

Accepted: February 15, 2011

# Mutual Isolation and the Fight for Care An Ethnography of South African Homebased Healthcare Contexts

Izak van ZYL
Faculty of Informatics and Design, Cape Peninsula University of Technology,
Cape Town, South Africa

Abstract. With the increasing pressure created by HIV/AIDS and chronic illness, home-based healthcare (HBHC) has become a vital counter-service in developing countries. Yet, initial observations in several HBHC setups in the Western Cape of South Africa have indicated that caregivers lacked proper support structures. This was either in the form of patient data administration, finances, emotional counseling, or informal educational opportunities. These challenges in turn may inspire a range of probable 'solutions', ICT and otherwise. These circumstances are the rationale, then, behind a full ethnographic undertaking. Indeed, an in-depth understanding of HBHC in its variety of contexts must precede any (abstract) solutions, be it in ICT, social development, or health provision. This paper sets out to elucidate some of the social and cultural factors that are pertinent in this environment, to explore the needs and desires of caregivers – particularly informational and educational – and to lay the early foundation for possible communication technology-based solutions (or counter-actions).

# 1. Introduction

The healthcare context in South Africa is characterised by an extreme polarity between the classes of rich and poor. Depending on the province they live in, only 9% to 28% of South Africans are covered by medical aid schemes (Erasmus, 2009). Moreover, the proposed National Health Insurance Scheme has barely penetrated public discourse, and is presently beyond effecting realistic change in the country's health framework. As an alternative, many disadvantaged individuals resort to Community Health Centres (CHCs) or Home-based Healthcare (HBHC) services for treatment or consultation. However, the majority of these facilities are historically underfunded and underresourced, resulting in a loss of adequate health services. These same institutions also lack (applicable) information systems and rely mostly on outdated paper-based administration and patient data organisation.

It has become of essence to introduce sound (socio) technological structures within these healthcare setups. This may reduce data inaccuracy, increase management effectiveness, and improve overall health provision. Yet, these setups often function in unstable environments where elements of social disempowerment are rife. This affects the introduction, integration, and ultimate recognition of any technological endeavour. Lacking or fractured technological undertakings further the polarity between classes of rich and poor, patient and clinician, and sustain the broader socio-political ills of "e-





Accepted: February 15, 2011

isolation" and "e-exlusion". These ills describe the general (or universal) *inaccessibility* of technology for the majority of South African communities.

Participative technological endeavours have, in this regard, become imperative within local healthcare contexts. Such approaches incorporate the perspective of the end-user or client, co-creating and co-managing a technological intervention to a specified context (Miettinen & Koivisto, 2009). The user/client is then a central participant and stakeholder in crafting technological involvement(s) in his or her community. In rural (or isolated) healthcare frameworks specifically, participative technological arrangement offers the possibility to improve or develop patient data management, basic treatment administering, and consultation (see Korpela et al.; Cushman & Klecun, 2006).

In light of the above, this paper describes some of the existing standards and emerging trends, both social and technological, in selected healthcare contexts in South Africa. Specifically, the HBHC services in four "communities in stress" were analysed. HBHC has become a growing and necessary provision to chronically and terminally ill individuals who are unable to access private health services. The World Health Organisation (WHO) (2004) defines HBHC as the provision of comprehensive services, which include health—and social assistance, to individuals in their homes. This paper will describe these individuals to be both socially and technologically disempowered, and therefore on the peripheries of techno-social participation. It will be argued that information systems may well be valuable within isolated communities, but that their successful adoption and integration will depend on bottom-up involvement and participatory development. It is concluded that the failure to recognise participatory approaches will perpetuate both e-exclusion and e-isolation.

# 2. Motivation and Objectives

Initial observations of three home-based healthcare setups in the Western Cape during 2009, <sup>1</sup> indicated that caregivers lacked proper support structures. This was either in the form of finance, emotional counseling, or information systems. These factors are, in essence, the motivation for compiling this paper. It has become clear that home-based care is an important and indispensable service to communities in need. Without it, patients in critical conditions would often be isolated, especially in rural areas. These circumstances are the rationale, then, behind an ethnographic undertaking. Indeed, an in-depth understanding of HBHC in its variety of contexts must *precede* any solutions, be it in ICT, social development, or health provision.

An ethnographic analysis – the results of which are presented in this paper – has the following objectives:

- To gain an understanding of the many complex dynamics at play within homebased healthcare in four care networks, located in the Western and Eastern Cape provinces. This includes specific social, political, cultural, economic, technical, and environmental flows/dynamics as they are relevant to the caregiver and care-receiver.
- To gain insight into the possible needs expressed within the mentioned care networks. This is specifically concerned with the flow of information (data)

<sup>&</sup>lt;sup>1</sup> Stellenbosch Hospice (Stellenbosch), YMCA (Athlone), and NAD-clinic (Melkbosstrand).





Accepted: February 15, 2011

and the subsequent betterment of care provision through the use of technology (ICT).

To lay the (early) foundation of possible ICT solutions for evaluated needs.

This paper has the ultimate or final objective of expanding the current research in promoting ICT for e-accessibility and e-inclusion, especially relating to communal health organisation. This research will assess the participative means through which persons – caregivers *and* –receivers – may incorporate technologies in the sphere of HBHC. The aim here is to build in-depth, ethnographic insights of these means within disadvantaged contexts in South Africa.

#### 3. Methodology

Four communities were assessed for this analysis. The first is Kayamandi – an informal settlement on the outskirts of Stellenbosch, Western Cape. The second is Motherwell, a poor urban node located 20km outside the Port Elizabeth Central Business District (CBD). The third: an extremely impoverished district in Idutywa, Eastern Cape (approximately 200km northwest of East London). The final evaluated community was an informal area on the outskirts of Grahamstown (Eastern Cape), in particular Extensions 4, 5, and 9.

The research also focused on four nonprofit organisations that provide home-based healthcare services to residents within said communities. In Kayamandi, Stellenbosch Hospice is the primary care provider. In the Eastern Cape, Olive Leaf Foundation (OLF) manages the HBHC activities in most of Port Elizabeth's satellite areas, including Motherwell. In Idutywa, the consulted care provider was the Mida Health and Poverty Project. In Grahamstown, the HBHC provider was the Grahamstown Hospice.

The abovementioned institutions were selected for this research due to their active involvement with home-based healthcare across impoverished areas. The coordinators at all four organisations welcomed research endeavours that would explore some of the key issues in caregiving and –receiving, especially in terms of information or data management. Our research team was thus allowed to accompany and assist caregivers in their daily 'care journeys'. During this time, (in-depth) interviews were conducted with caregivers, patients/clients, nurses, and coordinators.

The mentioned approach, where caregivers and patients were observed in their "natural settings", speaks to the anthropological method of participant observation. Essentially, participant observation denotes that the researcher partakes in the 'typical doings' of the persons under study (Bernard, 1998). This bestows upon the social scientist a deeper insight into the lifeways of subjects. Indeed, the analyst now actively participates in, and subjectively interprets, the many socio-cultural dynamics at hand. Participant observation has become a defining method of ethnographic analysis, where the researcher tries to gain the insider's view of a particular group or community (Savage, 2006).

<sup>2</sup> These organisations are not the only HBHC providers in the respective areas but service approximately 4500 households combined.



Submitted: April 15, 2010

Accepted: February 15, 2011

Overall, this research is conducted within an ethnographic framework: the data of cultural anthropology that is derived from the direct observation of behaviour in a particular group or society (Babbie & Mouton, 2001:279). An ethnographic methodology informs and brings about an insider's perspective – an account, if you will, of the myriad social and cultural dynamics at play in terms of the subject matter (see Wolcott, 1975). Spradley (1973) (cited in Babbie & Mouton, 2001:279) defines ethnography in a similar vein:

Ethnography is the work of describing culture. The essential core of this activity aims to understand another way of life from the native point of view. ...Field work, then, involves the disciplined study of what the world is like to people who have learned to see, hear, speak, think and act in ways that are different. Rather than studying people, ethnography means learning from people.

Ethnographic analysis, then, is taken as our point of departure. Yet, this examination concerns more than traditional ethnographic observation. Indeed, the four mentioned communities each constitute a valuable case study. A case study is an intensive investigation of a single unit (Babbie & Mouton, 2001:281). The majority of case studies may involve the examination of a multitude of variables, including their interactions and dynamics. It is the task of the researcher to scrutinise these variables in relation to one another so as to deduce scientific insights (in this case, via ethnographic observation). A powerful combination thus is found in ethnographic and case study methodology. One that may generate an in-depth social and cultural account of the South African home-based healthcare space.

#### 4. Context

# 4.1. The state of health in South Africa

South Africa has a legacy of inequality and violent discrimination. The majority of its population was oppressed under the apartheid mandate, officially initiated in 1948. During this time, the quality of life for the average South African radically diminished. To the present day, much of the past inequalities have not been redressed and remain influential in the socio-economic domain. The list is endless: vast unemployment, widespread political corruption, crime, illiteracy – to name but a few. The roots of a troubled past can be observed in the nation's present health state (adapted from Lancet, 2009; Erasmus, 2009):

- Since 1994, average life expectancy in South Africa has dropped by almost 20 years, mainly because of the rise in HIV-related mortality. Average life expectancy at birth is only 50 years for men and 54 years for women.
- South Africa has 0.7% of the world's population, but carries 17% of the global HIV burden. HIV prevalence seems to have reached a plateau, but there are 5.5-million South Africans living with HIV/AIDS.
- The overall injury death rate is 157.8 per 100,000 twice the global average. Road carnage plays a significant part: there are about 16,000 road traffic accident deaths every year. Around 7% of all deaths are alcohol-related.
- The homicide rate is five times the global average: 38.6 per 100,000 people, with the highest rate among men aged 15 to 29 years. The female homicide



Submitted: April 15, 2010

Accepted: February 15, 2011

rate is six times the global average, and half of these women are killed by their partners. It is estimated that a woman is killed by her partner every six hours in South Africa.

- Although South Africa and the then minister of health, Manto Tshabalala-Msimang, were signatories of the Millennium Development Goals, which were particularly focused on child and maternal mortality, children continue to be victims. Far from reaching the goals set then, South Africa has gone backward: it is one of only 12 countries in the world where infant mortality has risen since 1990. Every year, 23,000 babies are stillborn, and almost 75,000 children die in SA nearly a third of these in their first four weeks of life. 12% of children under 5 are underweight. Each year 37 200 children could be saved through the prevention of mother-to-child HIV transmission and safer infant feeding practices.
- There are 4.9 physicians, nurses and midwives per 1,000 South Africans double the World Health Organisation standard of 2.5. Yet, the majority of the population is still under-served: medical personnel are clustered in urban areas. Moreover, 79% of doctors in South Africa work in the private sector, where 60% of health spending happens, but which is accessible to just 14% of SA citizens.
- Depending on which province they live in, only 9% to 28% of South Africans are covered by medical schemes.
- Though the state's focus on health is significant, comprising 10,8% of total government spend, it is yet to recover from past mismanagement. If the policy of free antiretroviral therapy provision in public health services had been adopted in 2003, 330,000 lives could have been saved between then and now.
- The burden of TB has more than doubled since 2001. KwaZulu Natal is the hardest hit with an HIV prevalence of 39,1% and a TB notification rate of 1,066 per 100,000 people.

It is clear that South African citizens face a precarious situation. The frenzied state of health is but an indication of the many challenges ahead. Fortunately, there are a number of stakeholders who consider it their active duty to alleviate at least *some* of these strains. The outcome, among others, is home-based healthcare – the product of sheer dedication on the part of community caregivers.

# 4.2. Home-based healthcare

Worldwide, the onslaught of HIV/AIDS and related illnesses has increased. In South Africa, almost 6 million citizens suffer from this fatal disease. In addition, the majority of the citizenry is impoverished and lack crucial medical resources. The progression of HIV to AIDS can vary, ranging from a few months to, in some instances, more than a decade (National Department of Health, 2002:6). Moreover, the advanced stages of HIV are chronic, requiring intensive treatment and care. This situation has strained the national health system, asking questions as to its ability to administer and treat patients effectively.

With the increasing pressure created by HIV/AIDS, home-based healthcare has become a vital counter-service. Taking the earlier definition presented by the World Health Organisation, HBHC promotes, restores, and maintains a patient's maximal



Submitted: April 15, 2010

Accepted: February 15, 2011

level of comfort, function and health, including care towards a dignified death (ibid.). The care service is thus accessible to the patient in their personal space. This reduces the need to travel and facilitates an interpersonal engagement between caregiver and – receiver.

Home-care services can be classified as preventative, supportive, therapeutic, rehabilitative, long-term maintenance, and palliative (ibid.). As an ongoing community provision, it has contributed to the overall de-institutionalisation of the formal health system. This system has been largely unable to cope with increasing patient numbers, due to higher instances of TB, HIV/AIDS, and cancer. The universal HBHC approach addresses several shortcomings in the national health framework, including (ibid.):

- A shortage of hospital beds, resulting in over-crowding and resource depletion;
- A shortage of trained and experienced nursing staff and medical professionals;
- A lack of resources for treatment and prescription medication; and
- High and increasing costs of institutional care.

By providing a care service to patients within the comforts of their homes, community- and home-based care transcends the former boundaries between patient and clinician. Within these traditional confines, poor and chronic patients were often prevented from attaining (or affording!) necessary health services. This was due to the remoteness of their homes, or unemployment, or poverty, or a multitude of limiting factors. But a home-care service gradually brings the health service within reach of even the most peripheral communities and homesteads.

Such was the (potential) success of the HBHC process, that the Department of Health suggested various types of care models (see National Department of Health, 2002:7-10):

- Community-driven model driven by local activities, this model does not necessitate a central structure in which to coordinate care provision. Instead, it will involve one or a few individuals or initiatives that will in turn train volunteer caregivers. This model is somewhat dependent on private donors and government departments for resources.
- Formal government sector model led by various departments, including health and social development, this model ties influential state divisions with sectoral grassroots organisations. The model is coordinated by a multidisciplinary team of medical staff, usually from within the formal hospital structure. Patients are treated in the hospital, and transferred back to the home. Follow-up visits are conducted by hospital nurses, as well as informal caregivers. Community organisations or local initiatives may assist in this care network where possible and desired.
- Integrated home/community-based care centre model this model is structured around a community care centre, usually run by volunteers. Although the care centre is largely independent, state departments may allocate nurses or health workers to it on an individual basis. The care centre typically offers various services, including HIV counselling and testing, facilitation of income-generating projects, family health training, home-visit services, patient follow-ups, and hospital referrals. The scope of the clinic's services may be limitless, and may in some cases include patient day-care.





Accepted: February 15, 2011

- NGO home/community based care model similar to the integrated care centre model, this approach is structured around a community centre, but run by a non-government organisation. Community needs are determined and cared for by the NGO, but may be supported by neighbouring organisations. The activities of the NGO are largely funded by external business partners, public benefit institutions, and private donors. Staff may typically include caregivers, nurses, social workers, and volunteers.
- Hospice integrated community and home-based care model (ICHC) this model stresses the "continuum of care" between all sectors of the healthcare system, specifically emphasising palliative care. It is also structured around an NGO, with the difference being that this organisation is already well-established and self-sustainable (i.e. hospice). The advantage of a well-versed NGO is that it facilitates existing networks and skill sets around community-and home-based healthcare. This enables the rapid development of an extensive home-care network (ibid.).

The aforementioned models constitute the primary service approaches in homeand community-based care (in South Africa). At the heart of every model is the patient – an individual with a chronic or terminal illness. The patient's immediate family, neighbours, and friends form the core of this largely community-driven framework. The core is supported by various agencies, including the formal health care sector, community-based organisations, and hospices (National Department of Health, 2002:8). This intersection between formal organisation and community residents represents the continuum of care: a collectivity of care workers mobilised around a strong health network.

# 4.3. Technology in home-based care

As revealed by initial observations of HBHC setups in South Africa, <sup>3</sup> healthcare professionals and caregivers experience challenges with the recording, transmitting, exchange and storing of patient data. In this context, patient data is mostly paper-based and technology, it seems, is not utilised properly. Table 1 presents a detailed account of data flow in an HBHC service provider (Stellenbosch Hospice). In light of this, it appears data flow may be radically improved by the introduction of technology. For technological innovation may become crucial to the universal HBHC framework where citizens, communities, care providers, and health authorities rely on its quality for better service provision (see Figure 1).

Table 1: Stellenbosch Hospice Data/Information Flow<sup>4</sup>

Stellenbosch Hospice works closely with health facilities in the Stellenbosch area, including Stellenbosch Hospital and local clinics. Patients that need home-care are referred to the Hospice. These patients have varying problems and needs, ranging from palliative care, chronic care, physiotherapy, directly observed treatment (DOT), social grants, pap smear and pregnancy, community integrated management for child illnesses, and wound care. The Hospice assigns patients to caregivers based on area/region clusters. After formal assignment, the patient care manager develops an individual care plan and the patient is given a unique patient number.

-

<sup>&</sup>lt;sup>3</sup> See Page 5, Footnote 2.

<sup>&</sup>lt;sup>4</sup> Credit to Siphokazi Tswane, INSTITUTION, for drafting the original table.



Accepted: February 15, 2011

Caregivers play a vital role in the information/data flow in the Hospice. When they start working with patients, they are given a care plan, home-patient records, home visit forms, and home-based healthcare tally sheets. They are required to fill these out every time they visit a patient. Each form has a particular purpose. The home visit form is used by caregivers to detail daily visits: who was visited; when; how long for; what kind of assistance was given. The patient or family member is required to sign the form, thereby confirming the caregiver's presence and activities. At the end of each day, caregivers calculate the total number of patients they visited, and tally the different caring activities they performed. These statistics are sent to the area coordinator who then compiles care tally sheets for the area.

The Department of Health is the biggest funder of the Hospice and hence sends officials to inspect the care service. They accompany caregivers to patient homes to both evaluate the service and scrutinise the patient file. The Nursing Sister responsible for each area visits patient homes twice a week to assess the progress of care. She facilitates weekly meetings with the area coordinator and the caregivers. If patients are not progressing as expected, the Sister or Senior Coordinator reviews the care plan. Month-end, the Hospice sends its statistics to the Department of Health. This pertains to all services and dynamics of care – i.e. number of patients visited per week, number of caregivers deployed per area, number of patient deaths, and the like. The statistics are interpreted at policy-level, and provides the Department with an inclination of ground-level dynamics relating to its various (home-based) care networks.

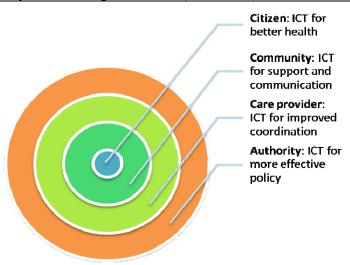


Figure 1: The holistic HBHC framework

Figure 1 is a typical onion-model representation of the home-based healthcare network. It depicts the citizen at the core of the service; the primary social benefactor, as it were. The citizen forms part of a larger community of citizens: immediate family, neighbours, friends, and general local residents. The Hospice or care provider (formal or informal) encircles the citizen and community. It may operate centrally – from within the community itself – or externally, outside the community borders. The Hospice reports to a state authority, in this case the Department of Health. This body is



Submitted: April 15, 2010

Accepted: February 15, 2011

(somewhat) responsible for resource allocation to the Hospice, and for the development of HBHC policy.

Within the holistic HBHC framework, it may be argued that each constituent has a different need for ICT. The citizen seeks improved health; the community calls for a support network; the care provider requires better coordination; and the authority demands more effective policy. This entire process depends on data quality and utilisation. If data was to be fractured, so the care network would become fractured. These assertions will be evaluated accordingly. For now, and in light of initial observations on data flow, it may be useful to explore the introduction of technology in the South African HBHC space.

Technological innovation in the framework of HBHC may require a long-term social and financial investment. The ideal technological "solution" will constitute the following:

- A meta-data repository containing all possible HBHC data elements. This
  application may serve to define and generate home-based patient health
  records.
- A bottom-up participative ICT framework that:
  - o proposes a practical technology via user-centred design methods;
  - o makes home-care data recording less cumbersome and timeconsuming for the care worker;
  - improves the sharing, utilisation, and interpretation of data for service coordinators;
  - o provides accurate, informed data that aids policy-makers in dictating effective health policy;
  - o cycles strengthened policy to the grassroots, resulting in improved care systems at the delivery point.
- A pre- and post-implementation training programme for home-based healthcare providers to use the proposed ICT solution.

It is essential that any technological solution be developed alongside the respective stakeholders (caregivers, patients, coordinators, and policy-makers) to establish collective ownership. Although the solution will concentrate on the immediate needs of the caregiver, it will have far-reaching impacts on other actors. Of foremost importance, though, is assessing the myriad socio-economic, cultural and political dynamics relevant to home-based healthcare communities in South Africa. Initial observations have indeed shown the dire state of data flow in the HBHC service. But there is no simple jump from a fractured information state to one of efficient technological processing. In what follows below, some ethnographic findings are presented around HBHC. From these, it may be determined if technological advancement may have the potential for adoption and integration within distinct communities.

# 5. Ethnographic Case Studies

During the second half of 2009, four communities were assessed in terms of home-based healthcare activities: Kayamandi, Motherwell, Idutywa, and Grahamstown (Extensions 4, 5, and 9). The first research phase included the evaluation of Kayamandi





Accepted: February 15, 2011

and Motherwell, whereas the next phase was concerned with Idutywa and Grahamstown. It is in these groupings that ethnographic findings and perspectives are presented below.

### 5.1. Kayamandi and Motherwell

The term "Kayamandi" is isiXhosa for "sweet home" – ironically an area characterised by rising poverty levels, with more than two thirds of the population having access to less than R1000 a month. This is below the national Household Subsistence Level (HSL) of R19,200 per annum (DPLG, 2007). Moreover, unemployment is set to reach 30% with HIV/AIDS prevalence estimated at 20% (Legacy, 2009). Traditionally the home of migrant labourers, Kayamandi was declared a "location" by the Stellenbosch Municipality in 1941. The downfall of apartheid, coupled with the abolition of influx control, has led to a dramatic surge in population (Prochorus, 2006). Today, the location is home to more than 30 000 people, and continues to challenge local authorities, especially in terms of its ominous socio-economic landscape.

Motherwell in the Eastern Cape was established in 1982, accommodating people who had illegally occupied areas located in the flood plain in Soweto-on-Sea. It comprises 17 neighbourhood units – referred to as NUs 1 to 12, and NUs 29 and 30 – as well as the communities known as Ramaphosa, Ikhamvelihle, and Steve Tshwete Village (DPLG, 2007). It has a large population of more than 200 000, and the community faces difficulties similar to those experienced in Kayamandi. Despite its Urban Renewal Programme, investing heavily in housing and infrastructure development, 76% of the resident population lives below the HSL. This alongside a soaring unemployment rate of 75% (DPLG, 2007).

Both in Motherwell and Kayamandi, residents have little to no access to resources like running water, sanitary facilities, schools, and formal employment opportunities. This ostensibly hampers local economic development in both communes, giving rise to a doubtful business climate (DPLG, 2007). Although both communities are characterised by unstable and harsh environments, they are somewhat different in both composition and socio-economic status. Kayamandi is, for example, much smaller than Motherwell, yet the latter it seems has a higher poverty incidence<sup>5</sup> and unemployment rate. Crime and violence, however, in Kayamandi is claimed by our study participants to be extremely high, ranging from petty theft to murder. Conversely, in Motherwell our interviewees were adamant that this was a peaceful community, despite its tensions fuelled by a resource shortage.

It is clear that the contexts of Kayamandi and Motherwell are volatile. In both communities, there is also a visible need for healthcare. According to our study participants, the South African Departments of Health and Social Development have little capacity to accommodate its increasing health obligations in rural and/or impoverished setups. Therefore it makes countless referrals to external providers of care. These organisations offer a variety of health services that range from in-house clinical care, to external or home-based care.

Home-based care in the greater Stellenbosch region in the Western Cape is managed by Stellenbosch Hospice. Communities in this care-network include Kayamandi, Klapmuts, Lanquedoc, Jamestown, Cloetesville, Stellenbosch central, Idas Valley, P'niel and Kylemore. Stellenbosch Hospice has grown considerably over the

<sup>&</sup>lt;sup>5</sup> The number or percentage of households that earn below the HSL of R19,200 per annum.



Accepted: February 15, 2011

last three years. According to its financial report of 2008, patient numbers increased by 315% from 2005. The last three years also saw a staff increase of 129%, a 125% services increase, and a 377% increase in operational costs. Facilities have also expanded, with 100% bed occupancy rates, new service areas (Farm Project; After Hours Clinic; HIV/AIDS network; etc.) and the sourcing of additional caregivers and administrators (see Smith, 2008). Home-based care is one of the Hospice's key service programmes, with 32 caregivers and 4 community sisters who provide palliative care to approximately 600 patients. These patients suffer mainly from TB or HIV/AIDS, though other chronic and terminal illnesses are also treated, ranging from high blood pressure to cancer.

Despite the Hospice's growth, it also faces many pressing issues. It continues to be under-funded, which hampers service delivery. Other problems include an insufficient volunteer base, a fractured information network, and a diminished support structure (personal counselling; administrative systems; incentives) for caregivers. The Hospice is chiefly funded by the Department of Health, additionally supported by the Department of Social Development and an array of individual funding bodies. In spite of these contributions, the Hospice fights the ongoing battle of trying to be financially sustainable whilst maintaining proper service delivery.

Olive Leaf Foundation (OLF) is a registered development organisation, providing a range of community services across the African continent. In the Eastern Cape, it operates in three districts in and around Port Elizabeth, namely iBhayi, Motherwell, and the Northern Areas. The communities in these regions battle with a range of socio-economic troubles, including crime, poverty, gangsterism, strikes, and a lack of basic resources, skills and educated personnel. Like Stellenbosch Hospice, Olive Leaf Foundation has seen considerable growth over the last 20 years. Its programmes support a variety of social concerns, including gender equality, community wellness and healthcare, orphans and vulnerable children, and voluntary counselling and testing.

OLF employs only 9 caregivers, which is far less than its Western Cape counterpart. These caregivers have a network of approximately 600 patients as well, but without the support of district nurses. The organisation takes a "holistic approach" to healthcare in its serviced communities. It focuses on all the aspects of care, including training, psychosocial support, and stigma reduction. However, like many care facilitators in the country, it faces financial depression, skills shortages, and unstable community contexts. Like its peers, it fights to provide effective care despite unforgiving circumstances.

# 5.1.1. Caregivers

At first glance, caregivers are dedicated, responsible community representatives assigned to provide 'mobile' health services to chronically and terminally ill individuals. Caregivers are the delivery points where patients experience the care service network. They visit between 8 and 14 patients a day, depending largely on the HBHC provider's official mandate. Ordinarily, these individuals are trained community members and not necessarily professionally qualified or experienced in the service of care. Nurses (if available) will take leadership and managerial roles in the NGOs/Hospices providing the care service.

<sup>&</sup>lt;sup>6</sup> At the time of writing (November, 2009).

<sup>&</sup>lt;sup>7</sup> At the time of writing (November, 2009).



Submitted: April 15, 2010

Accepted: February 15, 2011

Only rudimentary equipment is accessible to caregivers in Kayamandi and Motherwell. The technology these carers are exposed to includes mobile/cellular phones, but desktop computers are uncommon and only found in NGO/Hospice offices for administration. Caregivers do not usually partake in administrative duties at the service provider, and are limited to pen and paper during home-visits. Writing equipment and calculators are sometimes unavailable and this obstructs accurate data collection.

Despite a lack of proper equipment, the role of the caregiver is pertinent to the arrangement of data in and throughout the care networks in Motherwell and Kayamandi. As illustrated earlier, caregivers need to determine the number of the patients they visited and the various treatments they administered at the end of each day. These figures are utilised by the area manager to prepare tally sheets for each designated care area. Caregivers and coordinators in Stellenbosch state that this information/data system is undeveloped and outdated. For paper is often illegible or damaged in bad weather conditions. Moreover, caregivers in both regions are often illiterate or semi-illiterate, thus less proficient at reading and writing.

They point out that a combination of these factors often results in lost or mismanaged data, impacting negatively on patient care plans. The near redundant paper-based system has since become a grave concern to care providers in both communities. Indeed, carers need their hands and eyes free to interact with and observe their patients, so as to perform their care effectively. In Motherwell, where nurses are in short supply, caregivers must record symptoms for accurate diagnosis for treatment. This data is recorded on loose paper and is regularly lost or inaccurately completed. Caregivers once again find themselves burdened by paperwork both at the patient's home and when having to tally statistics at month-end.

On a different note, caregivers are shown much respect from the communities in which they operate. Being advocates of wellbeing and selflessness, they are rather well-known within these communities and are often seen as social leaders. In this regard, caregivers become unofficial spokespersons for issues regarding health, wellbeing, standards of living, social issues, and other basic needs. Persons will approach them with all varieties of concerns, and seek advice or counselling.

Due to the emotionally stressful nature of their work (especially in informal setups like Motherwell and Kayamandi), caregivers often find themselves in need of therapy and support. Patients remain at the centre of care, however, and priority for attention. But in dismally poor Kayamandi and Motherwell, counsellors and social workers are few and far between. Moreover, support groups are rarely available to carers and they have to rely on their employers for guidance and therapy.

In Kayamandi, caregivers work alone. They are allocated clients according to location and type of care required. Caregivers here travel on foot, by bicycle, and by public transport – the close proximity of clients is vital. In Motherwell, carers work in teams of two or three and occasionally rotate areas of work. They also travel great distances to patients and rely a good deal on patient proximity. In cases where patient homes are isolate or difficult to access, carers employ transport that is provided by OLF.

The majority of caregivers interviewed exhibited a sincere appreciation for their roles as 'community protectors'. They relished the opportunity to aid those in serious need of health assistance. Conversely, these carers were also somewhat troubled about their own wellbeing. They emphasised rising stress levels and weakened physical capacity as the leading job-related consequences. Carers have also noted the fact that



Submitted: April 15, 2010

Accepted: February 15, 2011

they cannot stop thinking about their patients, even when off duty. This prevents them from retiring mentally after each day, and strains them emotionally.

Both Stellenbosch Hospice and Olive Leaf Foundation hosts regular training and feedback events, where carers have the opportunity to express their thoughts and emotions. Although these meetings are an effective way of resolving issues, they are impermanent and impersonal. It appears that caregivers need a ubiquitous support structure – one that facilitates personal, intimate support and encouragement around the many challenges presented by HBHC.

#### 5.1.2. Patient environments

In both Kayamandi and Motherwell, there are many intersecting dynamics that affect the patient's perception of, and openness to, home-based care. Firstly, one often finds the patient in a volatile context. In both communities, where poverty and illness is pervasive, infrastructure and resources are sub-quality and often inaccessible. For example, in Kayamandi more than 70% of the population lives below a \$2-a-day poverty line — most residents simply do not have the financial means to consult professional health workers (see Prochorus, 2006). Add to this an increasing crime rate, tough weather conditions, ill maintained or non-accessible roads, schools, clinics, and a lack of general amenities (water, electricity, sanitary facilities).

These elements characterise a dismal health or care context. A caregiver expressed the following: "Some houses are very isolated. The roads are rough. In Kayamandi, the patient facilities [are terrible]. There is no power; the patient's house is too small. There is no toilet. It is the worst area for TB patients." In Motherwell, the patient environment remains much the same. According to one caregiver, "poverty is a huge problem". More than 70% of the resident population are unemployed and there is a lack of basic resources. Here, poverty is so severe that single grants are feeding entire families. Most residents and patients in this community use the 'bucket-system' as lavatory facility, further indicating the severity of the poverty experienced.

Another 'internal factor' that marks the patient environment is the household or family context. Family members are, in absence of the caregiver, the primary care providers at home. As revealed by the participant observation process in Kayamandi, family members sometimes display an air of resentment toward to the caregiver. They feel somewhat undervalued due to the patient being less reliant on them, and more dependent on an outside party. The patient-caregiver relationship is then experienced as a threat for certain family members, and may evoke negative feelings. In Motherwell, extreme protectiveness by family members was rarely experienced. Family members often joined in on the care process. They interacted with the caregiver and seemed to take much pride in administering care themselves. Caregivers expressed that family members are key in this community and that with basic training could reinforce much of their major care-giving activity.

A factor that is present in both communities is the stigma attached to illnesses such as HIV/AIDS and TB, as expressed by this caregiver, "The problem of stigmatisation has been there and I won't say it has been completely eradicated." Ironically, a caregiver's presence often perpetuates the stigma their patients face daily. Some patients have said that their friends and neighbours abandon them once they realised why the caregivers are there. It has become a point of concern for patients and caregivers alike, since it undermines the patient's support structure and may hamper the service of care.



Submitted: April 15, 2010

Accepted: February 15, 2011

Finally, in the patient environment there is the ever-increasing problem of patient files. As discussed earlier, caregivers need to record patients' progress, details of medication, observations, and any other details of visitations. Yet, due to unstable household conditions, patient files often get lost or damaged. This in turn reflects negatively on the caregiver, who has to report the data back to a care coordinator. Conversely, there are patients who take serious "possession" of their files, protecting them at all costs. Caregivers even described patients who slept on their files in the evenings, so as to avoid them getting lost, stolen or damaged.

The aforementioned findings paint a rather negative picture of patient environments in both Kayamandi and Motherwell. There are, fortunately, a number of positives to extract from these contexts. For one, patients seemed to take their medications and treatments very seriously. Despite the odd quarrel about anti-religious or –spiritual medication, most patients kept to their treatment schedules unfailingly. They also exhibited a great deal of respect for their carers, and would welcome their suggestions and/or proposed treatments. Patients would also anticipate caregiver visits and would sometimes be rather disappointed if carers failed to show.

Moreover, not all patient environments seemed to be characterised by extreme poverty, crime and unemployment. Large regions of Motherwell, particularly near NU 4, were more suited to health needs given their proximity to formal healthcare centres, district nurses, physicians, and home-based carers. And though this community has a high unemployment rate, it has a low rate of violent crime – the community at a superficial glance, seemed very peaceful. In Kayamandi, crime and violence were suspected to be much higher, and so too the demands of healthcare, year-on-year exceeding the capacity of Stellenbosch Hospice.

In summation, patients in both communities face the harsh realities of impoverished contexts. Despite that, patients adore and revere their caregivers, and follow their care plans religiously. Not to mention, care has been very effective in these communities. The research team visited a number of patients that in fact recovered well due to their continued, thorough treatment schedules. That said, home-based care functions in a precarious environment – one that persistently undermines its (potential) value to patients in need. The fight for care continues.

# 5.2. Idutywa and Grahamstown

The communities of Idutywa and Grahamstown were visited during December 2009. Idutywa is a rural district, northwest of East London. The inner town is densely populated, with rural outer regions that are sparsely inhabited. Formerly part of the Transkei, Idutywa is also the birthplace of former president Thabo Mbeki. The town – referring in isiXhosa to "place of disorder" – was founded in 1858 as a military fort and has a history of violent disputes between resident groups (see Wild Coast Towns, 2009). The town was made a formal municipality in 1913, and today forms part of the Mbhashe Local Municipality.

Grahamstown was founded in the 19<sup>th</sup> century as a military garrison, and quickly attracted Khoi and Xhosa settlers in the vicinity (ISERRU, 2001:2). By the end of the century, the population had grown exponentially, with many drawn to the town's railway construction activities. In light of the population growth, housing shortages, and rising inequalities spurred by colonial officials, informal settlements mushroomed near the town's outskirts. Dubbed formally as "Extensions", these poor





Accepted: February 15, 2011

neighbourhoods became characteristic of the now imminent university town during the mid 1980s and beyond.

Idutywa and the Extensions of Grahamstown, though markedly different, are comparable in terms of socio-economic dynamics. Both regions show signs of extensive poverty and unemployment. Facilities and services are limited, including telecommunications, electricity, toilet facilities, piped water, refuse removal, and tarred roads (see ISERRU, 2001:16). Few households have incomes that are above the Household Subsistence Level, and citizens continue to struggle financially. This places much strain on access to healthcare, with individuals mostly relying on the services of community clinics or home-based care providers.

In response to growing health problems and lacking access to proper facilities, several nonprofit initiatives were instituted in both Idutywa and Grahamstown. One such programme, the Mida Health and Poverty Project (MidaHealth), is an initiative of the Mission Centre Development Association (MIDA). Part funded by the European Union – although these funds seemed to have run out – MidaHealth provides a number of crucial services to the households of Idutywa. This includes support groups for HIV/AIDS patients, awareness drives on drug and substance abuse, and home-based healthcare provision for chronically and terminally ill individuals (Aidsbuzz, 2009).

Since its inception more than a decade ago, MidaHealth has expanded its aforementioned core activities. The organisation also distributes food parcels, facilitates a soup kitchen, assists in obtaining social grants, and offers training in life skills (ibid.). At the time of writing, MidaHealth employed more than 35 caregivers, with an additional 40 odd as volunteers. But the organisation is hardly able to keep head above water financially, only affording a small stipend to its caregivers. Although MidaHealth is supported somewhat by the Department of Social Development and local donors, it is for the most part financed by its key founder, one Mrs. Nowanda Salaphi. 8

Mrs. Salaphi is a resident community activist and leader, working fulltime as a teacher at a local school. She speaks of MidaHealth with much pride and reverence, emphasising its importance in a flailing economy and unstable political climate. She attributes her character and enthusiasm to her spiritual beliefs, and highlights faith as key in supporting the needy. But Mrs. Salaphi is not blind to her organisation's limitations. MidaHealth's patient base is expanding considerably, outgrowing its capacity. In June 2009, it serviced more than 400 home-based patients. Today, nearly seven months later, that number creeps closer to 1000. This situation has strained the organisation, restricting its resources and limiting its capability to provide effective, uninterrupted care.

For the informal communities on the outskirts of Grahamstown, the situation is both similar and different. The recognised care provider in this area is the Grahamstown Hospice – one of many subsidiaries of the Hospice Palliative Care Association (HPCA). Like its Stellenbosch counterpart, Grahamstown Hospice specialises in the care for terminally and chronically ill patients. It advocates a multidisciplinary strategy in care – the patient and his/her family actively participate in the processes and networks of care. This speaks to an interpersonal involvement between community members and patients.

The Hospice deems its care approach to be holistic, emphasising high-quality social, physical, emotional, spiritual, mental, and cultural needs as the primary aspects

<sup>&</sup>lt;sup>8</sup> Formal ethical approval was obtained to include the names of all study participants in this paper.





Accepted: February 15, 2011

of care. For its 250 odd patients, the organisation has set clear goals: maintain a high quality of life; assist with immediate social needs (food, grants, clothing, bedding, etc.); provide spiritual guidance; administer medication; and, provide emotional support (Grahamstown Hospice, 2009). For the patient's immediate family and friends, the Hospice aims to: help them cope with the situation of living with a very ill person; prepare them for bereavement; assist in everyday care activities; and, educate in the many facets of care (ibid.).

Aside from its core patient base, Grahamstown Hospice also deals with orphans and vulnerable children (OVCs). They maintain that the youth is essential to building South Africa's future, and therefore see it necessary to improve the social conditions of young, abandoned children. OVCs form part of the Hospice's family unit, mobilising around the needs of disempowered families. With these services in mind, Grahamstown Hospice has become an important care provider for the struggling communities/Extensions in the region. But it too is underfunded and –resourced, sharing the fate of many nonprofit initiatives in the HBHC sphere. Its foremost challenges include minimal corporate buy-in and an ever-increasing patient base. Nevertheless, the Hospice has proved to be a vastly successful initiative both in promoting improved health, and in bettering socio-economic conditions in poor communities.

# 5.2.1. Caregivers

Caregivers in Idutywa operate under the harshest circumstances thus far encountered in this research project. Travelling in groups of between two and four, they traverse muddy, rural plains on a daily basis to reach needy patients. Hence, without effective modes of transport, care workers walk great distances each day, with patient homes few and far between. They receive little financial support from MidaHealth, forcing them to use their own funds for taxi fees or telephone calls to coordinators. Essentially, they work in vast isolation and battle excruciating conditions, barely even affording to carry out their duties.

Of MidaHealth's more than 70 care workers, only half receive an approximate R600 per month stipend (at the time of writing). The remainder are volunteers, committing their time and effort to care for sick community members. When interviewed, the majority did not seem to mind – they understood that social gain superseded any financial benefits. They were aware too that Mrs. Salaphi sometimes paid them out of her own pocket, with her teacher salary. In fact, these caregivers expressed much satisfaction and veneration toward their roles as community carers. They admired their leader Mrs. Salaphi, and wanted to do everything in their power to support her cause.

Duty-wise, caregivers in Idutywa fulfil similar care tasks than their counterparts in other regions of the country. As mentioned, the conventional home-visit is done on foot and is accompanied by one, two or more caregivers. Once at the home, the responsible caregiver – the one to whom the patient is assigned – will administer the set of care duties. These are not limited to physical nursing or medication control, but encompass a full stretch of obligations: house-cleaning, food preparation, assistance with grants, idle chatter, bereavement support, bathing, ad infinitum. These activities have come to embody the typical care process for carers in Idutywa. For them, care is never limited

<sup>&</sup>lt;sup>9</sup> In terms of Corporate Social Investment (CSI) especially.



Submitted: April 15, 2010

Accepted: February 15, 2011

to treating wounds or to monitor progress. Rather, it is the improvement of (community) health at all levels: social, emotional, physical.

Although state departments have been largely absent in funding and developing MidaHealth, the Department of Social Development requests (basic) monthly patient data statistics. Caregivers are required to gather data on paper, either at the patient's home during a visit, or afterwards at the offices of MidaHealth. Stats are assimilated on a weekly basis, and sent to the Department monthly. Some of the caregivers and coordinators at the organisation are unimpressed by state involvement – they question the government's intentions and commitment towards health reform. These doubts, perhaps, are largely due to the government's continued absence juxtaposed to its obstinate micro-management.

Political tensions aside, a paper-based system of data collection proves challenging. Caregivers acknowledge the many weaknesses presented by this flimsy medium: paper gets lost or damaged due to extensive travelling and harsh weather conditions (rain, wind, sun, hail, thunderstorms). Furthermore, caregivers do not necessarily record data at the patient's home itself; they often complete patient forms only when arriving back at the office. They recognise that data gets lost this way, as they cannot always remember exact numbers, dates, or comments. Their memories fail them, as it were, and this obstructs accurate data gathering.

Despite Idutywa caregivers' perseverance and commitment towards an improved HBHC service, they are not ignorant to the many challenges that confront them daily. They acknowledge that they lack the capacity required to maximise their service so as to visit even more patients. This context of fractured resources implicates an arduous situation for caregivers. They are isolated and starve the advantages of working for a well-equipped care provider. A system of paper-based data collection, coupled with minimal cell phone use, is for them the only affordable and accessible technology. But as stated before, MidaHealth workers revel the opportunity to help community members in need. In this sense, they place much emphasis on faith, and claim that their ultimate reward is of a spiritual nature: to be God's servants in caring for their neighbour.

At this stage, it is important to note that Grahamstown Hospice makes a careful distinction between "caregivers" and "care workers". The former refers to local volunteers, donating their time and effort by visiting patients in their homes. The latter refers to Hospice employees – those individuals that get paid a stipend to provide a community care service. Besides the stipend, there are differences between the two categories in terms of gender, class, and race. Care workers are typically middle-aged Xhosa or coloured women, whereas caregivers may include whites and males. Caregivers are generally more affluent, and can afford to contribute much-needed time and skills at little to no cost.

As the Hospice facility encompasses a full spectrum of social services, care workers perform tasks that exceed basic healthcare provision. These may include general house cleaning, taking care of the patient's hygiene, family education, grant assistance, and emotional support. In terms of their primary service – the administering of medication and physical nursing – care workers follow patient care plans. Seriously ill patients are referred to sisters, which in turn may refer patients to one of 7 local clinics. The care network is also supported by social workers, assisting care workers in challenging cases if required. Care workers (and –givers) receive training on a weekly basis.



Submitted: April 15, 2010

Accepted: February 15, 2011

Care workers have limited involvement in rural areas, and focus predominantly on the (peri-urban) informal settlements within or near Grahamstown. These settlements are known as Extensions, and are largely impoverished. This environment strains the duties of the care worker and burdens the collection of data. Not unlike HBHC models in the greater Western and Eastern Cape, care workers operative in these regions rely on paper-based data gathering. However, this system is much less onerous than some of the processes used in Olive Leaf Foundation and MidaHealth.

For one, care workers in the Grahamstown Extensions fill out one form per patient on a weekly basis. Here, they stipulate the interventions done (if any) and they comment on treatment adherence. Each form is signed by the nursing sister and sent to the data capture for aggregation and consolidation. As is the case with Stellenbosch Hospice, data flow becomes integral to the overall care process. Statistics get sent to the Departments of Health and Social Development, as well as the Hospice Palliative Care Association. These actors dictate much policy around home-based healthcare in South Africa and rely, therefore, on accurate statistical information.

Yet the process of patient data collection is cumbersome within and beyond informal setups. Paper material is flimsy and vulnerable to harsh weather (as is, again, the case with the evaluated setups in Motherwell, Kayamandi, and Idutywa). Second, caregivers have acknowledged that they are often unable to recollect (all) patient interventions after treatment is done. In fact, they are prone to forget important information due to the large number of patient visits conducted every week. This translates into weaker, more incorrect data. The result being that service coordinator Grahamstown Hospice is left with data that cannot be analysed on the grounds of being accurately defined. The organisation has no immediate means to verify the legitimacy of gathered patient information.

In light of the above, it is clear that care workers in Grahamstown and Idutywa face ongoing challenges in their duties as community health workers. Like their colleagues in Stellenbosch and Motherwell, these carers are restricted by their immediate environments: weather, rural isolation, lacking resources, and fractured data collection. This context poses an arduous working climate, and limits the effectiveness of care. Yet, they have become respected members of the community, given their roles as health facilitators. It is because of this respect and appreciation from fellow community residents that care workers (-givers) continue their service. They are proud of their work, despite ominous surroundings, and revel the opportunity to aid their fellow man.

# 5.2.2. Patient environments

The social climate in Idutywa may be fairly intimidating for the newcomer. Upon initial entry into the small town, the research team found itself in the heart of Africa: bicycles, fruit vendors, loud music blaring from shop fronts, pedestrian goats, humid air (despite the rain!), and merry children. The town bustled with activity and yet veiled the many cruel dynamics that is to be the fate of the majority of Idutywa residents. For the entire region it seems, observable by the naked eye, is plagued by insidious, omnipresent sufferings: poverty, lacking infrastructures, unemployment, and illness.

Initial encounters with Mrs. Salaphi and her entourage of caregivers confirmed our suspicions: Idutywa was a place of much affliction; a harsh reality, somewhat blanketed by its lively centre. And yet, none of these persons spoke of the community with dismay. In fact, although not able to hide their frustrations, Idutywa was claimed a



Submitted: April 15, 2010

Accepted: February 15, 2011

"home", a "heritage", the "burial ground of forefathers". Nonetheless, neither of these citizens is ignorant of Idutywa's fair share of societal ailments – of economic and political challenges instilled more by a failing government than by an undemocratic past.

General patient environments throughout the community were lodged in similar circumstances. Houses were rural and isolate, with caregivers having to travel great distances between each. The majority of patients were, as expected, in terrible anguish. Most suffered from HIV, TB, or full-blown AIDS. Patient households were relatively poor, with incomes rarely exceeding the Household Subsistence Level of R19,200 per annum. Amenities were scarce and patients (and their families) relied on outside latrines and rain water for sanitation. Moreover, tarred roads were non-existent and electricity a luxury only few could afford.

It seems that like the informal environments of Kayamandi and Motherwell, patients in Idutywa relied mostly on the services of caregivers for their general wellbeing. Family members, neighbours, and friends played a valuable role here: they were the primary carers in absence of the formal care workers. In this regard, the research team noticed strong and affable relationships between caregivers and the patient's social circle of community members. In fact, the services of this "social circle" have become vital to the caregivers of MidaHealth – without it, patients may become even weaker, often succumbing to death. Essentially, the care network in Idutywa extends beyond the formal care provider (i.e. MidaHealth), and incorporates the active services of close contacts.

The patient's social circle did not perceive caregivers – for they often operated in groups of two or more – as immediate threats. Rather, they were viewed as invaluable to the patient's health, not only in terms of physical nursing, but also emotional support. When care was administered to a patient, the process was often (though, not always!) accompanied by much laughter and joviality. Caregivers were welcome guests, as they usually were bearers of an indispensable community service. They did not stigmatise or judge; rather, they treated patients and their families humanely. Ultimately, although the socio-economic climate in Idutywa is for the most part hostile, the simple act of care elicits much sincerity and hospitality.

In the informal regions of Grahamstown – in particular Extensions 4, 5, and 9 – the typical socio-economic environment remains much the same as those of Motherwell and Stellenbosch. The extensions are not quite rural, as is the case in Idutywa, but located in close vicinity to the well-known university town. The surroundings are characteristic of the average informal setting: questionable infrastructure (damaged roads, a splurge of illegal electricity connections, and minimal access to clean water); heaps of dirt; emaciated dogs; children playing soccer; and rows upon rows of small, quaint RDP (Rural Development Programme) houses, built by the government almost a decade ago.

It has to be said that not all areas in these Extensions are particularly similar. Some had "upper-class" suburbs; residences and infrastructures that were visibly well-maintained. Others were reminiscent of the common shantytown; residences comprised of shacks, structured with sheets of metal and bundles of plastic. This was a microcosm of the larger South African society, again underpinning the vast polarity between rich and poor. And yet, even within these Extensions, this polarity was not vast, but existed nonetheless. This situation would come to typify the context of care in a preeminent university town, and marked the starting point of the Grahamstown Hospice care network.



Submitted: April 15, 2010

Accepted: February 15, 2011

The research team accompanied several care workers on their daily "care journeys" and visited a number of patients and their families. When travelling through the informal areas, care workers pointed to the many challenges that face their community: xenophobia, politics, teenage pregnancy, a fractured schooling system, and lacking resources. "Our work is quite depressing", states one carer, as we approach a patient's home.

For the patients in these extensions, circumstances are even more depressing. One man, reduced to wearing an adult diaper because of uncontrollable bowels, has emphasised the severity of his surrounds. He cannot seem to speak a single word, and is confined to his bed for most of the day. His family explain that without their daily support, he would die. This man's plight was an immediate window into the realities of HIV/AIDS and tuberculosis. And yet, his care worker remains positive: "God is working here". For the ounce of strength still left in this patient is due to his faith; his devotion to a higher power.

Family connections have become indispensable to chronically and terminally ill patients. Family members are encouraged to support patients in every way possible: cleaning, cooking, administering medication, transport, feeding, communication, and the like. They have become the primary support pillar, in absence of the care worker. The importance of larger families cannot be understated here – they receive larger government grants, and are thus more financially capable of providing much-needed resources.

We have come to understand the harsh truths of the care worker and patient environments in (informal) Grahamstown. The situation here is almost characteristic of the typical home-based healthcare domain: large-scale poverty; high levels of crime; high instances of HIV/AIDS, TB, and cancer; invisible public services (roads, electricity, refuse removal, housing); and vast unemployment. Moreover, the local government has been largely absent, and has failed to meet the needs of its constituency. And yet, care workers continue their service unabridged, almost unaware of the many obstacles that may lie ahead. It is this tenacity, this determined spirit that has marked the essences of care in Grahamstown.

# 6. Concluding Thoughts

Home-based healthcare in South Africa is a dynamic space, characterised by an array of complexities. Throughout this text, we have come to understand and negotiate this intricate terrain via an ethnographic exploration. This has allowed both researcher and reader an intimate lens into previously untapped social domains. In light of this, the foremost objective was to gain a sense of the care activity in South Africa. This pertains to the (inter)relations concerning patients, families, local communities, caregivers, and care service providers. In particular, four communities – informal regions, if you will – were selected as research landscape.

Aforementioned communities – Kayamandi, Motherwell, Idutywa, and the Extensions of Grahamstown – share much in common in terms of local qualities. Each is exposed to insidious poverty, or at best, impoverished conditions. And each faces the direct and indirect repercussions (and causes?) of such a context: unemployment, crime, lack of resources, ad infinitum. But the notable similarity among all is the activity of resident HBHC providers. To various degrees, these agents carry out a service that



Submitted: April 15, 2010

Accepted: February 15, 2011

government struggles to provide: continuous, devoted, and omnipresent home- and community-based care.

Despite the unwavering presence of HBHC providers, it is clear that the mentioned contextual elements often disrupt the home-based care process and places an additional burden on both the caregiver and –receiver. For the care receiver, the "typical context" mostly reveals to be dismal. Severe poverty and exposure to elements of crime and seclusion may even perpetuate the poor health suffered by many chronically and terminally ill patients. For without access to basic resources such as water and sanitation, electricity, shelter, food, and support networks like neighbours or family members, a patient's ill health may well be beyond recovery. The patients in such communities are further hampered by rural isolation, often not able to access formal healthcare, educational and social facilities.

Moreover, it seems patients have come to *depend* on their caregivers. A diabetic patient in Kayamandi claimed that caregivers are essential to his daily routine. He views them as guardians, claiming their absence would leave him stranded. In Motherwell, two teenage sisters were encountered who had no parents and little to no means to support themselves. These patients are (often) not able to self-administer care or be self-sufficient, and are therefore at the mercy of caregivers, nurses and social workers. As a result, health workers in these communities command a sense of both respect *and* dependency from their patients.

Despite the adoration exhibited by some patients, a caregiver dependency is not necessarily positive, and may weaken the overall care process. Certain patients do get somewhat hostile if caregivers do not arrive on time or at all. Other times they are in total bewilderment when not directly supervised or assisted with administering treatment. Ultimately, with patients lacking the means to care for themselves, a great deal of responsibility is transferred to the caregiver. This strains the already strenuous endeavour of home-based care, and creates a stranglehold of emotional, physical, social and sometimes financial reliance.

Care provision, then, is a tough ask. In Kayamandi and Grahamstown, carers have the support of district nurses and social workers. Whereas in Motherwell and Idutywa, they do not. In all four communities however, home-based care has become somewhat of a necessity. Hence the facilitators of care, like Hospice, MidaHealth, and Olive Leaf Foundation, recognise that "caregivers *also* need care". The leaders of these organisations affirm that this notion needs to be central in organisational policy. Alas, care providers are under-funded, and thus not able to offer much financial assistance, especially in terms of technological or data systems. Nor are these providers able to invest into social workers or counsellors. The caregiver therefore continues to function in relative isolation, in need of an extensive support network.

This is not to say that support network is nonexistent. In all evaluated communities, caregivers enjoyed the backing of their organisations, and had a high regard for their coordinators. Indeed, these organisations provide moral support, monthly stipends, training, transport and even food. However, they cannot account for the emotional and social distress caregivers encounter daily. And what is more, caregivers across all four communities use paper-based systems to record patient data – systems that rouse high data inaccuracy and/or loss of information. The care provider (or network) simply does not have the means to replace these systems with socially and technologically sound initiatives.

Given that patient files and information flows are at the core of the home-based care systems in each of the assessed communities, their proper handling is vital. It is



Submitted: April 15, 2010

Accepted: February 15, 2011

apparent, regrettably, that patient files are continually mismanaged due to extraneous circumstances. Their handling poses a real problem for both care providers and patients. Moreover, (technological) alternatives to this paper-based standard are not readily accessible. To various degrees, caregivers have tried to employ mobile phones. But given unstable circumstances, phones often get damaged, stolen, or lost.

The many scenarios that are described here pose a double-edged sword. On the one hand, the patient is embedded in a "community with tension". If the patient is sick, their ill health will no doubt be perpetuated. For there is a lack of proper and formal care facilities, alongside an existing unstable environment fuelled by poverty. On the other hand, one has the caregiver. The caregiver's service is also undermined, given the relative isolation of patients, damaged roads, patient dependency, absence of amenities, and the use of outdated information systems. This is a case of mutual isolation, where both the caregiver *and* –receiver fights to provide and access care, respectively. This is despite the ongoing commitment on part of the carers and their NGOs, who unremittingly set about protecting their patients. One is faced with the grim scenario where not only patients, but caregivers also, are victims of their circumstances.

The possibility for sound technological measures arises, particularly concerning the strengthening of current systems and consequently, the overall betterment of care. It is not yet known what these measures may consist of, how much they will cost, or if they will be effective. But their *purpose* is clear: improve or supersede paper-based systems, free the "hands and eyes" of caregivers, and enhance data integrity. Yet, the described volatile contexts may hamper the development, integration, and acceptance of any technological endeavour (intervention). It is thus crucial to facilitate a bottom-up approach, where community participation is central in aligning a new, differing system of information gathering and utilisation.

#### 7. Acknowledgements

Omitted in this version.

# References

Aidsbuzz. 2009. Mida Health and Poverty Project – Idutywa. <a href="http://www.aidsbuzz.org/organisations-in-south-africa/">http://www.aidsbuzz.org/organisations-in-south-africa/</a> Accessed 27 January 2010.

Babbie, E. & Mouton, J. 2001. The Practice of Social Research. Cape Town: Oxford University Press.

Bernard, H.R. 1998. Handbook of Methods in Cultural Anthropology. California: Altamira Press.

Cushman, M., & Klecun, E. 2006. How (can) Nonusers Engage with Technology: Bringing in the Digitally Excluded. In: Trauth, E., Howcroft, D., Butler, T., Fitzgerald, B., DeGross, J. (eds). IFIP International Federation for Information Processing, Volume 208, Social Inclusion: Societal and Organizational Implications for Information Systems. Boston: Springer: 347-364.

Department: Provincial and Local Government (DPLG), Republic of South Africa. 2007. Nodal Economic Profiling Project. Economic Snapshot: Comparative Data: 1-8.

Erasmus, S. 2009. Health in South Africa: Shocking Statistics. Published in Health24, September 2009

Grahamstown Hospice. 2009. *Introduction to services*. <a href="http://grahamstownhospice.org.za/page.php?id=33">http://grahamstownhospice.org.za/page.php?id=33</a>. Accessed 02 February 2010.

Institute of Social and Economic Research, Rhodes University (ISERRU). 2001. Møller, V. (ed.) Living in Grahamstown East/Rini: A social indicators report. Research Report Series No. 6: 1-80.

Korpela, M., Mursu, A., Soriyan, H.A., de la Harpe, R., & Macome, E. 2006. Information Systems Practice for Development in Africa: Results from INDEHELA. In: Trauth, E., Howcroft, D., Butler, T., Fitzgerald, B., DeGross, J. (eds). IFIP International Federation for Information Processing, Volume



Submitted: April 15, 2010

Accepted: February 15, 2011

- 208, Social Inclusion: Societal and Organizational Implications for Information Systems. Boston: Springer: 15-35.
- Lancet. 2009. Health in South Africa. An Executive Summary for the Lancet Series. Lawn, J.E. & Kinney, M.V. (eds). South Africa Series Executive Summary core group.
- Legacy. 2009. About Legacy. Kayamandi. <a href="http://www.legacykayamandi.com/about-legacy">http://www.legacykayamandi.com/about-legacy</a>. Accessed 03 February 2010.
- Miettinen, S. & Koivisto, M. 2009. Designing Services with Innovative Methods. Kuopio Academy of Design, Keuruu, Finland.
- National Department of Health. 2002. Integrated Community-based Home Care (ICHC) in South Africa. A review of the model implemented by the Hospice Association of South Africa. Compiled by the Centre for AIDS Development, Research and Evaluation (Cadre) on behalf of The Policy Project. USAID: 1-43
- Prochorus. 2006. *Kayamandi*. Cape Town: Prochorus Community Developments. <u>www.prochorus.org</u>. Accessed 03 February 2010.
- SAFIPA. 2009. Proposal: University Networks for Community Empowerment. The collaborative creation of innovative ICT solutions to facilitate the improvement of the wellbeing of a community with tension.
- Savage, J. 2006. Ethnographic Evidence: The Value of Applied Ethnography in Healthcare. In: Journal of Research in Nursing, 11, 383-393.
- Smith, E. 2008. Stellenbosch Hospice Annual Report: 2007 2008. Stellenbosch.
- Spradley, J. 1979. The ethnographic interview. Fort Worth: Harcourt Brace Jovanovich College Publishers.
- Trauth, E.M., & Howcroft, D. 2006. Social Inclusion and the Information Systems Field: Why Now? In:

  Trauth, E., Howcroft, D., Butler, T., Fitzgerald, B., DeGross, J. (eds). *IFIP International Federation for Information Processing, Volume 208, Social Inclusion: Societal and Organizational Implications for Information Systems.* Boston: Springer: 3-12.
- Wild Coast Towns. 2009. Idurywa. http://www.wildcoast.org.za/wc/14.xml#8. Accessed 27 January 2010.
- World Health Organisation. 2004. Comprehensive Community- and Home-based Healthcare Model. In: SEARO Regional Publication No. 40: 1-77. India: Byword.