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# Information Needs in Home Based Healthcare in South Africa

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## Abstract

*Home based health care (HBHC) is advocated by the WHO "to ensure better accessibility to effective and efficient health care in community and home-settings to improve health and well-being, and contribute to morbidity and mortality reduction". In South Africa the government and many other role players see an increasingly important role for HBHC. Many researchers believe that the evolution of HBHC will follow the socio-technical network evolution. There can be no doubt that the focus is on using information and communication technologies (ICT) to implement HBHC solutions. The objective of this paper is to provide a rich picture of the current situation and needs for improvement in HBHC in South Africa today through descriptive research in one specific case. The longer-term purpose is to identify pain-points that require socio-technical solutions, including but not exclusively ICT-supported solutions.*

***Keywords:***

Home nursing, Home-based healthcare, Socio-technical systems, Landscape modeling.

## Introduction

A few decades ago house calls by general practitioners, midwives and certain other medical professionals were far from uncommon. Indeed, in developed countries they were considered the norm. As the burden of illness increased globally, and put increasing pressure on health professionals to speed up their patient throughput, the time (and later expense) of visiting patients at home became prohibitive. For instance Meyer and Gibbons [1] reported that even a decade ago in America house calls were on the decline.

Comprehensive community and home based health care (CCHBHC) is defined by the WHO as "…an integrated system of care designed to meet the health needs of individuals, families and communities in their local settings" [2]. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of HBHC is "…to ensure better accessibility to effective and efficient health care in community and home-settings to improve health and well-being, and contribute to morbidity and mortality reduction" [2].

The report further states that many of the recent efforts to establish home based health care (HBHC) initiatives have been driven by specific emergencies, in particular the HIV/AIDS pandemic [3]. Other major drivers of HBHC are maternal health care and geriatrics, and specific outbreaks of illnesses such as TB and cholera, although poverty driven interventions such as famine and drought relief tend not to fall under the same banner as HBHC. The WHO [2] also report that very often HBHC efforts are not derived from government controlled medical efforts, but rather from various NGOs, religious groups, international donors and even from the communities themselves.

As the burden on health services increases, these services will be pressurized to re-invent themselves [4]. Many researchers (e.g. [4-6] and others) believe that the evolution of HBHC will follow the socio-technical network evolution, as originally outlined by Kling and Lamb [7]. Coiera [4] proposes four "rules" to help guide the design of new socio-technical systems in health services, namely "(1) Technical systems have social consequences; (2) Social systems have technical consequences; (3) We don't design technology, we design socio-technical systems; (4) To design socio-technical systems, we must understand how people and technologies interact". This reinvention is not just limited to under-developed environments. Even such prestigious institutions as the Johns Hopkins Home Care Group (part of the Johns Hopkins University) are having to rethink their approach to this issue [8].

Bentur [9] states that different health care systems have different objectives with respect to the extension of health care service to the home. Amongst these are "providing services to small populations dispersed over large geographical areas, improving access, easing the burden of hospitals and responding to patient preferences." Cost containment without loss of quality of care remains a priority, however.

Although much work has been done in America and Europe on home based health care, it is clear that much benefit will be felt by applying these principles to under-developed countries, where resources of all kinds are stretched the thinnest. Epping-Jordan et al. [10] cite problems identified in the Caribbean, India and South Africa in this respect. Lehoux et al. [6] raise the issue of "information infrastructures" (II), and countries such as South Africa, being on the wrong side of the "digital divide", are particularly susceptible to the issues of scalability.

A number of models for addressing HBHC have already been documented. Ncama [3] cites cases from Malawi, Botswana, Zimbabwe and South Africa concerning HBHC for families living with HIV/AIDS. She mentions some of the many role players in HBHC, and the confusion amongst them as to what their various roles are, or should be. The Department of Health, NGOs, “concerned citizens”, religious bodies, and communities themselves have all, in various places and at various times, started HBHC initiatives.

Technology usage has also come under scrutiny. Although Shaibu [11] documents a non-technology driven HBHC situation in Botswana, there can be no doubt that the focus is on using information and communication technologies (ICT) to implement HBHC solutions. Kling and Lamb [7] describe research into the use and acceptance of medical technology in home care settings. Their findings indicate that, whilst such technology can prove to be useful, it isn’t necessarily so, and can have a negative impact of raising false, or at least dubious, hopes amongst the recipients. Lehoux et al.’s issue around scalability is largely reliant on the implementation and availability of ICTs [6].

Access to technology is not the only limiting factor in a South African context. Given that most HBHC will be implemented in the most chronically poor areas, concern will have to be given to the physical security of the technology. Anything requiring the use of a standard PC or mobile phone is likely to suffer from problems of theft. Anything requiring stable power will be subject to the country’s continuing national power crisis, and any attempt to overcome this using battery or generator backed equipment will run into the aforementioned security problems.

## Research objective of the paper

The objective of this paper is to provide a rich picture of the current situation and needs for improvement in HBHC in South Africa today through one specific case. Within the socio-technological paradigm [4] [7], we must start by developing an in-depth understanding of the social context of HBHC in the case. Thus at this stage the emphasis is on descriptive research. However, the longer-term purpose is to identify pain-points that require socio-technical solutions, including but not exclusively ICT-supported solutions.

## Materials and Methods

### The Socio-Tech SA project

The study was conducted within the *Socio-Tech SA* project (Made-in-South Africa socio-technical methods and education for local software industry to contribute to socio-economic development) funded by the South Africa – Finland Knowledge Partnership programme (SAFIPA). The purpose of the project is to develop socio-technical information systems development methods for South African software practitioners to contribute to socio-economic and human development in South African communities. Home cased healthcare was selected as the case environment where existing methods will be tried and further developed according to local needs.

### The data collection process

Several unstructured interviews were conducted, initially with HBHC coordinators and managers, to obtain an understanding of the HBHC landscape in this specific context. This was followed up with interviewing care givers (providing the home-care service) and nursing sisters (who are assessing and managing the patient’s care process). At the same time relevant literature was reviewed to establish what was found in other similar studies. A video recording was made of a care giver visiting patients at their homes to observe the entire care process. This allowed us to observe many other activities that the care giver performs that may not have been mentioned in the interviews. The relevant documentation, such as the care plan and care reports, was also studied.

The emphasis for this study and therefore for the data collection, is on the care service path but from the specific perspective of the care giver, patient and primary supporter. The roles of the professional healthcare professional, facility and authority are all to support the care giver, patient and supporter, i.e., those in the communities.

## Results

In this section the results of an initial exploratory HBHC study are given. In order to obtain an understanding of home-based healthcare in South Africa a community in the Western Cape was selected. This community suffers from many negative socio-economic factors that impact the well-being of citizens in such communities. They rely on HBHC to deal with many conditions that are beyond the care service provision of public healthcare. NGOs, NPOs and other interested organisations have taken the responsibility for providing home-care services. These organisations rely on funding organisations or otherwise have to raise their own funds to support an ongoing care service. They report to the Depart of Health, their governing bodies, (in this case the South African Hospice Board) and the respective funding organizations.

The NGO investigated is responsible for the home-based care service to a number of communities around Stellenbosch, a town in the Western Cape province of South Africa. They employ qualified nursing sisters as the healthcare professionals responsible for supervising the care givers; assessing the patients/clients who need home-based care by managing the care plan; and finally taking the responsibility for summarizing the data about the care service for reporting purposes. Healthcare professionals are important stakeholders in these communities serviced by the NGO and are responsible for the care plans of the patients/clients and are familiar with the condition of the community in general. They for example know what are the major problems experienced in the communities and are the first to pick up trends. They rely heavily on information about the care visits and spend too much time processing the data which is still collected from paper patient/client folders, daily and monthly care reports.

The care givers themselves are generally from the respective communities and have only a basic training in home-based healthcare. They are responsible for the ongoing daily care provision to patients/clients according to a schedule compiled by the responsible sister. Their training is of a very elementary level and they can only provide a basic care service. They often have to provide this service in unfavourable conditions where both their safety and comfort is often compromised. Their commitment and dedication is extraordinary but they feel that the recording of data is taking up too much of their time and that this takes their attention away from their patients.

The actual care service at the home of the patient/client is often attended by many family members and other supporters involved with the patient/client and it is clear that they are actively involved in not only the visit but also taking care of the patient/client on an ongoing basis. The care givers also observe the condition of the home, the availability of food and other supplies, and whether children are looked after. Care givers are well respected and accepted in the communities although in some cases they are refused entry to homes where patients/clients fear that they may be stigmatized, e.g. HIV/AIDS is still a very sensitive issue in many communities where much folklore about this condition still exists. This also applies to some psychiatric conditions. It is therefore clear that the primary care giver, family members, friends and neighbours are important and active participants in a home-based care service. Many of these supporters are ill informed about the condition of the patient and as a result are ill-equipped to care for the patient.

Patients are often referred to as clients since their home care needs may not result from a medical condition, e.g., malnutrition through poverty. In poorer communities their only access to a care service is overcrowded public health facilities which are often at a far distance from their home. The condition of their homes is often inadequate and they do not have the basic necessities and are often not protected from the outside elements. The home-based care service is an absolute necessity for the patients/clients in the poorer communities to provide them with access to a much needed healthcare service. They are often not well informed about their condition and may not be able to assist with administering their own care. Many are illiterate and cannot read the instructions for their medication.

Following from the above findings the landscape model was used as a basis to depict the home-based healthcare service path and the different stakeholders' involvement. The main emphasis of this study is on the needs of the care giver, the patient/client and supporters from the community. Specific research questions were derived from the above to direct further studies to incorporate ICT into an improved home-based healthcare service model to address the information needs. In order to ensure that the different stakeholders' needs are met any design and development of systems with ICT components need to be done with the active collaboration of the stakeholders. The landscape model is an important aid to unpack the complexities around home-based healthcare. It is important to consider the context of home-based healthcare because the different communities are affected by factors that related to their contexts. The context of the HBHC case is depicted in the canvas part of the landscape model illustrated in Figure 1.

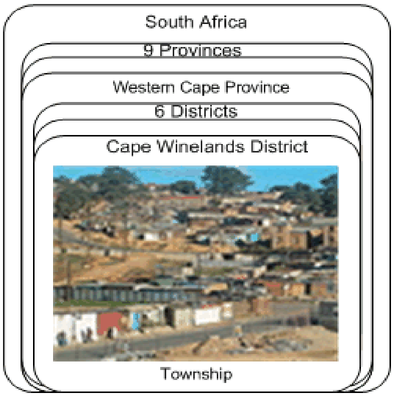

*Figure 1 – Context of the Township*

In Figure 2 HBHC from the patient's perspective is depicted. Most organizations providing a HBHC service prefer to refer to clients rather than to patients. Although clients sometimes live alone, they live mostly in dwellings with many other relatives or other citizens. In order to address the information needs of the patient the indicated questions need to be answered.

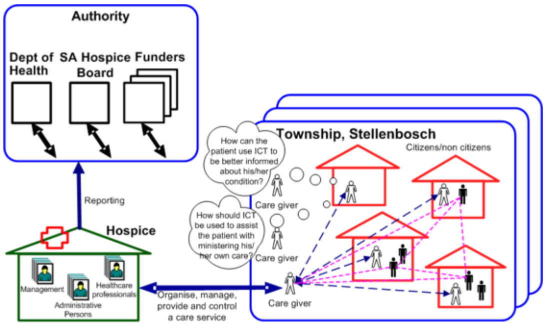

*Figure 2 – HBHC from a patient/client perspective*

Although the individual members in a community can be referred to as citizens it is also the case that in many communities citizens from other countries also find a home. In some cases the presence of these refugees causes tension in the community where resources are already stretched to a limit. Although there is already a sense of caring for each other present in the community this often is without sufficiently being informed about the condition of the person being cared for and also without knowing who else experience a similar situation. An example is when a person is diagnosed with TB and receives care for it; the supporters of that person may want to know more about TB in order to deal with their perplexities about the condition. Persons fulfilling the role of supporter can gain tremendously from being part of a supporting network where information and experiences can be shared amongst persons dealing with similar situations. In Figure 3, the shaded persons represent the supporters and the dotted lines indicate how such a network can be formed aligned an interest in a particular condition or issue. The information needs for the primary care giver are to support them when caring for the patient or for interacting with each other and the care giver.

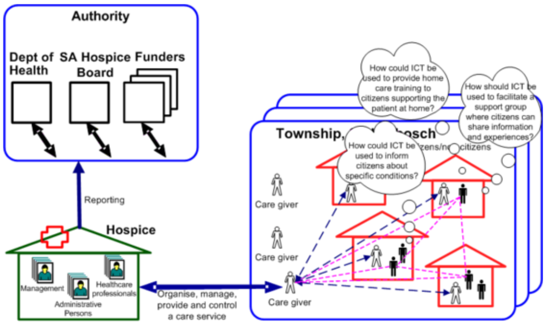

*Figure 3 – HBHC from a primary care giver perspective*

The care giver's information needs are indicated next as illustrated by Figure 4. They obtain the details for the patient/client's care from the care plan which is kept at the home of the patient. The care plan is compiled by the healthcare professional who does the initial assessment of the patient/client and based on the care needs devise a suitable care plan. They record the details of what they have done to the care plan and write the visit details on the daily care visit report. The patient/client has to sign the report and in the case of illiterate persons to make an "X". The care givers communicate with healthcare professionals to ask for advice when the care plan is not specific enough or the patient has developed another problem. This is not always possible since not all care givers have access to a mobile phone. They meet once a month to give feedback to the NGO and discuss common problems. Care givers not only rely and information to care for the patient but at this stage the manual recording and summarising of data waste much of their time.

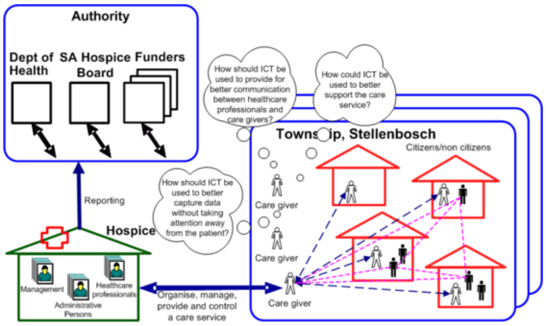

*Figure 4 – HBHC from a care giver perspective*

Facilities rely on data of good quality in order to manage the home-based care service. They need to know who are the patients and care givers; details about the location of the patients/clients and their care needs as well as availability of care givers are important to assign care givers and to schedule care visits. They need to know how many patients they have in the different areas; what types of care are required; any trends; etc. The paper care plan folders are collected from the homes and brought to the NGO every three months to be updated before being taken back to the homes. A copy is also kept at the facility which means that data is duplicated.

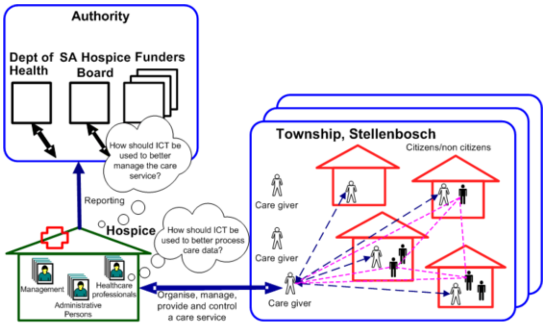

*Figure 5 – HBHC from a facility perspective*

Not only are organisaions, e.g., NGOs, hospices, etc., responsible for the home-based care service in the communities but are they also accountable to the different authorities. They need data of good quality to report to HBHC situation to the different authorities and each wants it in a different format. Many hours are used to capture, transfer, process, aggregate and summarise data. The primary data is manually collected from the different paper reports and entered into the computer which currently uses spreadsheets to manipulate the data. Little of this manipulation is automatic and the administrator has to still transfer data to the different sheets. Stats are not compiled from the individual source data but instead the aggregated figures are calculated manually and then these are entered in the computer. There is currently no electronic patient record system in use.

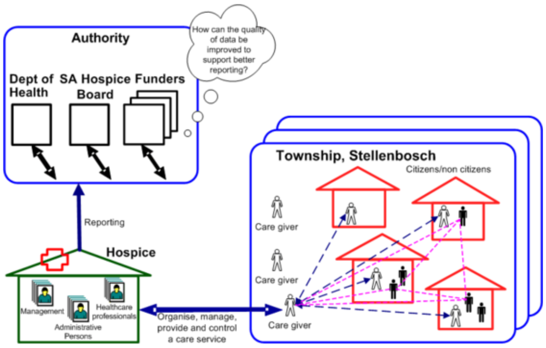

*Figure 6 – HBHC from a authority perspective*

The current focus of this study is not on the authority's information needs but it already follows from the other perspectives that if their information needs are addressed then ultimately the authorities could also gain. Data of a better quality will improve reporting of home-base care cases, issues, etc. which ultimately enable authorities to better respond to specific community needs. It will also be possible to identify trends in time to cater for a specific condition, e.g., the number of swine flue cases will indicate whether there is an urgent need for inoculation and to put other preventative measures in place.

## Discussion

It follows from the above that HBHC is an important and necessary service to citizens in communities that have a need for a healthcare service for citizens not having easy access to public healthcare facilities. It is also clear that often NGOs take the responsibility for delivering such a service. The five landscape models depicting the main perspectives show the care service paths and questions that represent the stakeholders' information needs. The HBHC landscape is even more complex than anticipated and the introduction of technology solutions will add to the complexity. The results confirm that a comprehensive community and home based healthcare (CCHBHC) system is required that will have social and technical components [2]. Any design for such a system will have to follow the four rules [4] for socio-technical design, accepting that social and technical systems have consequences for each and that it is important to understand how people and technology interact. The CCHBHC system should provide for a care service that addresses the needs of the entire care path. In order to obtain a better understanding of how stakeholders interact with technology this interaction where the social and technical worlds overlap need to investigated.

The proposed socio-technical approach provides for close collaboration between the users and developers of a system with both social and technical components. It is also necessary to consider all the other social aspects in addition to where the users interact with technology to cater for an improved care service provision.

## Conclusion

The importance of HBHC is not only confirmed but in fact emphasized. In countries where there is severe pressure on an over-burdened healthcare system such a service is crucial and necessary. This may be in contrast with affluent countries where the emphasis is more on comfort for care at home. The stakeholders involved in HBHC are already committed and therefore the only possibility to improve the care service is to consider technology solutions to address their information needs. Further research should be directed to address these needs.

## References

[1] Meyer, GS, Gibbons, RV. House calls to the elderly: a vanishing practice among physicians. N Engl J Med. 1997;337:1815-1820.

[2] WHO. Comprehensive Community- and Home-based Health Care Model. World Health Organisation SEARO Regional Publication. 2004:(40).

[3] Ncama, BP. Models of community/home-based care for people living with HIV/AIDS in Southern Africa. J Assoc Nurses AIDS Care.2005;16(3):33-40.

[4] Coiera, E. Four rules for the reinvention of health care. BMJ. 2004;328:1197–9

[5] Sahay, S, Walsham, G. Scaling of health information systems in India: challenges and approaches. Information Technology for Development. 2006;12(3);185–200.

[6] Lehoux P, Saint-Arnaud J, Richard L. The use of technology at home: what patient manuals say and sell vs. what patients face and fear. Sociol Health Illn. 2004;26(5);617–644

[7] Kling, R., and Lamb, R., IT and organizational change in digital economies: a socio-technical approach. In E. Brynjolfsson & B. Kahin (Eds.), Understanding the Digital Economy. Data, Tools, and Research. The MIT Press, Cambridge, MA, 2000.

[8] Scott, L.S. Phoenix and the leaders: the transformation of an academic health system–based home care provider. Home Health Care Management & Practice 2003;15(4);284-290

[9] Bentur, N. Hospital at home: what is its place in the health system? Health Policy 2001;55;71–79

[10] Epping-Jordan JE, Pruitt SD, Bengoa R, Wagner EH. Improving the quality of health care for chronic conditions. Qual Saf Health Care. 2004;13;299–305

[11] Shaibu, S. Community home-based care in a rural village: challenges and strategies. J Transcult Nurs. 2006;17(1);89-94

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