dressings or disinfectants. The following exchanges describe these realities in detail.

> *We see that there is no soap. No nothing. No towels. And no kimbies. People don't have money for those things. Kimbies are so expensive. (I)*

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> *A challenge for me is when I see that the client doesn't have anything. And we as an organisation can't afford these things, we've no money at the moment. From December last year up until today, we've not received anything, or had money for dressings. So we can't assist them. I can't assist my patient with soap even … We see up to 4 clients a day. If they don't have soap and things, we don't see them because we don't have those kinds of supplies… (K)*
>
> *No gloves. No nothing here … We also need dettol, or soap. We must bring our own dettol. (B)*
>
> *But if there are no towels, I find anything, any cloth or something. If I see the situation, I bring my own towel, or soap, the next time I visit. (G)*
>
> *[W]e get a very minimal amount of equipment from [our organisation]. There are very little bandages. Gauze is scarce too. And it's first come first serve for equipment. Sometimes we work for 2 months without gloves. The bandages we cut up to use as gauze to treat the wounds. (F)*

More significantly, poor service delivery in poor communities complicated carers' ability to care.

> *When I get to the houses, there is no soap, no electricity, no water. Then I have to go next door to ask for water, and whatever the next door neighbour can give me to wash these patients (E).*
>
> *[S]ometimes we have to find water. Some houses have running water, but its cold water. So we have to boil water to get hot water. (I)*

With little control over their work, leading to less control over their own health, carers also contend with the daily reality that the care they do provide is little more than simulated. Participant F reflected on this point specifically:

> *The main challenge is when I get to the house. There is no food. No soap. No electricity. The water is cold. No towels. No equipment. There is no-one taking care of my patients at home. I am the only one. Whenever I go wash the patient, it is frustrating because there is nothing I can use to wash the patient. So now I take my own things. I take Vaseline. If I put Vaseline on, at least the patient thinks I'm doing something for the wounds. It makes them feel that I am doing something. (F)*

Participant E echoed the frustration of not being able to 'care properly'.

> *What are your challenges?*
> *The lack of supplies. I feel that, if I go to a house without dressings, sometimes I wonder 'what am I doing here'. If I don't have equipment how can I care properly?*
> *What do you do?*
> *What can I do? I do my best, but without dressings, gauze, the wounds get septic, and my job is harder the next visit. (E)*

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Participant F reflects on the particular impact this 'simulation' has on her; she finds herself in a position where she feels helpless. Participant E asks 'what am I doing here?' This adds a complexity to the notion of deprivation as discussed in this section: having no control over the circumstances of lack and poverty in which they perform care work, carers are also deprived of their own sense of worth in what they are doing. The lack of job satisfaction could re-entrench emotional deprivation.

Carers also expressed frustration at the lack of opportunity to develop themselves as carers, either within this 'sector', or to progress into more formal caring sectors, such as the Department of Health, as nurses, or the Department of Social Development, as social workers, or other auxiliary health worker posts. Some had tried, but failed, to find information about career pathing into formal employment. On the whole, carers were unclear as to what benefits various training programmes provided by the departments of Health and Social Development afforded them. Participant E expressed frustration that completing a training course did not improve her opportunities.

> *I want to know what am I going to do with the NQF4.[7] When I asked them at the course, they never explained to us about what we do now. I hope the government won't be training us to just sit at home. I think they are making money out of us. What does the training mean? (E)*

Participant E's response reflects doubt as to the usefulness of this qualification, and the government's intention for requiring it. It represents another deprivation in the sense that time was used to participate in this course, time which could have been spent generating income. In addition, the statement 'I think they are making money out of us' shows that participant E has invested in this course; money which could have been better spent. She

[7] The South African Qualifications Authority (SAQA) oversees the implementation and development a National Qualifications Framework (NQF). The NQF was implemented in 1995 to integrate 'diversely skilled human resources', and in post-apartheid South Africa, diverse skills levels as well as varied mechanisms of learning, incorporated into a 'Recognition for Prior Learning' system. The NQF was intended to as a standardised qualification system able to recognise skills and categorise these accordingly. NQF 4 training is of benefit to South Africans who did not complete high school, and is the ea high school diplomat and entry-level trade certificate. Many care organisations, on behalf of their state funding agency, require carers to complete NQF4 to ensure literacy. In discussion with carers, an expectation was established for further qualifications and career advancement.

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expressed frustration at the realisation that she had been deprived on a number of levels: loss of time, loss of finances, and loss of the opportunity to invest both more effectively. In addition, her disappointment at being treated like a pawn is palpable; carers are doing the government's bidding for those left out in the cold by economic priorities which increasingly move away from providing the care and social safety nets our society requires. Charging economically precarious carers to attend compulsory training of questionable relevance to carry out the state's responsibilities is unacceptable.

Political control over one's environment is the ability to 'participate effectively in political choices that govern one's life' (Nussbaum, 2000: 80). One of the questions I posed was 'do you know about the community care worker policy?' None of the carers had heard about the policy, despite it having been under consideration since 2005 (the interviews were conducted in 2009). My interview question was the first any of the eleven participants had heard about the policy. Responses included: 'It is the first time I heard about such a thing, from you, now' (A), '[n]ot until you told me about it today' (D) and '[t]his is the first I hear of this thing' (F).

As will be discussed in more detail, access to information and public participation constitute some of the pre-requisites for enjoying political control over one's life. Participant D was cited earlier as saying: 'They must cancel this policy, if they say this is right!' Her response to a carers' policy, which strives to maintain the status quo vis-à-vis care work, is unequivocal: it is wrong.

Discussion about the carers' policy brought about the following exchange, which relates back to the issue of material control over one's environment, specifically, 'having property rights on an equal basis with others' and 'having the right to seek employment on an equal basis with others' (Nussbaum, 2000: 80). The exchange also reveals the inter-relatedness of material and political control through gender inequality.

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Is there anything else you want to tell us?

There is a problem with men who do care work. When they get a man who is doing the care work, he gets more money. He gets R910. We get R750.

In your organisation?

Yes.

How did you find out about this?

The men told us. And when we sign the register for our stipend, we see how much they earn.

And are they doing the same work as you?

Yes.

So why do they get more money?

Their response is that, men are so scarce in this work. It is very difficult to find males. That is why they give them more money. They tell us that women are strong, and they can bear the pain of doing this. Men can't bear the pain of doing this work. They can't handle it. So they must be compensated more for doing it.

Who told you this?

The Director of the organisation told us this. It's difficult to get males to do this. But it's so easy to get women, that's why they only need to get R750. But to get men, because there are so few, they must get compensated. (Dτ)

Participant D's experience shows an explicit articulation of how gender norms operate in her context of care work. That there are more women than men doing care work is a stated fact. In addition, participant D articulates the value of men's labour as more than women's as an unmitigated fact. Further, while it is acknowledged that the work is difficult, even 'painful', it is the very fact that women can 'handle it' that is used as the justification for them to earn less. They are somehow better equipped; the work comes more naturally to them, and therefore they do not need as much compensation as men do.

It is interesting to see payment for care work (even if only a stipend) thought of as compensation, not remuneration. It implies that care is not thought of as work, rather as an activity which attaches a reimbursement, a payment of damages, a remedy for loss incurred. Remuneration is payment of a fee for work done. More naturally inclined to do care work, women suffer less damage or incur less loss, while men who do care work suffer more and thus need to be provided with a more substantial remedy. If women do care work anyway then there is no responsibility to compensate them, but, men have to be compensated to convince them to engage in care. This exchange also implies that caring is

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segregated from conceptions of work which attract remuneration.

In this discussion, the operation of gender illustrates the duality and simultaneousness of Nussbaum's notions of material and political control over one's environment. Participant D articulates exactly this point: she collapses her material well-being into the 'political'. She starts her discussion by saying 'there is a problem with men'. Despite the explanation given by her organisation's Director (a man) she sees this situation as problematic. Her experience of this problem is itself of interest: she is working in an environment where care work is clearly acknowledged as the women's natural domain. She reflects on a script which points to her deprivation not only because of financial under-compensation; her material deprivation is clearly linked and rooted in her political deprivation.

Other instances of carers' representations of *being women* surfaced in the interview data. For example, participant G spoke about the difficulty of caring for men. Enduring cultural norms emerged from her care for fellow amaXhosa community members.

> *Is it different caring for a woman than for a man?*
> *Yes. It can be difficult. Especially men are sometimes difficult. They ask why these women are coming to take care of me? So before we start, we must sit down with them, and counsel them about what we are coming to do. Because its not right for women to come alone to the man's house, and then to wash them. (G)*

Despite being in need of care, participant G's client has to be convinced to accept care from a woman. She has to take time to 'counsel' him, to explain her intentions. Preservation of cultural ways of being almost prevails over the preservation of self. Yet, we see the carer able to negotiate and navigate around the prescriptions of culture. It brings to the fore significant considerations for carers who do not share a cultural understanding of the communities in which they work. They may not be able to read the operation of gender through culture, and thus may lose the opportunity to care for someone in need. This exchange shows the influence of culture on care, as well as the complexity and nuance

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involved in providing care.

Participant D also experiences cultural norms through her position as a coordinator; as a middle-aged amaXhosa woman in a position of leadership, she is required to navigate the various and simultaneous hierarchies imposed by 'work' and 'culture'.

> *…when I talk to them, according to my tradition, I need to go down, but also I have to coordinate them. This is challenging.*

The carer has to manage her cadre, and in a sense be above them, while also having to 'go down' to ensure that the elders whom she manages will be able to respond to her without feeling that they have been disrespected. However, a contradiction emerges.

> *There are difficulties. If I can tell you, as I'm working with the community, firstly, they are not in the same age.*
> *What do you mean?*
> *There are young ones, middle ones and the old ones. The young ones are the ones who are challenging me. (D)*

Here we see the carer face a challenge related to the younger carers. They do not 'go down' to her despite her location as both a leader in the work place and an older woman. Participant D has articulated the fluidity of culture: it is not static, seen in the differing behaviours across generations. One of the consequences with respect to doing care work is that the younger carers 'need more attention…it needs you to talk to them a lot' (D). Participant D needs to manage not only their care work, but how to ensure that cultural norms are negotiated in a way that can allow the work to get done. The previous example showed the importance of understanding cultural scripts in providing care. If younger carers do not understand this, they may not be able to access particular clients who may have high levels of need, such as the elderly. Management of younger carers is also required to ensure successful engagements among carers within an organisation who are of different ages and thus may approach each other informed by different cultural

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expressions and practices.

The above findings are of interest to quantitative work which strives to elicit the burden of care work. For instance, Budlender's expert work (2002) incorporating time use surveys to quantify care work comes to mind. Participant D and G show that time is not spent exclusively on actual care work. There is a time cost in preparing the caring environment, which, in the instances described above, include negotiating important cultural norms with both clients and carers. Another consideration is the emotions involved in negotiating cultural expectations: culture can have an impact on how carers are able to care, and how they feel about themselves.

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Conclusion

Applying the capabilities approach has not only surfaced specific deprivations as experienced by carers, it reveals how deprivations are iterative, overlap and reinforce each other. The capabilities approach surfaces multidimensional, complex and variegated meanings of deprivation. For example, care work can compromise the carer's ability to be healthy, which in turn impacts on her emotional health through the stress of economic vulnerability. As 'an approach to comparative quality-of-life assessment and to theorising about basic social justice' (Nussbaum, 2010: 18), the capabilities approach has provided a framework to articulate carers' performance of care work as having complex, multiple, simultaneous consequences for sustainable development and social justice. As such, it makes the argument for re-engaging with theory an imperative. How these meanings of deprivation, as they operate through gender, poverty and power, impact on theorising about care work will be expanded upon in the Discussion.

Chapter 5

ANALYSIS II

Capability Formation

Introduction

In the second part of my analysis, I wanted to highlight carers' positive representations of their work. For carers there are very clear articulations of the value of their work and their pride in doing it. To reveal these experiences, I applied the following capability categories: (1) practical reason; (2) emotions; (3) affiliation and (4) sense, imagination and thought (Nussbaum, 2011a: 33-34). By applying these categories, I hoped to reveal ways in which carers articulated capability formation.

According to Sen (1999) and Nussbaum (2011a), practical reason is a category that reflects agency, that is, a person's ability 'to form a conception of the good' (Nussbaum, 2011a: 200). This conceives of a personal, individual expression of what a person values in 'aiming at the good (Nussbaum, 2011a: 200-201). It also involves an ability 'to engage in critical reflection about the planning of one's life' (Nussbaum, 2011a: 34). As such, I argue that this category could assist in foregrounding carers' agency; the actions they were able to take to achieve what they believe to be good and just. I again apply the category of 'emotion' in the sense that it reflects the ability 'to have attachments to things and people outside ourselves' (Nussbaum, 2011a: 33). Affiliation is a way of identifying how carers articulate their ability 'to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction' and 'to be able to imagine the situation of another' (Nussbaum, 2011a: 34). The capability described as 'sense, imagination and thought' will be used to surface meanings around how carers are able to think, reason and imagine in connection with their experiences of care work. It is

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also connected to being able to have pleasurable experiences.

Practical Reason

Many carers reported coming to care work due to personal experience with HIV/AIDS. In these instances, there is a sense of not only 'doing good' but also a critical reflection on how their own experience has led them to take action in this way:

> *The reason I do this job is me. I'm sick. So, my sister helped me. Because that time when I was lying on the bed, it was difficult to do anything. So I took a decision. My sister helped me. So me, I have the strength now to help other people. (D)*

Participant D expressed the choice to do care work as a way of giving back, of making up for the sacrifices her sister made for her by doing good for others. Participant C lost her sister to AIDS and spoke about how this experience led her to care work:

> *I had an older sister, her name was Martha. She had HIV. But she never told us … I was older than the others at home, I had to do the cooking for her when I got home from high school. So when I was doing that, each and every time I looked at her, she's like, she's becoming weaker and weaker, and she never said anything about the HIV. And she used to talk to me whenever she had pains. She would say 'my health is not well', but because of this stigma, she was keeping this inside… In 2003, she died. I had looked after her for 3 years. We were trying, and hoping that it would come right. I was doing caring for her, but I didn't know it was HIV. Just before she died, she did disclose to me. She did disclose at the end, so then I knew. But I understood why it was hard for her to tell me.*
>
> *That is when I involved myself in the organisation, to get training. So I learned that it was HIV. This was a new thing to me. So I involved myself. I wanted to 'do'. Every time that something was coming up, I wanted to do it, get involved. If there's a training, they knew to put my name down. Because of that, it empowered me, because now I understand everything about HIV. I can identify the different sicknesses.*
>
> *… There was no stipend. But to me it was not a major thing to have a stipend. It was about understanding. Get empowered. It was about being fully empowered.*

This excerpt reveals many things. First, it starts by describing a stereotypical scene: a child in the family takes on the role of carer at personal cost, cooking and caring for her sister, foregoing time she could have spent on her studies. It ends, however, with a description of

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the carer feeling 'fully empowered'. It shows something other than 'carer as victim'.

Participant C has an emotional connection with her sister, and is also able to feel empathy: 'I understood why it was hard for her to tell me'. Based on her personal experience, she makes a decision to inform herself, to join an organisation and learn about this 'new thing'. She wanted to 'do', and has, through this experience, experienced a sense of agency. Her empowerment is articulated through her own journey to learn about HIV/AIDS, something she was unfamiliar with and powerless over: 'now I understand everything about HIV. I can identify the different sicknesses.' Her understanding of the epidemic gives her a sense of being 'fully empowered', more so than financial reward. Participant C shows the overlapping and multidimensional nature of capability formation. All four categories chosen are evinced in her experience.

Participant J left her factory job to take care of her mother.

> *I worked in a factory all these years. Then my mother got ill. I had to leave my job and look after her. But with no experience it was very difficult. And when she died, I decided that is what I want to do. I want to be a benefit to my community. I want to help other people like I couldn't help her.*

In this instance the carer has chosen to remedy what to her was an unacceptable situation: she could not help her mother. Thus, personal experience has led participant J to choose care work, to choose to do good for her community: 'I want to be a benefit to my community'.

> *She first experienced this with her own husband. Her husband got sick for 3 years and she had to take care of him. For three years. Until he died. And he died in her hands…She looked at this job and said: 'Let me also do it, because I've been in this situation. Let me go out and help other people. I know how.' (Gτ)*

In the above quote participant G articulates how her experience in caring for her husband created a type of experiential knowledge. There is a sense of empowerment in the statement 'I know how'. Rather than express defeat in the face of loss, participant G seems

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steeled to bring her experience to others who need it. Carers reflect the need to impart what has been learned, noting the importance, and scarcity, of this particular, situated knowledge.

The most obvious way in which carers reflected an ability 'to engage in critical reflection about the planning of one's life' was the articulation that care work is an opportunity.

> *I finished my matric in 2000. Then I'm looking for a job, but I didn't find it. So I just see in the paper, the training for HBC, I attended that training at St Johns in Nyanga.*
> *Did you find work after the training?*
> *Yes. I started to volunteer at St Johns. (E)*
>
> *She started this job because jobs are scarce. Then she heard there was this organisation looking for volunteers. Then she went … She wanted to work, instead of sitting at home. Rather go and do this. (Fτ)*

Due to limited education and training opportunities, some interviewees see community care work as a possible 'stepping stone' into the nursing field.

> *I began when I was 13 years old. I helped a lot of old people. My passion is from childhood. I dream of being a nurse. To help people who are sick and so on. And since then, from the age of 25, I started here at TUAP, volunteering. No pay. No nothing. It was the passion, you know. For me it is a pleasure to help someone else. So, I love my work. My biggest dream is that I want to work in a theatre, a theatre nurse. That is my goal in life. (H)*
>
> *[W]hen I was a teenager even, it was always my dream to become a nurse. Then I became involved in this organisation. They sent us on training. (J)*

As a stepping stone, as opportunity, here we see care work articulated as 'capability formation'. For participants H and J in particular, care work is seen as a possible way to achieve one's 'goal in life', one's 'dream'.

Emotions & Affiliation

Due to the nature of the experiences articulated in the data, I have collapsed the categories of 'emotions' and 'affiliation'. The former is conceptualised as the ability 'to

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have attachments to things and people outside ourselves', and the latter as the ability 'to live with and toward others, to recognise and show concern for other human beings [and] to be able to imagine the situation of another'. The idea of attachments and the ability to show concern for others is closely aligned in the examples used.

Participant B articulates her emotions about a relative's inability to disclose her HIV-status.

> *My cousin's sister was sick. For a long time. And she never disclosed to us. She only told one cousin. And that cousin told me, that she has HIV and AIDS. And she said I mustn't tell anybody. She was sick until she died. Then after that, I thought, if I'm a caregiver, I can help those who don't want to disclose to their families. If you are a caregiver, all of the people knew that you are looking after the sick people. So it's easier for them to come to you and disclose.*

Her emotions, in turn, inform an empathy towards others who may be similarly located: 'I thought, if I'm a caregiver, I can help those who don't want to disclose to their families'. There is a depth of empathy to note here: participant B articulates an understanding that people 'don't want to disclose'; she is 'imagining the situation of another' by understanding why someone may not want to disclose, and that this requires a particular type of 'help'. As a caregiver, her task is not to force disclosure, but to provide 'help' in the form of an alternative avenue for disclosure. In her experience, not being able to disclose was a factor in her relative's death.

Care work also seems to provide a more nuanced conception of affiliation, in that it evokes the notion of kinship. There was a sense that people, the sick, those affected by HIV/AIDS especially, had been abandoned. About two-thirds of the interview participants originally hailed from the Eastern Cape. Many expressed the idea of caring for an 'extended self', the greater circle of kin, which includes the extended family structure, or in more traditional settings, the clan. In an informal conversation, an elderly carer living in the community of Gugulethu expressed the sentiment thus:

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> *It is strange for us, the older people, who remember living in the Eastern Cape, to see these things…where people are left alone, alone when they're sick, left alone to die, and where we have street children, these children begging on the streets. Where are their people? It is something that wouldn't happen before. Your people would come and get you. It would cause them great shame to know that one of their people was alone like this, dying, or begging on the street. But maybe HIV did this to us. Or the townships. Or both. (Personal notes, Share Shop, June 2010)*

In the quote below, participant J reflects this particular point:

> *You know, clients don't always have someone. We come to a house and there's nobody in the house. And the person is just laying alone there. And my concern, I mean, just being sick, and being alone. It's not nice (J).*

Participants A and G empathise with their clients who do not have relatives nearby:

> *I found out that there are so many people, who need help ... They don't have homes, they don't have people, so they need people like us. (A)*

> *[W]e feel the pain of the person. Maybe there are no relatives in Cape Town, or they are just alone, so you must put yourself in that person's shoes, because that could be me one day. So it's like that.*

Another way in which carers expressed empathy or concern for their clients is with respect to exploitation by family members:

> *Another challenge we face at the moment, is when the person who is sick has a family. But when its time to take care of that person, the family is not around. But when the grant gets paid, the family comes closer to the patient, and they take the money. So, the money does not help the patient (Gτ)*

> *The children don't look after their parents. For us, it's very hard to see that. (H)*

While there is no question as to the carers' ability to feel empathy or show concern for other human beings, having this emotional capacity is also a way of experiencing deprivation: considering the extent to suffering within circumstances of extreme poverty and neglect means that feeling empathy can be extremely draining for the carer. In fact, carers take on responsibility for their clients in many ways which deepen their own deprivation:

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> *[S]ometimes when you get to the home, there is nothing to eat. We sometimes take money from our own pocket. They see us as hope. They see us as better than them – even when we only get R750. They don't know we only get R750. They think we are a better person, with more money. They don't know that we are hungry people. So we must get them something to eat. You must take out of your pocket and get them something to eat (B).*

Participant B does not question the solution: 'you must take out of your pocket ... we must get them something to eat'. Participant A echoes this feeling: 'You see the bad situation they are in. Then you take money from your pocket, because you have no choice' (A). While the emotional toll is clearly substantial, it cannot be overlooked that a choice, informed by a deep sense of empathy and humanity, is made by the carer.

Sense, imagination and thought

Carers articulated a range of meanings in connection with their experience of care work.

For participant A, care work is clearly articulated as her 'conception of the good': 'I want to be a community worker, because I just want to make a change ... I can make a difference.' Doing care work is her way of contributing to the betterment of her community. Carer H also sees her work as 'making a difference', and views carers as 'a resource' for the community. Participant C reflects on the 'big picture'; beyond the physical care, 'we restore their dignity'.

Carer A states:

> *But luckily, there we are, strong women, trying to do the best we can, to help, to make them strong, to give them strength to carry on with their lives. (A)*

There is a sense of confidence about the value of her work. There is an acknowledgement that care workers are (need to be) strong, and her generalisation 'strong women' indicates her own view that care work is feminised. However, her sense of confidence is muted by

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two points: first, the word 'luckily' implies that she is aware there is not other recourse for her clients, and second, the phrase 'trying to do the best we can' acknowledges that carers are often not as effective as they would like to be 'under the circumstances'. In her own articulation of what she 'does' - helping members of the community to 'carry on with their lives' - she provides an accurate reframing of the definition of 'social reproduction'. In addition, carers reflect on the fact that they are carrying this burden on behalf of the state, and that the trade off is unfair.

> *They think we must do everything, and they complain when we don't. They don't see what we do. We rescue, but we are rescuing too much. (B)*
>
> *[T]hey just want us to do more. But we have rights … We must get a proper wage. Nothing comes for free, but we are doing the free work. They're depending on us … 'You must do it. You must do that' they say. Who is 'they'?*
> *The hospitals, the nurses, Social Development, you know. They're depending on us. (H).*

In the above excerpts, we see carer B reflect on the invisibility of care work: 'They don't see what we do' while also being aware of the fact that care workers are picking up where other systems fail. Participant G notes: 'there are not enough nurses. And we do more than the nurses do most of the time'. Whether through task shifting or holding unravelling safety nets together, care workers are filling the gaps: 'they're depending on us'; 'we are rescuing too much'. The burden is too great, and yet 'they just want us to do more'. Participant H's articulation of care work as 'the free work' is interesting, reflecting an understanding that there is a type of work that is free. The work that helps people to 'carry on with their lives', that rescues 'hospitals, nurses and Social Development', is free. The reality of social reproduction is understood, but not unchallenged: 'We have rights. We must get a proper wage. Nothing comes for free.'

The ability to think about and make meaning out of one's experiences and work includes the ability to have pleasurable experiences. Carers do reflect on their sense of

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fulfilment, despite other deprivations. For example, participant G is unsatisfied with the remuneration, yet she feels 'happy' to be gaining knowledge.

> *We need to be paid better. I am not happy that the pay is bad. But I am happy that I'm getting knowledge for this work. (G)*

In addition, she expresses a sense of agency in articulating the 'need to be paid better'. Both carer H and G exhibit a conception of the good and just in articulating that carers 'must' and 'need' to get a proper remuneration. Participant G goes on to say (in translation):

> *She says she loves it. She sees the little money. She doesn't mind that. She's very grateful that she's doing this. And she knows that it's very important. She has so many certificates for this. When she goes back home, to the rural area, she will be proud to tell the people what she did, and she'll be able to help the people who are sick out there.*

Participant G values that she is 'gaining knowledge for this work' and is 'grateful' to be doing 'very important' work. She feels proud of her trainings, and refers to her 'many certificates'. She feels pride in sharing her accomplishments with her family in rural Eastern Cape, and in a sense of being able to help 'people who are sick out there'.

Participant H loves her work because it is 'her passion' and 'pleasure to help someone else'. Similarly, carer J says care work 'is what I always wanted to do. I want to look after people'. Participant E remarks that she 'loves' her work and 'would be glad if I can be developed in this field…I want to go higher.' In articulating her enjoyment, participant E also reflected on the respect carers receive from the community. While on the whole positive, she spoke of those who treated carers with contempt

> *Those who are negative about my work, are the people who never went to school, the people who don't work, they sit there, they are not enlightened. They are the ones who look down on us, on our work.*

She also notes:

> *When I get to the houses, sometimes you get people who are rude. They ask why this stranger must wash their family member. They say the job I*

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do is so low. This is from the family from the sick people. They don't want to care for their family member, but I am low to do this work.

According to participant E, it is the unenlightened that do not appreciate the value and importance of care work. She challenges and interrogates the perceptions of those who do not respect her work; how can caring be low? Her conception of the good is to care for those in need, and she questions the morals of those who do not.

Conclusion

This chapter used the capabilities approach to highlight moments of 'capability formation' (Sen, 1999; Nussbaum, 2011). As with the chapter on capabilities deprivation, we see that capability categories can overlap and co-constitute each other. As such, clear instances of capability creation are evident. We are thus faced with two sets of data which reveal, firstly, that community HIV/AIDS care work deprives women and secondly, how women articulate moments of capability formation.

Thus, the data presents the dilemma of carers' dichotomized experiences: deprived women versus women who are surviving harsh circumstances to perform a critical service to their communities. What does it mean if these findings present women carers as deprived *and* capable, simultaneously? The social phenomenon that is care work clearly constitutes capability deprivation on multiple levels; what, then, do we make of the moments of capability formation identified? This dichotomy, and the meaning thereof, amplifies my argument for re-engaging with existing care theory.

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Chapter 6

DISCUSSION

Introduction

Given my interest in women carers' experiences in this thesis, this discussion will focus on the meaning of care workers' own representations toward understanding how care work can be imagined within the politics of development.

Taking development seriously means moving away from solely economistic analyses to treating people as ends in themselves, 'as if they mattered' (Benería, 2003). In this dissertation, exploring the capabilities of care workers afforded two primary opportunities: first, it allowed me to explore women carers' individual representations, in so doing taking their *individual* experiences seriously; second, it allowed for a deepened analysis which goes beyond the purely economistic (and I would argue one-dimensional) findings about the poverty of carers, their household income or their location relative to the poverty line. Through using aspects of Nussbaum's capabilities approach, I was able to learn more about what it *means* to experience deprivation as a carer, and in this way, identify conceptual gaps in the theory.

The first part of my discussion will explore these conceptual gaps. The second part will discuss what taking care workers' experiences seriously vis-à-vis capabilities might mean for development theory.

Social Reproduction: new work, new space, new body

It is apparent from my own and other research that community HIV/AIDS care work challenges traditional notions of 'social reproduction' on many levels. First, theory needs to tackle more carefully HIV/AIDS community-based care work in South Africa as a

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new variation of care work. The capabilities framework revealed how the type of work, and the manner in which the work is done, affects women carers' capabilities. As such, this analysis surfaced how the epidemic not only presents new *needs* for care, it has changed *how* carers work (Lund and Budlender, 2009: 26).

The analysis revealed that community HIV/AIDS care work entails meeting complex needs beyond palliative care. For those sick with HIV or AIDS, the implications of opportunistic infections means that a range of physical (and often extreme) care is required, such as wound care, acquiring the client's antiretroviral treatment, and ensuring adherence or physiotherapy. The people being cared for in this context are also poor, which raises issues around social needs; from the basic, such as food, to assistance in accessing state social provisions, such as social grants. Cooking, cleaning clients' homes and bathing clients are also routine. Emotional support in the face of isolation (and bereavement) due to the loss of family to the epidemic or due to the disintegration of kinship structures are also reported needs. Carers describe 'having to just spend time' with the client, to 'make them feel better'.

The way in which HIV/AIDS care is provided is also considerably different from conventional formulations of 'social reproduction': reproductive, unpaid labour performed in the home, usually by women (Ferguson, 2010: 3-4), entailing care for the home, the sick, the husband, the children, the family and the elderly (Nussbaum, 2001a: 242). This implies *one* home, the caregiver's home. Community HIV/AIDS care is provided in *many* homes. Carers walk from client to client, providing care in each *client's* home. Carers, in many instances, and in all instances in this study, receive a stipend. Notwithstanding the extremely low payment, this does shift this particular type of social reproduction from the realm of 'unpaid work'.

Therefore, carers' experiences reveal that by leaving social safety-nets to market

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forces, the operation of the productive market has penetrated the domains once considered 'the antithesis of market principles: the spheres of family reproduction and the domestic economy' (Harcourt, 2009: 72). Feminist economists have argued that the private realm serves the public productive realm (O'Hara, 1999), however, the case of care work makes this argument more robust. HIV/AIDS care confirms the co-constitutive nature of social reproduction and production (Ferguson, 2010: 3; Katz, 2001; Razavi and Hassim, 2006).): it is work (production), albeit undervalued, to maintain existing life on a daily basis in the form of care for the infirm (Laslett and Brenner, 1989).

Thus, the experiences of care workers raise questions around how to theorise about this new space, both public *and* private; where care is provided in the household, but not one's own; and where work usually thought of as 'domestic' and free, attracts in some instances, a stipend. The following discussion will attempt to address aspects of these questions.

The carer operates 'between health system, community and home' (Schneider and Lehmann, 2010). As such the carer engages with the public realm. She is therefore confronted by community challenges, such as poverty, violence, and poor service delivery. She also experiences challenges in the public health sector, such as under-resourced community health facilities and a lack of basic equipment. She is regulated, albeit informally, by a community-based, non-profit organisation, to which the State outsources the task of community care. How then, do we theorise about *work* in this ambiguous, 'fuzzy' space (Lund and Budlender, 2009: 25) which blurs the (constructed) boundaries between 'home' and 'work'; between 'household caring, volunteerism and regular labour' (Schneider and Lehmann, 2010: 62)? And why is it important?

On the surface, the analysis revealed that carers face multiple deprivations in the conduct of care work. I argue that interrogating this new fluid space is important because

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it surfaces a more diffuse oppression beyond basic 'capabilities deprivation' (Nussbaum, 2000). First, in the conventional setting of social reproduction, it could be argued that the carer would benefit in some manner from belonging to the household, whether in the form of food security, familial support or shelter, for example. Community HIV/AIDS carers, however, provide the benefits of social reproduction outside the normative household, and thus are unlikely to benefit as part of the household. Unregulated and informal, community care workers also do not have a claim in the public sector, that is, their work is not recognised, valued or rewarded by the formal wage economy.

Second, 'community care work' seems to contribute to the already persistent devaluation of women's reproductive labour. I explain it thus: a carer provides care for a client in his or her home; she is not part of the household, and does not enjoy the cumulative benefits which may accrue in performing social reproduction in one's own home; the carer receives a stipend for her care work; the stipend is usually (as reflected in this study) the primary source of income in her own household; however, she spends much of her stipend to care for her clients (purchasing basic materials such as bandages, soap, disinfectant, food, electricity or paraffin); her own household is thus deprived of her reproductive value (she has less time to spend on her own household's needs) and her productive value (after caring for her clients, little income is left for her household, and she has no time to engage in additional income generating activities). Therefore, we have a new space where *some* value is attributed to social reproduction, yet, the way in which value is attributed within the broader socio-economic conditions of care work seems to contribute to greater deprivation. The dilemma presented by remuneration in this instance reveals the value of a feminist economic analysis: income alone cannot serve to change the capabilities or living circumstances of the working poor; an income does not preclude a survivalist existence (Sen, 1999). Activists should note that a call for carers'

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remuneration is not sufficient to address their material conditions.

In this section, I argue that, in addition to a new type of work, and a new way of working, the needs imposed by HIV/AIDS care has also constructed a new caring *body.* Economic liberalisation has, simultaneously, expedited the integration of people into the market economy while drastically reducing social expenditure in the service of an efficient national machinery which seeks to limit responsibility for social security (Razavi, 2007: 378). I contend that this has made 'staying at home' to engage in social reproduction too expensive for poor households. As more household members are drawn into the productive economy - driven by the needs and demands of capitalism - the traditional pool of carers is no longer available. Those who may have stayed home to care are now compelled to *earn* in the productive economy. Because it would require someone to give up productive work, which earns a wage, care work, in this sense, is too expensive. It is as if care work, while virtually invisible and not of quantifiable value, has become too expensive. Not adequately valued to begin with, social reproduction has not always attracted economic planning; in wage-oriented economies, productive labour alone draws value, and thus budgeting considerations. How then does society provide for something which has not been visible or counted?

Community care work thus creates a new 'body', gendered as woman, located outside of normative structures, such as the home or public facilities, to fill the gap left by what has been lost in the battle to survive neoliberalism and the devastating needs of the epidemic. The way in which bodies are used and deployed in capitalism differs from, for example, a more kinship-oriented, rural or subsistence existence. Participant D's experience is an example:

> *Her children, they are all working, so no-one takes care of her. So only the caregiver cares for that lady.*

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It is therefore not surprising that the need for community care workers has burgeoned, not only in the context of the epidemic, but by simultaneous impacts brought about through globalisation and economic liberalisation. While policy development and even activist work may get lost in semantics, I propose that it is this new *body* that is of most concern: she is not so new, she is a worker. The new context, the new type of work, the new way of working may all serve to obfuscate this fact; patriarchal interests will most especially continue to do so if left unchallenged.

Touched on already, the second aspect to be addressed is value. Social reproduction - and care work especially - has traditionally not attracted (much) value in economic terms - it is either unpaid or underpaid - but the burden of HIV/AIDS care work presents a fallacy: if the state cannot afford to care for the burden of HIV/AIDS, then HIV/AIDS care, logically, has value. Here a clear challenge can be made against 'capitalocentric' (Gibson-Graham, 2006) economic conventions: the only reason care at the community level costs less than providing it in the public health system is because the state employs persistent and oppressive gender norms in the 'objectification of labour' to render care work value-less (Gibson-Graham, 2006; Marx, 1994 [1867]): this 'trick of capitalism' (Marx, 1994 [1867]: 290) must be interrogated. In addition, if value resides in activities that sustain capitalism (Gibson-Graham, 2006: 32), then it can be argued that the cost-saving by the state serves the neoliberal interest (Razavi, 2007: 378). Finally, the data presented in the analysis reveals the varied costs borne by women undertaking care work, whether buying the basic supplies needed to provide care, to protect themselves, or to provide sustenance to their impoverished clients.

To re-iterate, if care work costs, it has value. Thus, carers' are not only economically deprived, they also experience a particularly unjust deprivation by the State's steadfast implementation of the myths (of value, of gender) re/constructed to ensure the supremacy

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of patriarchal and 'capitalocentric' interests (Gibson-Graham, 2006; Harcourt, 2009).

The third area that requires revisiting is the caring as 'moral' versus 'natural' debate. Indeed, some carers may feel a moral obligation or duty to care for others. Some, like in other professions, may find that care work 'comes naturally' to them. However, in the context of social reproduction, both may be constructs of patriarchy whereby 'symbolic normative images of ideal gendered behaviour' are perpetuated through the 'construction of desires and thoughts', influencing what choices women (and men) make (Chambers, 2005: 330, citing Bourdieu). This research supports the feminist argument that care can be grounded in women's *experiences*, not in an essential, biologically pre-determined nature (Hamington, 2004; Gilligan, 1982 [1993]). Why care is more frequently women's experience, is a matter of gender; specifically, the socially constructed gender division of labour which has historically served patriarchal interests (Kuumba, 2002; Nussbaum, 2000; Laslett and Brenner, 1989).

My data shows that most carers interviewed came to care work due to personal experiences with HIV/AIDS. Hamington (2004) argues that, through our experiences - in particular and complex contexts, through connections to others - care becomes embodied (2004: 3) through knowledge gained, imagination, and habits (2004: 3-6). Caring habits (or the actions related to caring) are not mere instinct, they 'integrate the epistemic (caring knowledge) and the ethical' (2004: 5). Carers' knowledge of those cared for 'creates the potential to care' (2004: 5), while the bodies we inhabit, as human beings, may provide the 'possibility of care' (2004: 5).

Hamington's notion of care therefore conflates the moral/nature argument. People are generally empathic beings, who through their connections to others, may come to care for them. This experience may create a particular type of knowledge which may lead to our potential to imagine the needs of others, and provide for them. Being human alone

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provides the possibility of care, not a *gendered* human.

Many participants in this study acquired 'caring knowledge' by taking care of sick relatives. The 'caring knowledge' thus acquired evolved into a collective consciousness around the caring required in communities as a whole – as the burden of the epidemic grew and the health system crumbled. Participant G's experience provides an example: she became conscious that her experience of caring for her husband was a form of knowledge or expertise, needed in her community:

> *She first experienced this with her own husband. Her husband got sick for 3 years and she had to take care of him. For three years. Until he died. And he died in her hands … and then the brother of the husband did the same work. She looked at this job and said 'no, let me also do it, because I've been in this situation. Because myself, I am also HIV positive. Let me go out and help other people. I know how.' (Gτ)*

The 'caring imagination' extends embodied knowledge through 'caring habits' toward the needs of other community members. Experience, as an analytic category, provides a better understanding of why carers *do* care work.

The final point I will raise with respect to social reproduction and theories related to care is the long-held contention that care forms part of the construction of 'an unrewarding feminine ideal' (Freedman, 2007), a notion popular since Friedan's *The Feminine Mystique* (1963). The interview participants in this study reported experiencing numerous instances of fulfilment and reward in their work.

Participant A wanted to 'make a change' to the problems in her community. Carer H wanted to 'make a difference' and valued being a resource to her community. Carer C finds reward in knowing that she, as a carer, restores people's dignity. Participant J valued 'being a benefit to her community'. Other carers reflected on 'reward' as opportunity: owing to the limited educational and career opportunities in their contexts, some carers valued the training they received as part of their participation in community care organisations. Care work, for carer F, was a way of dealing with her frustration at the lack

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of employment opportunities: she wanted to work, instead of sitting at home, even if, at first, it meant not receiving any remuneration. Participant G, while unsatisfied with her remuneration, feels 'happy' to be gaining knowledge and experiences a sense of empowerment through her work. She is proud to share her accomplishments as a carer with her family, and she feels a sense of gratitude to be doing such 'very important work'. Carer H spoke of care work as her passion: 'it is a pleasure to help someone else'. She also saw reward in the potential for care work to lead her into the formal nursing profession: 'my biggest dream is that I want to work in a theatre, a theatre nurse. That's my goal in life.' This discussion shows important and powerful representations which challenge more traditional approaches to women's development: contexts of limited opportunities can simultaneously evince lack, disempowerment, victimhood, empowerment, opportunity, pride and pleasure. The meaning and mechanism of reconciling the dichotomized experiences of women carers will be discussed later in this chapter.

The capabilities approach was able to surface data which challenges existing thinking about theories related to care work. In the above discussion, I highlighted a new variation of care which requires theoretical consideration, as well as the increasingly artificial and unhelpful divide between the private and public realms vis-à-vis social reproduction. I point to the fallacy in the attribution of value (or lack thereof), present a more useful, non-essentialist category for understanding why women do care work and provide examples which dispel the myth that women engaged in care work may not experience reward.

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Development as social justice

This following discussion locates community care work in a feminist development framework. I propose that Nussbaum's capabilities approach (2000, 2001, 2010) presents

a useful strategy in this endeavour. It is not the only approach, nor is it without its critics. For example, Feldman and Gellert (2006: 446) argue that Nussbaum's approach 'leaves unchallenged the relations that generate and sustain inequalities', especially the 'institutions and structures of inequality whose benefits accrue to men and to capitalism as a mode of production'. I propose, however, that in a feminist analysis committed to interrogating the inherent, histo-politically constructed divisions and inequalities within the social and economic organisation of society (Raaber, 2010) which serve to 'deprivilege women relative to men' (Kuumba, 2002: 505; Nussbaum, 2000: 265; Laslett and Brenner, 1989), Nussbaum's is a complementary tool in generating discursive depth. Therefore, my interest, personally and politically, in locating community HIV/AIDS care workers' experiences within a development framework was served by this approach.

Using the capabilities approach provided concrete ways to think about poverty and community development, and based on the evidence presented so far, suggests a broad, contextualist approach to evaluating women's quality of life within the context of development politics (Austen and Leonard, 2008: 325) with a 'forthright commitment to social justice' (Feldman and Gellert, 2006: 445). It is an approach that overcomes the shortcomings of purely economistic analyses which employ indicators not necessarily able to account for the 'invisible' economic contributions related to 'caring and connectedness' (Austen and Leonard, 2008: 328; O'Hara, 1999: 83). The capabilities approach was able to foreground individual expectations and desires, and the diverse influences on these individual aspirations. As such, it provides a deeper, more textured interrogation of women carers' representations (Fahs, 2011; Markussen, 2005).

With this in mind, I attempt to engage the principles of the capabilities approach in this discussion: I explore capability *deprivation* through the carers' various representations of their respective capability *formation*. In this way, my discussion (tries

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to be) more than a reflection on, or 'listing' of, carers' deprivations and victimhood (Sen, 1999; Giullari and Lewis, 2005); it strives to identify carers' ability to theorise about their circumstances, which in turn points to 'agentic thought' about their lives (Cavalieri, 2011: 1448). In addition, it aims to take women's experiences seriously, in a way that acknowledges the epistemic agency and value of their representations (Biseswar, 2008; Power, 2004: 11, Narayan, 2003; Taylor, 1998).

Capability deprivation

The analysis revealed that women carers are deprived on multiple grounds. I highlighted four particular areas of deprivation according to Nussbaum's list of ten central human capabilities: bodily health, bodily integrity, emotions and material and political control over one's environment. As a strategy, the capability categories were able to expand my understanding of carers' situated realities. For example, I came to this research project as an activist with a sense of outrage at the plight of carers. Engaged in policy contestation and community activism, I was compelled to research and describe the horrific realities of care work and the deprivation of thousands of suffering women care workers.

The act of theorising about the experiences of care workers, however, leads to an interpretation of deprivation as complex and multiple. In addition, it reveals that being deprived *means* something objectively - carers have less economic wherewithal, but it also means something *subjectively* - which often has much more to do with a woman's ability to expressly live a life of meaning encompassing her values of choice (Austen and Leonard, 2008: 347). An understanding of the former enrages the activist but does little else; understanding deprivation subjectively may inform more effective activism for substantive change.

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In exploring carers' capabilities with respect to Nussbaum's category 'control over one's environment' (2000: 80), the well-known problems related to poor remuneration surfaced. However, carers' reflection on what this meant is of theoretical significance. When this issue surfaced, participant B's immediate concern was for her family and the potentially intergenerational aspects of her economic deprivation. Participant B's representation of what her economic insecurity means is intuitively feminist: it foregrounds *human* development over purely *economic* development (Benería, 2003). Here carer B points to the fact that her deprivation creates more than a 'deprived woman', a victim of poverty. In her connectedness to a family and household, as the sole breadwinner, her deprivation leads to a web of consequences for a range of people. The finding that the average person in a carer's household lived on R152.50 per month shows this in concrete terms. This matters because, in carer B's economic deprivation, her household's means to achieve well-being, whether in terms of health, education, human development or other advancement, is also deprived (Martins, 2007: 52). To address economic insecurity in a way that *matters* to carer B, to provide her with the capabilities to live a life *she* values, would mean being able to provide for her family's financial future, and not leaving them with the shame and burden should she die before she can afford a 'burial policy'.

The data shows that the majority of carers interviewed were the sole breadwinners for their households. As discussed earlier in this chapter, HIV/AIDS care work deprives not only the carer, but also her household, both in terms of the productive and reproductive value. We can see this reality emerge in quantitative economic data: if 91% of care workers in South Africa are women, 45% of South Africans live in absolute poverty, 80% of female-headed households have no formal income and if the burden of care work is highest for women in households with the least income (Budlender, 2008; Ogden, 2006),

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we can deduce that economically precarious working conditions are being perpetuated by the burgeoning informal care sector, or at the very least, we can identify informal care work as a strategic point of entry for community development initiatives.

Participant D also locates her economic situation in the impact it has on others. She 'worries' that her inadequate stipend is 'not enough' to care for her clients. Carers buy food for clients, who are often more impoverished than themselves, but the cost of care also extends to buying protective materials necessary to protect oneself, such as gloves and disinfectants, or paying for electricity or paraffin to heat water, which may also need to be paid for (in this interview, D refers to clients who do not have running water and her task of sourcing water from a neighbour who 'fights with you because they say they rent this water'). Participant D's experience shows how task-shifting in the context of community care is deprivational: it has 'displaced the responsibility for care downward and outward onto un-resourced communities' (Lund and Budlender, 2009: 24). Poor service delivery exacerbates this situation, as does the state's neoliberal economic policies aimed at limiting public expenditure, even in some of the poorest communities. Thus, for participant D, the concept of economic security would include the ability to provide adequate care for her clients, *and* being able to protect her own health while doing so. Participants E and F also connected their economic fragility to its impact on their clients: they feel helpless and deprived of their own sense of worth as carers because they cannot afford the material necessities to provide 'proper care'.

Participant D goes on to explain the personal costs incurred by her care work. After the financial outlay related to her work, carer D is unable to afford to live on her own. She 'wants to be independent' but 'can't afford it'. In this instance, we see manifest how the 'lived experience of poverty is conditioned by gender identity' (Jackson, 1998: 81). Gender division of labour and caring experiences (as well as caring habits) thus gained brings

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participant D to be engaged in care work, which is economically deprivational due to it being undervalued as a form of social reproduction. To survive, she lives with her boyfriend, a choice she would not make if she had the financial wherewithal to live on her own. In this way, we glimpse the pull of patriarchal economic paradigms which reward more normative social arrangements through economic incentives, such as making co-habitation more affordable for women than independence. The home, as fundamental to the reproduction of the economy, is thus reinforced and protected (Nussbaum, 2000: 265-270). As noted in the literature, 'home' is a critical space where gender operates to maintain and re/produce capitalocentrism and heteronormativity, thus maintaining the oppressive status quo (Harcourt, 2009: 74).

Why is it important to surface that economic security may *mean* something different for each carer? Economistic development policies are (potentially) unsuccessful because they do not focus on the 'social' (Benería, 2003). Ensuring economic security would mean more than increasing carers' remuneration: it would mean that carers' have the capabilities necessary to exercise material control in their lives. In the examples presented here, this would mean: being able to provide proper, quality care, and to feel a sense of self-worth in being able to do so; being able to protect one's own health while providing care for others; being able to provide a degree of financial security for one's family in the event that they no longer had your income (as the sole breadwinner in the household) and to be free from anxiety in this regard; or to be independent and autonomous.

In conclusion, I would challenge the criticism of the capabilities approach as individualistic (Jackson, 1998) and note this as a strength. With respect to care work, feminist theorists have argued that society as a whole benefits from care work more than women themselves, predicated on the ideological claim that the interests of everyone are

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more important than the individual well-being of the carer (McFadden, 2000; Gqola, 2008: 44). Therefore, I agree with Robeyns' interpretation of the capabilities approach as one which rejects the idea that women's well-being 'can be subsumed under wider entities such as the household or the community' (2004: 65). Instead, as this dissertation shows, by starting with the capabilities of women carers, we are able to surface the interconnectedness (individuals are after all 'connected' to other individuals) and overlapping nature of capabilities within particular contexts (2003: 63-66).

Taking the development needs of carer B seriously would have positive repercussions for the capabilities of her family and her clients. Furthermore, it would require approaches which reject siloed development initiatives, appreciating the overlapping nature of, for example, women's development, health, social welfare and community development, as evinced in this example. The capabilities approach prevents 'oversimplifying complex social phenomena that affect the least advantaged' and provides a tool to understand fully the relationship between a woman and the experience of doing care work (Cavalieri, 2011: 1457).

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Capability formation

As noted, I come to my research interest through my experiences as an activist. From this position, I was not surprised by findings revealing the deprivational nature of care work. I did, however, find the fact that community HIV/AIDS care work could *create* capabilities noteworthy. Reflecting back on the analyses distilled through Nussbaum's category 'control over one's environment' (2000: 80) vis-à-vis capability deprivation is especially interesting.

Carers' ability to exercise practical reason (Nussbaum, 2011a: 200) refers to agency and reflecting critically on one's situation. Participant F described care work as an

'opportunity'. As an unemployed job-seeker, F was frustrated. Volunteering as a carer, at first without a stipend, was better than 'sitting at home'. She wanted to work, and providing care was an opportunity to work. In her representation, we see that the need to *be* employed, to *be* working, could be conceived as a 'good' in itself (Nussbaum, 2011a: 200), even if the work was unremunerated. Participant E was also looking for a job after leaving school, 'but didn't find it'. She did, however, find an opportunity to receive training at a care organisation.

> *I just see in the paper, the training for HBC [home-based care], I attended that training at [an organisation] in Nyanga.*

Once she completed her training, she sought out an opportunity to use her skills by volunteering as a care worker at the same organisation. Despite the lack of economic reward, care work provided her the opportunity to develop herself. It also provided her the opportunity to participate in a 'space' (Sen (1999) refers to this as a 'capabilities space'; Hill, 2003: 131) which could present additional opportunities in the future. At the time of the interview, participant E was earning a stipend.

From carers' representations, we learn that opportunity means not only the opportunity to earn, it is the opportunity to *do.* Opportunity is also the ability to dream, or to engage in activities which fulfil one's sense of working toward one's dream. Participants H and J both said that they had 'dreamed of becoming a nurse'. For participant H, doing work which resembled her dream was an opportunity, even, again, if it had no monetary reward.

> *I started here … volunteering. No pay. No nothing. It was my passion, you know?*

If carers' representations of what may constitute capabilities mean something *subjectively*, then understanding what 'opportunity' may mean to carers is of interest. Meanings are 'conditioned by social and economic experiences' (Austen and Leonard, 2008), as well as

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norms related to tradition, culture, race or gender (Robeyns, 2010: 228). Meanings thus constructed influence women carers' perceptions, preferences, aspirations, and 'effective choices' (Robeyns, 2010: 228). Carers' representations of 'opportunity' may therefore be influenced by what they perceive opportunity to be in their setting, a perception mediated by the factors described above. How then, are capabilities created by the (perceived) options available to carers' in their contexts?

In contexts of great economic deprivation and high rates of unemployment, many school leavers believe that the opportunity to be employed and earn a decent wage is one which is not open to them. In this context, opportunity is perceived in the ability to be busy, to do something, even if it is unpaid, rather than 'sitting at home'. To receive training - any training - in a context where opportunities for personal advancement are limited, is an opportunity to gain a competitive advantage, either in being more equipped than another job-seeker, or to be located in spaces which may *potentially* create opportunities (Sen, 1999; Hill, 2003).

This adds a dimension to my previous discussion challenging essentialist notions of why women do care work. In addition to experiences, which may be embedded in conditioned preferences, this example shows that, in contexts of poverty, opportunities for (perceived) advancement arise out of the enormous need for community HIV/AIDS care.

Carers' are clearly able to engage in practical reasoning about their future and to act according to the opportunities thus identified. However, in the context of care work, when reflecting back on capability deprivation, carers' actions and reasoning related to their opportunities reflects more on the deeply deprivational nature of care work - in this particular context - than its potential to provide substantive capability formation.

Nussbaum lists 'emotions' and 'affiliation' as central human functional capabilities (Nussbaum, 2011a: 33-34). Carers' representations were deeply emotional and evinced a

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great deal of empathy with their clients' situations. This stands whether carers came to care work through personal experience, or through recognising care work as providing potential opportunities for economic and personal development. Often, emotion was experienced through a sense of affiliation. One carer recalls cultural ways of being and says:

> *it is strange for us to see these things…where people are left alone, alone when they're sick, left alone to die.*

Another empathises with clients who

> *don't have someone…the person is just laying alone there. And my concern, I mean, just being sick, and being alone. It's not nice.*

while carer G 'feels the pain of the person' and says 'you must put yourself in that person's shoes, because that could be me one day'.

When emotions are 'blighted', however, by overwhelming trauma and anxiety (Nussbaum, 2000: 79), it can amount to capability deprivation. Thus, even as carers express their ability to form attachments, to feel emotions, to be empathic about the plight of others, and to act on the choices thus informed, their emotional experiences describe a reality of daily distress, trauma, and grief. Thus, while care work creates a space for people to experience emotional connections to other human beings in meaningful ways, the experience of community HIV/AIDS care work, in the setting explored here, is extraordinary in its encumbrance on human emotion.

The task of focusing on capability creation in the context of care work is a complex one. I suggest that Austen and Leonard's (2008) description of 'coping' is useful in this exercise. Coping, or adapting, is an act of agency, a way of exercising one's capabilities to greatest effect in one's circumstances (Austen and Leonard, 2008: 342-343). Carers' representations comprise a powerful exposition of coping strategies. Individually, carers are coping with the task of providing care in an informal, un-resourced 'space' (Sen, 1999).

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Organisations are not funded sufficiently to provide materials to carers, and carers find that they face additional material challenges in the clients' homes related to service delivery or sheer poverty. Carer K explained:

> *... you see to the social problems of the client. If they don't have food....We haven't gotten anything [food parcels] from social services for a while now. So we do what we can. (K)*

Carer A says 'we're trying to do the best we can' and 'as care givers, as women, we do whatever it takes'.

Carers also come to care work as a coping strategy. Participant J had to leave formal employment ('in a factory') when her mother became ill. The type of care required meant that carer J had to be at home with her mother 'full-time'. She adapted to her circumstances, and through this experience, learned how to cope as a carer. In this way, we see how carers' coping 'knowledge', as described by Hamington (2004), is an adaptation to circumstances where care is not available to communities in need, need brought on by the HIV/AIDS epidemic.

Austen and Leonard (2008) therefore point to the negative aspects, or 'costs' of 'having to cope' in contexts of poverty (2008: 343). Despite women's 'adaptive capabilities' (agency), the preferences and choices open to women in the setting of community HIV/AIDS care work are 'de-formed' (as opposed to capabilities being 'formed') and should themselves become the focus of any analysis on capability deprivation (2008: 343). Furthermore, the coping mechanisms activated within communities under these circumstances are more about exploitation (Kang'ethe, 2009: 84) than an opportunity to create capabilities. Specifically, the coping ability of carers - within the context of the state's emergency response to overwhelmed public health services due to HIV/AIDS - has resulted in normalising care work as a coping mechanism (Lund and Budlender, 2009; Tarimo, 2009; Zachariah et al, 2009). Austen and Leonard (2008) argue that this coping

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ability heightens 'the risks of complacency about the human ability to adapt' (2008: 343).

Conclusion

The capabilities approach facilitates a 'harmonized feminist account' (Cavalieri, 2011: 1447) of care work. It can evince that 'multiple oppressions are not the sole defining characteristics of women's existence' (2011: 1448), and it can highlight how women are able 'to agentically assert a self-defined vision of the good in their own lives' (2011: 1458). Simultaneously, it can highlight how agentic thought and action may be limited in the face of oppressive realities. The first interview undertaken in this study sums this reality up:

> *It is not an easy task … But luckily, there we are, strong women, trying to do the best we can, to help, to make them strong, to give them strength to carry on with their lives … We as care givers, as women, we do whatever it takes. (A)*

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Conclusion

I come to my research interest through experiences as an activist, holding firm to the belief that community HIV/AIDS care work is profoundly deprivational for the women who do it. With a commitment to feminist research, I was interested in exploring what care work meant for gender equality and commensurate development consequences. A discursive exploration revealed tenets of feminist development economics to be a suitable framework for assessing what the representations of care workers could reveal about the meaning of care work as a form social reproduction which perpetuates and reproduces systems of gender inequality (Laslett and Brenner, 1989; Folbre, 2006).

Nussbaum's work on the capabilities approach to development has had significant influence on feminist theorising a propos the operation of multiple, intersecting 'axes of domination' which 'deprivilege women relative to men in society' (Kuumba, 2002: 505). Premised on the idea that 'poverty combined with gender inequality leads to the acute failure of central human capabilities' (Harcourt, 2001: 3; Sen, 1999; Nussbaum, 2010), Robeyns agrees that the capability approach is 'a promising evaluative framework for gender inequalities' (2004: 1). It is a useful way of illuminating how personal, social, environmental, political and economic factors act with, and not independent, of each other to deprive women of central human capabilities (Giullari and Lewis, 2005: 15; Robeyns, 2004; hooks 1984 [2000]; Sen, 1999). Incorporating Nussbaum's notion of the capabilities approach into the analyses enabled theorisation about women community care workers' experiences.

From the position as a feminist activist embedded in the world of community HIV/AIDS care worker policy contestation, I was not surprised that carers' representations confirmed the deprivational and often debilitating nature of care work. I did, however, find

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the fact that community HIV/AIDS care work could *create* capabilities significant. Thus, a position which promotes carers as victims of care work is not only unhelpful, but also erroneous. The capabilities approach, applied in the over-arching framework of feminist analyses, could distil carers as agentic individuals within deprivational contexts (Cavalieri, 2011). Agency in the context of community care work, however, often amounts to coping or 'adaptive capability' formation (Austen and Leonard, 2008). The capabilities approach is thus able to differentiate between agency which contributes to the quality of life women are able to achieve, and agency which 'de-forms' capabilities, and which should thus be assessed as an analysis on capability deprivation (2008: 343). Furthermore, this approach points to the exploitation of women's adaptive or coping capacity to normalise and re/entrench heteronormative and oppressive ideals about gender and care in the service of neoliberal patriarchal interests.

This dissertation attempted to integrate a capabilities approach within an overarching feminist framework that incorporates methods able to take women's experiences seriously in a way that acknowledges the epistemic agency and value of their representations (Biseswar, 2008; Power, 2004: 11, Narayan, 2003; Taylor, 1998). The data from this research process evinced carers' dichotomized experiences. In the context of HIV/AIDS, women carers are deprived by opportunistic and expedient state practices, predicated on oppressive gendered norms, driven by economistic ends rather than human development. Women carers' representations also reveal agentic individuals coping *and* struggling, experiencing hope, pleasure and immense distress. A capabilities approach, within an overarching feminist framework, could identify moments of capability formation within deprivational contexts. Capability formation was most often in response to deprivation, thus crystallising the way in which care work deprives women. Feminist analysis can interrogate this simultaneous, material reality of capability deprivation and

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formation. Cavalieri argues that the capability approach serves the feminist goal by seeing women carers as 'agentic and self-determining in the face of limitations' rather than ascribing the 'narrow status of victim or agent' (2011: 1455-1457). Thus, understanding the experiences of women carers', whether in theoretical or political endeavours related to informing development practice, requires conceptualisations and interventions which interrogate the exercise of agency under extreme constraints. A holistic understanding of agency in such circumstances may also illuminate strategic entry points for effective development initiatives: that is, when understanding carers' experiences, we learn that their agentic action is often in opposition - and thus points to - the causes of deprivation experienced in their settings.

With respect to the policy strategies discussed earlier in this dissertation, it is imperative that a comprehensive, accurate knowledge base be consulted. Policy formulated on partial knowledge will be ineffective, and as suggested in several instances pertaining to community care workers, deleterious (Budlender, 2002). A feminist analysis proves invaluable in creating such a knowledge base, illuminating the causes and consequences of unjustifiable inequity: that is, capability deprivation. Critically, the extra value of this approach is that the identification of that which deprives us of capabilities points to that which must be addressed to 'enable people everywhere to live full and creative lives' (Nussbaum, 2010).

While this is a small research project intended for scholastic purposes, I have benefited from the interest and support of many activists and academics working in the context of community HIV/AIDS care work. The experiences of carers' and the ideas generated around their own representations will be shared with these partners. Specifically, the findings and feminist analysis will contribute to conceptualising care-for-the-carer support programmes facilitated by AIDS Response, the non-governmental

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organisation which supported this research and provided entre to the participants interviewed in this dissertation. Further, the evidence will inform arguments for pursuing gender-responsive policy activism within AIDS Response, who have shown great commitment in pushing the boundaries of understanding the needs of carers in holistic ways to shift discourse away from 'carer as victim'. Not only has feminist scholarship provided a platform from which to articulate the problems incumbent within the current care work context, this articulation is in itself transformative in how it enables those engaged in this work to think about carers themselves: agentic women struggling in the face of oppressive realities.

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