

AT-HOME 2.0 – An Educational Framework for Home-based Healthcare

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Abstract: This paper intends to describe some of the primary social and cultural dynamics in South African home-based healthcare, using ethnographic case study material and design methodology. This constitutes a detailed narrative of the “care experience” in a poor community, emphasising the needs of and barriers to educational information, particularly concerning caregivers. In reaction to this context, a collaborative training model – AT-HOME 2.0 – emerges through design intervention. This is foreseen as a basic framework whereby caregivers (are encouraged to) develop educational content via information and communication technologies (e.g. mobile phones and social media). Such content can and may include experiences, suggestions, and guidelines that are relevant to the practice of caregiving. AT-HOME 2.0 will conceptually – and in some cases practically – demonstrate how educational content may be generated, published, and disseminated in the sphere of home-based healthcare.

Keywords: home-based healthcare, informal learning, digital technologies, socio-cultural dynamics

Categories: L.2.1, L.3.0, L.3.6, L.6.0, L.6.2

1 Introduction

“Enabling and encouraging people to participate in education and learning during their lifespan is a key political and academic concern in contemporary society” [Selwyn 2004].

Home-based healthcare (HBHC) is the delivery of basic health services by caregivers to persons in their homes. This community-oriented service is usually for individuals with physical and mental nursing needs, but may extend to emotional, social, and even financial aid. Typically, HBHC serves those who are not able to afford or access formal healthcare facilities [WHO 2004]. In developing nations, HBHC has become an important provision to communities in need. In South Africa particularly, where HIV/AIDS and tuberculosis is rife, a home-based system reaches those patients that are beyond the reach of the Department of Health (DoH) – the government body responsible for healthcare in the country. In fact, each year the DoH makes countless referrals to various HBHC providers, operative across South Africa’s nine provinces [Van Zyl 2011]. This often bestows – as we shall come to understand

– upon such facilities the ‘duty’ of communal wellbeing, perpetuating the cycle of informal care networks in desperate communities.

For the post-apartheid state, challenged with much socio-economic disarray, HBHC has then become an almost accepted service. Indeed, the majority of South Africa’s population is deprived of the basic resources needed to ensure a healthy life. And with the country carrying 17% of the world’s HIV/AIDS burden [Coovadia et al. 2009], HBHC has become somewhat of a necessity. For many community residents, hampered by ill health and immobility, consistent home-based care is an only hope. That said, the home-based care process is marked by troubles of its own, as will be evidenced in our case study. For one, care-networks lack sufficient funding. As a result, caregivers are both underpaid and -resourced. This undoubtedly affects the quality of service they provide to care-receivers. Second, the flows of information between the caregiver, patient, and care-network are often fractured and unclear. Many HBHC facilities make use of rudimentary paper-based systems to record and transfer patient information. This results in high data inaccuracy and loss of valuable information [Van Zyl 2011]. Lastly, HBHC is often active in volatile environments, where crime, illiteracy, unemployment, ill health, insufficient resources, and political instabilities are rampant (among the lives of caregivers as well).

In light of this context, caregivers are not given adequate (emotional, financial, educational) support, and do not necessarily have sufficient access to information and learning opportunities. This results in home-based care being an arduous pursuit, further undermining the impact of care. Hence, caregiver support has become a point of concern for both the Department of Health, care facilitators, and several non-profit initiatives across the country. The Kujali HBHC Project is one such initiative that endeavours to mitigate the many HBHC difficulties on the part of the caregiver. Kujali specifically targets caregiver empowerment, with a “current focus on developing solutions based on mobile technology to help facilitate HBHC care activities” [Kujali 2010]. The Kujali project plan, in terms of the eventual technological ‘intervention’ (for lack of a better term), was to advance research into the field of Interaction Design. As a design-based solution, the goal has expanded to the aspect of communication and (informal) learning, since these have been recognised as recurrent barriers in the fight for care.

In this paper, the aforementioned elements and arguments will be scrutinised more closely, with a particular emphasis on caregiver education. It has become clear, through the Kujali Project not least, that citizens in recipient communities are on the peripheries of formal education. Moreover, the caregiver may be perceived as a change agent here, able to disseminate information and promote health via digital forms of ‘edutainment material’. The authors will evaluate the feasibility of such an approach, and will eventually demonstrate a collaborative, educational training model for home-based healthcare workers. Yet, to navigate the dynamic home-based healthcare context, a holistic understanding of its socio-economic and cultural framework is required. In fact, as we will come to understand, the service of care has become increasingly socially and culturally embedded. Therefore, before we can design any educational intervention, or information system, we must first gain an insider perspective. This specifically calls for a design-based ethnographic analysis that forms an integral part of the AT-HOME 2.0 model. This paper is ultimately built

on a descriptive, emic premise – one that aims to make plain some of the intersecting dynamics that shape home-based care in South Africa.

2 Context

2.1 The state of health in South Africa

To grasp the intricate context of caregiving, one need only glimpse at the state of health in South Africa. The country has a violent history of racial discrimination, which has spawned an array of post-apartheid concerns. These include high rates of illiteracy, poverty, inequality, unemployment, corruption, and crime. This in the context of a state body that has been slow in tackling said concerns [see Zuma 2010]. Moreover, access to proper healthcare in the country has greatly diminished as HIV/AIDS and tuberculosis rates continue to inflate. This arduous situation is evidenced by the statistics below [adapted from Coovadia et al. 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. 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 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.
- 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 South African citizens.

- 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 1066 per 100 000 people.

The state of health(care) in South Africa continues to be troubling. However, stakeholders from various fronts have campaigned, viciously and actively, against disintegrating health systems. This includes, for the most part, nongovernment institutions and (informal) community clinics, deploying critical resources across South Africa's nine provinces. Home-based healthcare has also become a major service, reaching communities in isolate, formerly inaccessible areas. But as we shall come to understand, this service is essentially under-funded and –resourced, and operates in increasingly harsh conditions.

2.2 Models of home-based healthcare

“Care in the community must become care by the community” [National Department of Health 2001:1].

Using the earlier WHO definition, home-based healthcare improves and maintains patients' levels of comfort, function and health [WHO 2004]. The care service is facilitated within the patient's home, and thus ensures an interpersonal engagement with the caregiver. The WHO suggests several categories of care: preventative, supportive, therapeutic, rehabilitative, long-term, and palliative [ibid]. Respective categories are then embedded in a number of care frameworks, each oriented towards a specific goal. In South Africa, these are adopted in varying models, and generally depend on local needs [National Department of Health 2002]:

- Community-driven model – run by several initiatives or volunteers from within the community. Not characterised by a central structure for coordination and management.
- Formal government sector model – certain state departments may collaborate with local organisations in providing care. Managed by a multidisciplinary team of medical staff, usually within formal hospitals.
- Integrated home/community-based care centre model – structured around a single community care centre, often run by volunteers. The state may allocate individual resources (nurses, health workers) to it depending on the need.
- NGO home/community-based care model – similar to the above model, but managed by a non-government organisation.
- Hospice integrated community and home-based care model (IHC) – This model embraces all the characteristics of the aforementioned models. It is structured around a reputable, well-established NGO (i.e. Hospice). The advantage of this is

increased resources and a pool of experience, enabling the rapid development of a home-care network.

The models described here all depict the various collective approaches to care in South Africa (and perhaps elsewhere). The case study material will present these elements in more detail, and we will see the adoption of different strategies and attitudes. However, it is important to note that whilst the presented frameworks for HBHC are sound in theory, they are not practically feasible without ample resources. Limited funds and lacking human capital are indeed the biggest challenges in this space. We will evaluate these assertions in more detail as they become apparent.

2.3 Home-based healthcare and (informal) education

As will become apparent in the analysis below, the lack of access to educational services is a foremost concern for caregivers in Kayamandi. It is exactly this previously unexpected circumstance that ignited the development of AT-HOME 2.0. We therefore mention it here as part of our contextual review. Currently, there is limited to no research on the informal education of home-based caregivers, both in South Africa and globally. This includes issues of access to ubiquitous and on-demand learning. However, there has been significant progress in the general area of patient, user, or public education. The invaluable work by the Medical Knowledge Institute (MKI) in the Western Cape and Gauteng is one example [Medical Knowledge Institute 2009]. This initiative underscores healthcare education and information as an intrinsic human right, and is responsible for several new information centres across the country. These are aimed especially at rural or disadvantaged communities; those citizens without reliable access to information resources (e.g. in Soweto or Khayelitsha): “MKI is convinced that accessibility to relevant information is the most effective strategy to improve healthcare. I’m very pleased to partner with Cotlands to create a Health Information Centre for the local community and children of Soweto” [MKI 2009:2].

There are numerous studies that emphasise patient- or community-based education [Nguyen et al. 2004; Block 2002; Bandura 2004; Lundy 2009]. Yet, the focus has not encompassed caregivers, or volunteer care workers, per se. Past research has suggested that participative education programmes may mitigate the effects of caregiving [Cooke et al. 2001; Gallagher-Thompson et al. 2000; Schulz 2000; Zarit et al. 1999]. However, these studies are Western-based and hardly include an African perspective, much less Southern African. As we shall come to understand, caregiver education is a fundamental concern in the sphere of HBHC, so much so that it can no longer be neglected.

3 Objectives

This paper firstly intends to describe the context of caregiving in South Africa, using case study material from predominantly one HBHC site. The larger Kujali study analyses a number of sites, and data from an additional site in Athlone is also used on a secondary basis to augment the analysis (more on this later). These cases will demonstrate ethnographic narratives of the “care experience”, emphasising the needs

of and barriers to educational information, particularly concerning caregivers. As part and parcel of this context (i.e. emerging from it), this paper then grounds a collaborative training model: AT-HOME 2.0. This is foreseen as a basic framework whereby caregivers (are encouraged to) develop educational content via information and communication technologies (e.g. mobile phones, social media, and the like). Such content can and may include experiences, suggestions, and guidelines that are relevant to the practice of caregiving. Moreover, AT-HOME 2.0 will conceptually demonstrate how educational content may be generated, published, and disseminated.

The actual development of the proposed model will also be demonstrated in this paper, although more research is required to unpack the specific educational and technological aspects of the intended 'solution'. Moreover, the interrelationships between identified stakeholders are vastly complex, and require more in-depth analysis. The eventual outputs of this paper will be a description of the care context and a proposed collaboration model with identified stakeholders that may participate in the design and development of a care education (software) framework.

4 Methodology

Over the course of two years, several South African HBHC communities were engaged as participants for the larger Kujali study. For the purposes of this paper and at the risk of repetition (but at the benefit of clarification), the data from a single site will be presented: Kayamandi informal settlement as administered by the Stellenbosch Hospice in the Western Cape. This "site" (although not in the narrow, fixed sense of the word) constituted the very first research field for the Kujali team. The methodological process has for the most part been concluded here, with the exception of training and monitoring caregivers in social media use. In this case, data from another care provider, the YMCA in Athlone (Western Cape), will be referenced. This data is employed on a secondary, augmentative basis, and only concerns instances where social media usage is reported.

Kayamandi respondents included the managing and nursing staff at Stellenbosch Hospice, community representatives, volunteer care workers, and formal caregivers. The selection for individual respondents followed the criteria as proposed by Spradley [cited in Babbie 2001]: enculturation (those respondents that are familiar with the local contexts); current involvement (individuals that are actively engaged with the issues at hand); and adequate time (respondents have sufficient time for participating in interviews, surveys, and observation). Two methodological frameworks were employed for this analysis, ethnography and interaction (specifically, user-centred) design.

4.1 Ethnography

All respondents were questioned by means of structured and unstructured interviews, conducted by the principal investigators in Kayamandi: the ethnographer/social scientist, and the interaction designer. Structured interviews took place on the premises of Stellenbosch Hospice and were considered more formal, allocated discussion slots with caregivers and management staff. Interview questions here were pre-conceived; the interview structure remained relatively organised. Unstructured

interviews were conducted mostly in the field (the Kayamandi community), and were necessarily preceded by observations that needed clarification or elaboration. An unstructured arrangement was preferred here, as the field was rather disruptive. It was challenging (and inflexible!) to follow any organised or pre-conceived protocols that did not account for fluctuating circumstances.

Data was collected through video- and sound recordings, as well as field notes. Participant observation was also employed throughout the information gathering process. Generally, participant observation is recognised as the defining method of research in cultural anthropology [Bernard 1998]. It concerns the partaking of the researcher in the everyday activities (interactions, daily routines, and events) of the persons under study. Participant observation facilitates the means whereby data is gathered in an unstructured fashion in naturalistic locations. Researchers are then able to join in on daily interactions, whilst consciously examining the situation and then recording observations. For this analysis specifically, caregivers were accompanied (and aided) in some of their daily routines: training, travelling, visiting patients, and administering care. Time was also spent at formal care facilities.

NVIVO 9 was used as computer-aided data analysis software. Interview and observation content was imported in the program, and coded under first order constructs (denotata) and second order constructs (categories). Key relationships and uncertainties were identified, extracted, and mapped. It was then determined whether there was any correspondence in respondents' accounts. On the back of this analysis, several inferences were made and will be presented throughout this text.

Ultimately, the research methodology is lodged in the ethnographic paradigm: the data of cultural anthropology that is derived from the direct observation of behaviour in a particular group or society [Babbie 2001]. This framework allows one to gain a subjective experience – and hopefully, understanding – into the social domains of research participants. Spradley 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.” [Babbie 2001:279]

4.2 Design

As stated earlier, the Kujali project plan was to advance research into the field of Interaction Design. The team had a graduate industrial designer on board; someone that was familiar with the principles of interaction design. Interaction Design is a well-established school of practice within design and shares many characteristics with Industrial Design. Central to this paradigm are the methods of user-centred (UCD). With the use of various design tools for idea generation, communication and critical thinking, design can greatly influence the outcomes and success of any technological developments that somehow affect human life. As the interest into design research continued, the emerging field of service design was eventually identified. Service design takes a broad perspective on the problem context and seeks not to develop individual products, but innovative service experiences. This take on a problem context can affect a larger spectrum of facets than just a single product, to include a host of products and systems that services may involve. It became evident that service

design would fit the profile as a field of design thinking and practice needed to address the problem context of HBHC service delivery.

UCD acknowledges the need for the traditional qualitative methods such as interviews, questionnaires, and focus groups. These typically produce results resembling counts and statistics or personal accounts, while more innovative methods such as design workshops, card sorting and cognitive mapping yield results like content analyses, categories, patterns, themes, affinities and clusters. These methods hence allow for creativity and participation, and can complement traditional qualitative techniques. They can also be tailored to each context of use. Such projective methods can allow research participants to express themselves more freely [Mattelmäki 2006].

Several tools and activities were employed for the design aspect of the methodology, each for their specific advantages at different strategic phases. ‘Insight tools’ consisted of: assumptions (addressing bias and preconceived ideas), conversation cards (a set of cards that serve as talking points), service touch points (concrete interfaces where the user interacts with a system), context mapping (activities that extract the needs, experiences, hopes and expectations of the participants), user journey mapping (plotting individual journeys and interactions with touch points), and stakeholder maps (relationship building). These were accompanied by design tools, notably: co-design workshops (conceptualise, prototype or test ideas alongside respondents), word of mouth (informal communication, storytelling, debate), personas (fictitious characters that represent particular user types), prototyping (paper or cardboard mock-ups), and scenarios (diagrammatical representation of client journeys).

5 AT-HOME 2.0: towards an educational framework

5.1 Perspectives from ethno-design

Ethnography corresponds to the observations and other collected data like artefacts and personal accounts from interviews and design sessions into a holistic depiction. Through gathering the respective data elements, an accurate account of the situation was gained. This was experienced through the interviews with caregivers, following them through a day of work and collecting and examining artefacts used, or present in the environment. This understanding was reflected later on in the co-design activities where caregivers were able to relate back to the activity diagrams and “lo-fi” prototypes despite their initial scepticism. The research and development team gained an improved understanding toward the caregivers and their work context. By closely interacting and co-designing solutions with caregivers (end-users), the Kujali team was able to present a hard-coded prototype which was very well received. Understanding therefore aids in the co-design of more appropriate systems, which take into consideration the context of use and physical and social environment.

Table 1 below details the respective design actions over the research period. The first column indicates the vertical organisation of tool types while the second column is divided into three tool types: ethnography, design, and communication. The categories follow from the phases and activity types identified in the design methods and the outcomes these seek to achieve. The third column lists the service design tools used to collect data. Where each tool is used in the research activities is marked with

the symbol “◆” in the rows of the table. The top row indicates the three different development phases which are named: “pre-design”, “design” and “post-design”.

| | | Phase: | | | Pre-design | | | | | | | | Design | | | | Post-design | | | |
|--------------|--------------|-----------------|---|---|------------|---|---|---|---|---|----|----|--------|----|----|----|-------------|----|---|---|
| | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | | |
| TOOL TYPE | Ethnography | Un-S. Interview | ◆ | ◆ | | | | ◆ | | | | | | | | | | ◆ | | |
| | | Assumptions | ◆ | | ◆ | | | | | | | | | | | | | | | |
| | | Str. Interview | | | ◆ | | | | | | | | | | | | | | | |
| | | Observation | | | | ◆ | | | ◆ | | | | | ◆ | | | | | | |
| | | Conv. Cards | | | | | | | | | ◆ | | | | | | | | | |
| | | T. points | | | | | ◆ | | | | | | | | | | | | | |
| | | Context map | | | | | | | | | | | | | | | | | ◆ | |
| | | Journey map | | | | | ◆ | | | | | | | | | | | | | |
| | S-holder map | | | | | | | | | ◆ | | | | | | | | | | |
| | Design | Exp. Target | | ◆ | | | | | | | | | | | | | | | ◆ | |
| | | Personas | | | | | ◆ | | | | | | | | | | | | | |
| | | Scenarios | | | | | ◆ | | | | | | | | | | | | | |
| | | Co-Workshop | | | | | | ◆ | ◆ | | | | | | | | | | ◆ | |
| | | W-of-mouth | | | | | | | ◆ | | | | | | | | | | ◆ | |
| | | Concept sketch | | | | | | ◆ | | | ◆ | ◆ | | | | | | | | |
| | | Prototype | | | | | | | | | | ◆ | ◆ | | | | | | | |
| | | Exp. prototype | | | | | | | | | | | | ◆ | ◆ | ◆ | | | ◆ | |
| | Communicatio | Presentation | | | | | | ◆ | | | | | | | | | | ◆ | | ◆ |
| | | Storyboards | | | | | ◆ | | | | | | | | | | | | | |
| | | Filmmaking | | | | ◆ | | | | | | | | ◆ | | | | | | |
| Journals | | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | ◆ | | | | | |
| Blogs | | | | | | | | | | | | | | | | | | | ◆ | |
| Online space | | | | | | | | | | | | | | | | | | ◆ | ◆ | |

Table 1: Design Activity Spreadsheet

Generally across the research/time phases a pattern emerges. Pre-design focuses on the current situational context and people’s perceptions thereof. The design phase shows more focus on structure and future capabilities. The post-design phase focuses on the social impact of proposed technologies. There is undoubtedly a flow here too, where each phase is reliant on the outcomes of the last to inform its direction and focus.

5.2 Contextual foundations: Kayamandi

Kayamandi is the isiXhosa term for “sweet home”. There is a cruel irony attached to this name, now home to more than 30 000 people. For the region is plagued with rising poverty levels, with nearly 70% of the population earning less than R1000 per month. This is far below the national Household Subsistence Level (HSL) of R19 200 per year [DPLG 2007]. Although exact statistics are hard to come by, it is estimated

that unemployment in this community is at 30%, with an HIV/AIDS prevalence of at least 20% [LCDC 2009]. Historically home to migrant labourers, Kayamandi was acknowledged as a formal “location” by the Stellenbosch Municipality in 1941. The disintegration of apartheid, along with the abolition of influx control, has led to a dramatic surge in population [see Booï 2011]. Today, the Kayamandi settlement faces increasing socio-economic, environmental, and political challenges. These are rooted in history, but have been elevated by present conditions. And this situation is, inevitably, the backdrop of home-based healthcare activity in the region.

Home-based healthcare in Kayamandi is managed by Stellenbosch Hospice, which serviced areas include Lanquedoc, Jamestown, Klappmuts, Idas Valley, P’niel, Kylemore, Cloetesville, and Stellenbosch central. A member of the South African Hospice Palliative Care Association (HPCA), Stellenbosch Hospice has expanded considerably over the last few years. Since 2009, patient numbers more than doubled, staff has increased with 27%, and operational costs increased with almost 40%. The Hospice now (2011) has a 100% bed occupancy rate, and several new service areas (after-hours clinic, local farm project, and the like). HBHC is the foremost service for the Hospice, employing 40 caregivers and 9 nursing sisters. Palliative care is provided to a network of nearly 900 patients, of which 202 reside in Kayamandi (at the time of writing, April 2011). Patients predominantly suffer from TB and HIV/AIDS, although chronic and terminal illnesses are also treated. Notwithstanding its continual growth, Stellenbosch Hospice is relatively under-resourced: its support structure to caregivers is yet to incorporate aspects of emotional support, full-scale administrative systems, competitive salaries, and incentives. Though supported by the Departments of Health and Social Development, among a number of financial backers, it continually struggles to be financially sustainable whilst meeting its service needs.

As part of the overall Kujali project, several care institutions were selected to receive training on Web 2.0 and social media. One of these organisations is the YMCA in Athlone, Western Cape. Caregivers at YMCA have undergone a series of new media training sessions hosted by Reconstructed Living Labs (RLabs). The aim here was to introduce different means of expression and communication to caregivers, who often are at the peripheries of digital interaction. The short-term output of the training was a formal blog, hosted on the Kujali domain. Here, caregivers now write (“blog”) about their various activities. Even though the Kayamandi carers have yet to be trained on this aspect, gathered data from the YMCA site reinforces many of the sentiments expressed by Kayamandi caregivers.

5.3 The caregiver experience

Caregivers can be formally trained nurses to semi-trained or informal carers, such as family members. The primary role of the caregiver is to provide basic nursing and palliative care to persons (also referred to as ‘clients’) in need. This includes post-operation and –hospital care as well as long-term care for those suffering from chronic illness. Essentially, caregivers are the delivery points where patients are exposed to the care service network. In rural and poor communities, caregivers are often informally trained, and not necessarily experienced in basic care provision. Nurses (if and where available) will be absorbed in respective nongovernment health organisations in various managerial roles. It may be noteworthy here that caregivers are usually considered to be women; there was not a single male carer encountered

throughout the research period. This may be of certain cultural significance, as we shall come to understand at a later period.

In Kayamandi, caregivers often work in groups of two or three, and visit their allocated patients daily. Hospice management allocates patients based on area of residence, and type of care activity required. Carers usually travel on foot, by bicycle, or public transport. It is vital that clients are within reasonable proximity, since caregivers have to travel great distances every day. Moreover, roads are often tough and strenuous, especially within rural or under-developed areas. Kayamandi, fortunately, is fairly close to Stellenbosch Hospice itself, but it can be disastrous to navigate in harsh weather conditions. The Hospice does provide the occasional taxi-bus service in situations where patient homes are cut off or impracticable to access otherwise.

Stellenbosch Hospice is not amply resourced in information and communication technologies (ICTs). There seem to be sufficient equipment available for administrative duties in the office, but caregivers per se lack any distinct access to technology. When in the 'field', they are limited by and large to mobile phones, notepads, and calculators. Patient data collection is paper-based; home visits are detailed on folio sheets with any pencil or pen available. Most respondents have expressed dismay at this, citing paper as a flimsy, unreliable means of collecting data. This overall 'information system', they claim, is terribly outdated, and often results in inaccurate or lost data. Despite this, data collection is central to the functioning of both Hospice and the HPCA. Month-end, patient and care information is sent to the Department of Health, and used to inform best practice or better care policy. Any damage to data integrity certainly undermines the entire flow of information within this network. Moreover, caregivers have emphasised the importance of having their 'eyes and hands' free whilst attending to patients. Having to collect data, even intermittently, ties them down and presents the additional burden of having to tally statistics at week's or month's end.

In terms of social dynamics, Kayamandi caregivers express that they quite enjoy their work, and that they took pleasure in interacting with patients. Writing on the Kujali Blog [Kujali 2010] in a post titled "Changing Mindsets", a caregiver from the Athlone YMCA shared this sentiment:

"Working as a homebased carer is so exciting. I got this one patient that had a stroke about six years ago. She can't walk and when she talks the words do not come out properly. When I enter her room, she always has a smile on her face. Her right side of her body is affected from the stroke she had. She already knows what the purpose is for me being there. While I am busy washing her, we chat about different things and make jokes. Sometimes she will say her leg is painful when I touch her leg. I will then rub her leg with arnica oil and the pain will be gone. I then dress her and make her comfortable. That is how I spent my time at this specific patient and making her feel good for the rest of the day."

The above account illustrates the pride caregivers take in caring for their patients. In Kayamandi specifically, caregivers seem to be respected and admired within the community. They are well-known in the area, and are sometimes perceived as social community leaders. This has often resulted in them becoming the (informal) voice of the community for issues that concern healthcare and wellbeing, meeting basic social needs, employment, and living standards. Residents and patient families have

regularly approached them with a variety of “inquiries”, seeking their opinions, help, or counselling. This has had a rather strenuous emotional effect on caregivers. For now, not only are they tasked with physical patient care, they are given additional responsibilities in the community. This extends to the patient’s home as well, where caregivers may sometimes have added ‘duties’, like cleaning the house, bathing the patient, or cooking food. It has become clear that the practice of caregiving can be emotionally and psychologically demanding. One carer expresses the following:

“I had a very busy week with my patients most of them are bedridden and some are very emotional. One of them is going to hospital today for his legs; they are going to amputate both his legs. I really felt sorry for the other day because he didn’t want to go through with [it]. I had to talk him through it because there’s nothing doctors can do to save his legs because the gangrene did spread right through both his legs. I really felt for him because his going through so much pain...wish I could take the pain away.”

Given the emotional turmoil that may often arise from patient encounters, caregivers find themselves in need of counselling and support. It was noted by some that they have little means to express themselves, and that they do not receive intensive psychological support from the respective management structures at the Hospice. Although moral support among caregivers is claimed to be high, Stellenbosch Hospice does not have sufficient means to provide concurrent, exhaustive support structures. Caregivers thus depend on one another for assistance, and rely on monthly training and counselling meetings with Hospice nursing and management staff. The research team observed strong interrelationships between caregivers, characterised mostly by the sharing of experiences. This was crucial, according to some, in helping to deal with the emotional constraints they faced daily.

With respect to support and guidance, a critical area identified by caregivers was (access to) information. Currently, caregivers working in Kayamandi have limited access to that information which, by and large, is educational in nature and may help them improve their care service. Current forms of educational information exist only in textual form (books, brochures, training manuals, and the like). But these are of little use, since most of our respondents are semi-literate or completely illiterate. Moreover, such forms of information are not readily available, and inaccessible when carers are working in remote areas. And as we shall demonstrate further along: the types of available information are confounded by numerous barriers. These may include language restrictions, complicated terminology, illiteracy, innumeracy, and physical limitations (paper material, not easily redistributable, not readily publishable, and the like). These aspects will be explored in more detail in light of the AT-HOME 2.0 framework. For now, let us evaluate the context and environment of care recipients.

5.4 The patient environment

In Kayamandi, there are various dynamics that influence the patient’s readiness to home-based healthcare. By and large, patients in this community find themselves within an unkind environment. Throughout this paper, the case has been made that Kayamandi is dismally under-developed and subject to severe poverty. Residents face the ongoing predicaments of lacking service delivery; high unemployment, especially amongst women; single-headed households, loss of skills, low monthly income,

shoddy housing conditions, high instances of malnutrition, TB, and HIV/AIDS; low educational level; insufficient infrastructure; and high levels of crime and domestic violence [Du Toit 2009; Lindner 2006; LCDC 2009]. These elements contribute to an unforgiving health context; one in which incidence of disease is especially high [Lindner 2006].

In terms of the in-house patient environment, the situation is equally dismal. One caregiver remarked: "Some houses are very isolated. The roads are rough. In Kayamandi, the patient facilities [are poor]...there is no power; the patient's house is too small. There is no toilet. It is the worst area for TB patients." Servicing such households can become a nightmarish endeavour for any caregiver working in Kayamandi. Yet, the one upside to a commune of this nature is family ties. Research by Lindner [2006] has described a variety of family units that may be distinguishable in the community. Although units are often disrupted – absent parents, migration, single- or child- headed households, and divorce – they remain vital to the process of care. When caregivers are absent, family members are seen to resume responsibility of the patient, and become the primary care providers at home. Caregivers have expressed their relief at this occurrence, claiming how vital it was for patients to receive permanent care. Participant observation did however reveal an air of resentment to caregivers in certain instances. This was, according to respondents, ascribed to family members feeling somewhat undervalued and insecure; the patient has after all become less dependent on them, and more reliant on an outsider. Stigmatization has also contributed to family conflicts; families receiving care treatment are often avoided by friends and neighbours. These negative feelings were found to be the exception, as community members generally joined in on the care activity, and revered the caregiver.

There are certainly a number of positives to take from the general patient environment. For one, patients seemed to use their medications carefully, and determinately. Treatment schedules were religiously followed, and patients express utmost gratitude for having received substantial care. In this regard, patients much respected their carers, and would even anticipate their visits. In some cases, patients were rather disappointed when their carers failed to show up. Caregivers surely appeared to be valued among the community, and their presence was almost always welcome. Ultimately, Kayamandi proves to be a community facing a grim reality. Its impoverished nature is not for the faint of heart and yet, caregivers are regarded with heartfelt deference. What has been so far left unsaid is the fact that HBHC has been largely effective in Kayamandi. Stellenbosch Hospice quoted improved numbers in patient recoveries, and the research team encountered several patients that recovered visibly well. That said, it is imperative to understand the volatile context in which home-based healthcare operates. A context that may undermine the overall value and impact of care.

5.5 The sharing of experiences

The backdrop of home-based healthcare in Kayamandi has been provided. It is clear that there are many disruptive elements that pose a threat to the provision of unabridged care. In light of the above analysis, to improve patient wellbeing is only half the battle, since, evidently, caregivers themselves are in need of care. Indeed, it would appear patients are dependent on their caregivers. One diabetic patient stated

that his carer's presence is indispensable; without this, he would be stranded and helpless. For patients in these cases are often at a complete loss without some form of aid; they are not able to self-administer care, nor can they necessarily be self-sufficient. Thus, they are at the complete mercy of their caretakers: nurses, social workers, volunteers, and caregivers. Yet this situation poses a double-edged sword: on one side, caregivers command respect and admiration in Kayamandi; on the other, patient dependency may give rise to emotional stress, bodily strain, and psychological tensions, which eventually pervade every aspect of caregivers' lives.

By and large, as the Kujali research project has revealed, caregivers are usually from within or around the communities in which they work. They are often volunteers, or in some cases, professional health workers. At Stellenbosch Hospice, they receive brief training, guidance, and counselling every month. They are sparsely remunerated, and are not afforded any substantial resources that may aid them in their care. This is largely due to the growing demand of HBHC in the area [see Smith 2008], and of decreasing resources. The overall outcome of this arduous context is one of disillusionment. Caregivers have expressed the great desire to improve their professional activity by any means necessary. Emotional and psychological strains may be reduced by measures that employ counselling and training, but the implementation and impact of these are beyond the scope of this paper. However, the more immediate and pressing need – one that may be tackled from the bottom, up – is that of (access to) informal learning.

Prior to tackling the issue of education however, it should be asserted that, since caregivers often emanate from the communities within they work, they are strongly familiar with the local community dynamics. Moreover, since caregivers share a profession, and many inherent professional values (empathy, kindness toward patients, social obligation), they may constitute a 'community of practice' (CoP). In a brief introduction to CoP, Wenger [2006] states the following: "Communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly". This is relevant to the groups of caregivers in Kayamandi, who continuously share their understandings of the care process. Furthermore, caregivers also share experiences about patient encounters. This, aside from irregular guidance at Stellenbosch Hospice, is one of the means they employ to counter emotional distress.

It may be possible to observe a shared system, which constitutes collective experience and value systems, as the foundation to care activity in Kayamandi. In this sense, any generated, pooled knowledge remains contextual: it is socially and culturally embedded within the local environment. When approaching an educational intervention, therefore, it is crucial to take heed of said 'localised knowledge'. Initiatives that do not address the socio-cultural aspects within the caregiver CoP may not achieve desired outcomes, since they are bound to exclude significant internal paradigms. Stated more plainly: 'external' educational material developed for caregivers may not be relevant to the 'internal' context. Several 'outside' aspects could be at play here: difference in language level, unfamiliarity with present situation and cultural backgrounds, racial tensions, gender bias, top-down instruction vs. bottom-up innovation, and the like. Conversely, communities of practice may be invaluable in promoting (and developing!) social presence, motivation, tacit and

explicit knowledge, collaboration, and collective participation [Sveiby 2002; Tu 2002; Ardichvilli 2003; Duguid 2005; Wenger, 2006].

As a community of practice, caregivers in Kayamandi have little opportunity but to verbally recollect and share experiences. They rely strongly on physical proximity (and intimacy) when exchanging ‘care stories’ with their colleagues. This exchange acts as both as a professional tool – by improving knowledge of ‘care provision’ – and an educational instrument – by growing current knowledge and obtaining new knowledge. For any other informational or educational purpose, they rely on the monthly training sessions at Stellenbosch Hospice. But this is where the boundaries of formal and informal knowledge acquisition (relevant to home-based healthcare) end for most. Through some of the presented ethnographic observations, we may observe numerous barriers to accessing and utilising both information and education: socio-economic (poverty, illiteracy, extra duties, patient dependency); environmental (bad weather, poor infrastructure, rural isolation); political (limited political buy-in, lacking policy directives); cultural (stigma, the role of resentful families); and technological (inaccessibility, inaccurate data recording and transfer, loss of patient files).

The aforementioned elements represent a simplification of the many obstacles to obtaining information and educational resources on the part of Kayamandi caregivers. According to our respondents, this scenario is not easily alleviated. Most of the sourced funding for Stellenbosch Hospice goes toward expanding or improving the care service, or for other bare necessities. And as expressed by the Hospice management body, there is little additional funding for installing any infrastructure that may address the aspect of ‘information provision’. Caregivers per se do not have the means to receive additional training or educational material; they rely mostly on what is provided by the Hospice. In short: any intervention – ICT or otherwise – should by all probability be funded from the outside. Yet, the very act of exploring this possibility is costly, and may divert attention from the core Hospice service, which remains home-based care.

Furthermore, introducing (educational) technology in an already disruptive environment may only add to the existing complexity. For the technology to be successful, it has to be met with stakeholder buy-in (across the board) and ample resources. Stakeholder buy-in is critical here – it has already been argued that external interventions may do little but serve the interests of outside authorities. Designing, implementing, and distributing a “technological solution to education” for caregivers may only become a reality if it builds on internal value [see Wenger 2006]. Literal adoption of the solution may depend specifically on this proposition. At the Athlone YMCA, caregivers revelled in the fact that they can connect with others and thereby ‘effect real change’, simply by blogging through their mobile phones: “I feel very chuffed with myself. We the YMCA athlone bloggers are the first ever to be blogging from our mobiles. Impressive or what? Go rlabs!!! Go YMCA !!!”.

Indeed, the respective Kujali social media training has thus far yielded positive results. The key premise here is that caregivers (as a CoP) are central in devising their own, personalised solution to the problem of education. At this stage however, there is little research on using mobile technology in/for home-based care in South Africa. To understand the relevant complexities, there has to be a definitive call for more

analyses. Universities are, perhaps, significant agents here, given possible access to funding, expertise, and experimentation facilities.

5.6 Edutainment

The move toward a framework of education, be formal or informal, has underlined the need for an omnipresent caregiver support network. Throughout the design process, one aspect that gained prominence was that of “edutainment”: educational material with somewhat of an entertainment value. During the design phase, caregivers expressed much interest in a mobile application that would publish visual accounts of their experiences, cartoon-style. There was much enthusiasm about this possibility, and it certainly has a central role in the proposed collaboration model, as demonstrated below through an ‘edutainment campaign’.

Edutainment content can be delivered to mobile phones via the mobile web. With increased access to the net, decreasing data costs, and the development of mobile literacy, edutainment data could prove to be a viable approach. An edutainment campaign needs to be driven from within the community, and is determined by community needs (in this case, that of lacking educational opportunity). It is this dialogue that edutainment can harness to gain acceptance and to generate popularity. Edutainment content will aim to be interactive in this respect, to always remain relevant to contextual issues, and to respond to community opinion.

Edutainment content will be produced as community generated stories that are personal accounts (for example blogs) and interviews with caregivers and community members. Through an educational content provider (see below) the relevant themes and contextual backgrounds of these stories can be refined and adapted to provide informative, educational material. Caregivers can in turn use this material to assist them in informing patient and patient families around health related topics. This material may also be useful for nurses and coordinators when training caregivers.

Content will be presented as a series of pictures, cartoon-style, with accompanying text and/or voice clips. The series may consist of about 5 to 10 slides or more, depending on the content. During, or at the end of the series, questions can be asked of the audience, who then can respond by multiple choice, ratings or opinion polls. Respective story lines may be able to adapt to public response, or these opinions may be presented back to the community as a live poll. This type of audience participation can be used as a tool by the producers to design content and storylines.

The edutainment campaign will feature *mascots* as key role players in the respective community. In terms of HBHC, there will be a caregiver mascot, acting as a role model and community ambassador. Additionally, the mascots will have Facebook accounts, and also participate in interviews and forums.



Figure 1: Edutainment mascots

An edutainment campaign has much promise in addressing the urgent need for information around the caregiver experience. As the ethnographic analysis points out, many if not most caregivers are illiterate and lack formal educational opportunities. A relevant mobile application may alleviate the challenge here, providing on-demand access to useful content in supporting informal learning.

5.7 Content repository

The next step towards building an inclusive educational framework for caregivers is a content repository. We refer to it here as the M(obile) Care Educate Repository. The M-Care repository was never co-designed per se, but was developed by the Kujali research team in light of the ethnography-design intervention in Kayamandi. It is essentially informed by the primary research findings here, and is seen as one of outputs of the research process. Overall, the M-Care repository demonstrates an abstract intention that structures or encapsulates the argument for an educational framework.

The repository is framed as a pipeline, constituting four layers of content, produced by caregivers. Respective ‘content clips’ may become part of a general information thread: content is filtered, converted, and added to the following layer. Provided the content clip is suitable (for the next layer), value is added through the conversion. Each layer has its own access rights and is useful for a specific purpose:

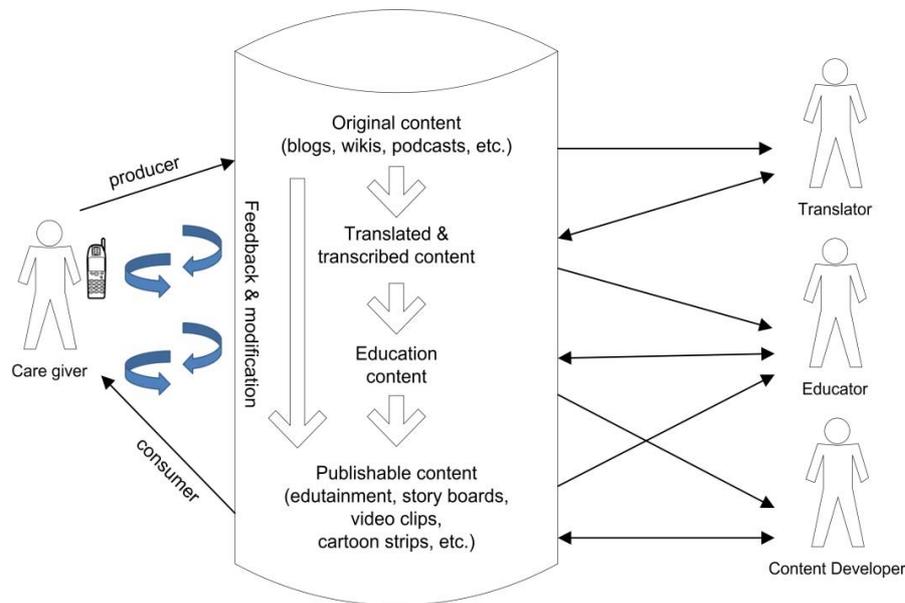


Figure 2: Ubiquitous community m-care education repository and relevant stakeholders

The top/first layer may include caregivers' unaltered accounts. Each carer – later extended to community members – will be registered and will be given access rights to this layer; only they will be able to contribute here. Each 'account' may be a personal experience, or a guideline as to how to perform certain care activities. Content in this layer is thus regarded as 'raw' stories/conversations; caregivers are encouraged to voice their opinions, thoughts, and emotions. All accounts (text or audio) will be captured using low-end mobile phones – since basically every Kayamandi caregiver owns one or more (particularly the Samsung E250) – or blogs, wikis, and podcasts. Content clips will be relayed to the repository in its original form. Said raw content will also be *stored* in their unaltered form, which may be useful for future research purposes.

It is entirely possible that content in its rawest form may be unsuitable for broader distribution, as it may contain private data, information about unsafe practices, or information that is generally irrelevant or inappropriate. It may also become crucial for this layer to capture the employed tone, context, and language of expression regarding every caregiver account. A reference framework for each account should ideally exist, thus creating an additional content filter. All content clips, suitable or not, will constitute the first layer of the M-Care Educate repository. They may be added to further levels of the overall content thread by a content developer (role to be defined).

The second layer contains the translated and transcribed versions of content clips. Clips will be translated into the desired language – in the case of Kayamandi, either isiXhosa, English, or Afrikaans – and transcribed into text format for reproduction

and –use. The role of the translator becomes significant here, as all newly filtered content must be suitable to the care environment. Ideally, the moderator should be knowledgeable in local dynamics to ensure a sufficient understanding of the content. Once clips are translated and/or transcribed, they may be referred to the caregiver for feedback and modification, and subsequently distributed to the third layer. Here, original or filtered content is converted into appropriate educational content. It is important at this stage to determine if content is suitable for educational purposes before the conversion process. Once determined, the respective educator will integrate the relevant educational components. The educator must be knowledgeable in the educational requirements of ‘care education’. Moreover, to maximise relevance, the developer should have a clear understanding of the target audience. Content in this phase may also be sent to caregivers for further inputs and feedback.

The final layer contains ‘publishable’ content, that may be distributed to mobile (or other digital) platforms. Caregivers then become the consumers of the content they helped produce. Informed by our observations in the field, caregivers should relate to this educational content with fervour, since each of them would have a part in its overall design. As expressed by this ‘caregiver blogger’, they are indeed a community of practice and do share in the care process: “I’m learning lots of new stuff that I can share with my colleagues and patients. I love socializing and sharing and also giving advice to other people so that whatever they do, I can make [a] difference in their lives. Loves to share.”

The foremost concern here would be to create narratives and personas appropriate to the care context (in Kayamandi, for example). Ideally, this would consist of interactive content – i.e. edutainment – that encourages active participation and invokes optimal learning. Content may also be controlled via quality feedback mechanisms or loops; caregivers may continuously suggest new or improved features. Moreover, the educator/training provider needs to be aware if sufficient learning takes place, and that recipient caregivers will be well-equipped for care tasks. Some form of assessment (or quality control) may be required for activities that relate to formal care practices.

The M-care Educate repository is the central component to AT-HOME 2.0’s collaborative process. Various stakeholders make up the framework, including that of caregiver, translator, content developer, educator, and the like (see Figure 2, below).

5.8 Collaboration model

In addition to the aforementioned agents, there exists an overarching network. This network, although pre-existing, was extracted through the ethnography-design methodology, particularly context mapping, and persona and scenario sketching. It is now an abstract demonstration of the collaboration possibilities around Kayamandi’s HBHC sphere. The network constitutes a primary character (the caregiver), responsible for original content. Caregivers will ideally be trained on social media (and Web 2.0 technologies) by a training institution (in the case of Kayamandi, this is RLabs). Accounts will be moderated through the M-care repository/pipeline, developed perhaps by a university institution (here, CPUT) and monitored by a selected NGO (possibly Stellenbosch Hospice in this case). Suitable content will be converted into educational material – here, +27, a partner of the Kujali project – where possible and necessary.

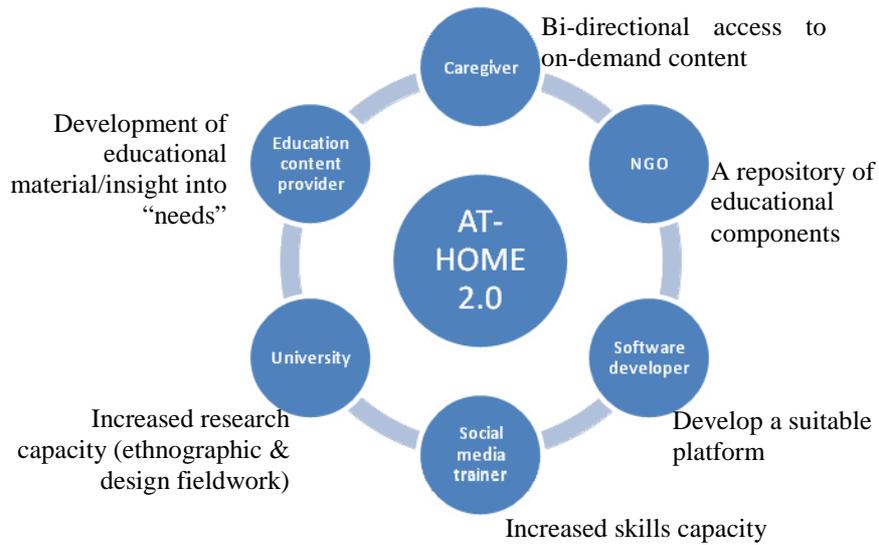


Figure 3: Collaboration model with stakeholders and their potential inputs in terms of the proposed ubiquitous community M-care Educate Repository

Each stakeholder will have varying roles and inputs throughout the Model:

| Stakeholder | Role | Content | (Ideal) Requirements |
|---|---|--|---|
| Caregiver | Produce blogs, wikis, podcasts, etc. | Original content (“raw” accounts, stories, etc.) | Must have access to a mobile phone; be willing to experiment with alternative ways to share experiences; and be interested to access edutainment material on mobile phone. |
| | Consumer Provide feedback | Edutainment content | |
| Translator | Translate or transcribe original content into relevant content | Original content Translated content | Must have sufficient understanding about the producers of content, as well as local context. This person must be able to moderate the original content for suitability. |
| Educator (usually an NGO working in poor communities) | Ensure that content is appropriate for training (select & moderate) | Relevant translated content Moderated suitable training content | Must have sufficient understanding of education needs of caregivers. They must be qualified in healthcare services and as educators. They must understand the care education pipeline well enough to disseminate training material and to process any feedback. They must be able to moderate content for suitability (as educational content). |

Table 2: Roles and activities for each stakeholder in the Collaboration Model

| Stakeholder | Role | Content | (Ideal) Requirements |
|--|---|--|--|
| Content developer (producer, director, coordinator, audio engineer, writers, visual communicators) | Convert moderated content into edutainment content | Suitable training content Edutainment content | Must have sufficient understanding of the suitability of the content for the target audience (contextual, e.g., culture, language, etc.). Must be able to develop suitable characters and story lines in venturing toward successful educational outcomes. |
| ICT developer | Design, develop, deploy and maintain the platform for the care education repository | Database to contain the different levels of content | Must have sufficient understanding of caregiver needs; to design and develop a care education repository to: capture caregivers' stories and accounts of care activities; facilitate the translation, transcription and moderation of these stories and accounts; select and display edutainment material on mobile phones and websites; facilitate the feedback from caregivers and other stakeholders. |
| Social media trainer | Train caregivers on the use of social media to capture their stories and content, as well as to access relevant edutainment content | Original content Edutainment content | Must have sufficient understanding in training people that are IT illiterate or semi-literate – caregivers are mostly adults with limited formal school education. They must be familiar with the platform in order to facilitate the publishing of caregivers' stories. |
| Researcher | Investigate the design, development and use of the m-care education repository | All content as well as the actual repository and methods | Must have sufficient understanding of care service provision and the context in which this takes place. |

Table 2: Roles and activities for each stakeholder in the Collaboration Model (cont.)

In light of the analysis throughout, it is evident that AT-HOME 2.0 should be relevant and contextual, by accounting for varying language and literacy levels, as well as other local factors within the care environment. Moreover, the implementation of this model should consider a number of critical elements: availability of mobile phones; type of infrastructure required, e.g. availability of electricity; social media training; financial investment; and, perhaps late commercialisation. Indeed, the ultimate goal of the proposed framework is its practical adoption in resource-limited settings. AT-HOME 2.0, albeit in a conceptual stage, necessitates a localisation of social and cultural dynamics, and must consider stakeholders at the grassroots in its implementation. This localisation does not concern the offhand implementation of

edutainment material, content repositories, and/or collaboration models. The value is rather in effecting the proposed *methodology* in response to the local context. Herein lays the crux of AT-HOME 2.0, where the outcomes of collaboration around educational content outweigh and supersede the outputs of fixed, narrow models.

6 Concluding thoughts

“The information and learning needs of family care givers and primary and district health workers have been ignored for too long. Addressing this need by increasing the availability and use of relevant, reliable health care information has enormous potential to radically improve health care world wide” [Pakenham-Walsh 2009]

This paper intended to outline and describe some of the foremost issues in home-based healthcare in a South African community. Kayamandi, an informal settlement on the outskirts of Stellenbosch (Western Cape) was presented as a case study. This was (in certain instances) augmented by data from another care HBHC service area in Athlone. Kayamandi residents are subject to severe poverty, unemployment, crime, and a lack of basic resources. This community is also characterised by a large number of individuals in need of serious social, physical, and emotional support. Home-based healthcare has become a necessity here, formally provided by Stellenbosch Hospice, a nongovernment organisation. The contexts for care in this region are volatile. Patient environments are extremely unstable, often disrupting the care process itself. Caregivers are burdened by emotional, psychological, and physical distress, and the additional responsibility of being unofficial community counsellors or spokespersons. Moreover, the rudimentary style of patient data collection adopted by carers perturbs the flow of information in the care network and compromises the value of data for coordinators.

Clearly, caregivers and –receivers function in a cycle of mutual isolation, where both parties fight to provide and access care. This cycle is especially characterised by an unstructured, sporadic approach to information (patient data) collection and dissemination. This aspect is further inflated by caregivers’ lack of access to information and educational facilities. The possibility for innovative technological measures arises, especially in reinforcing current systems of informational and educational access and use. In light of some of this context, the authors set out to conceptualise a collaborative training framework: AT-HOME 2.0. This framework architects a new approach to creating and disseminating original educational content. Its key premise is participatory interaction, whereby stakeholders from across the HBHC landscape partake in developing content clips, relevant to the processes of care.

AT-HOME 2.0 takes caregivers as the primary content producers in the HBHC domain. As a community of practice, caregivers are used to sharing experiences and emotions between them. With the addition of Web 2.0 and social media technologies, they are now able to simultaneously create and absorb new educational accounts. These may consist of stories, advice, or recommendations regarding the general practice of home-based care. The repository with its content threads could become a valuable resource for caregivers that want to access relevant and appropriate content ‘on-demand’ – that is, anyone, anywhere, anytime. It will become invaluable for researchers in investigating aspects that may inform educators and care service

providers alike. This may eventually contribute to the strengthening of the general care service.

Furthermore, the competitive advantage of this solution is that it may offer on-demand content that encourages active learning. Caregivers are now able to be producers as well as consumers of knowledge – ultimately empowering them by allowing for both personal innovation, and recognition for tacit in-practice knowledge. AT-HOME 2.0, and particularly the M-care Educate repository, brings caregiver inputs to the forefront and allows for a cross-platform dissemination of care information. Yet, the described contexts (in Kayamandi) may obstruct the design, integration, and adoption of the proposed ‘solution’. It is thus critical to structure a participative approach, where stakeholders direct the flow of activity, and determine the outcomes of said endeavour. There are, of course, obvious concerns with this framework, including questions of ownership, business modelling, and commoditisation. It is hoped that future research may focus on refining and technically implementing AT-HOME 2.0.

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