



Cape Peninsula
University of Technology

**FORMATS FOR STORYTELLING BY CAREGIVERS FOR SHARING
KNOWLEDGE IN HOME-BASED HEALTH CARE**

by

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DECLARATION

I, **Michael Ebere Chidubem**, declare that the contents of this thesis represent my own unaided work, and that the thesis has not previously been submitted for academic examination towards any qualification. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.

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Date

ABSTRACT

Home-Based Health Care (HBHC) is the provision of health services and social assistance to individuals in their homes. It is an indispensable service to communities in need; presently in South Africa, these health care services are provided by local non-profit and non-governmental organizations. It is mainly targeted at poverty-stricken and under resourced communities and is an important aspect of healthcare in South Africa. A lot of communities in South Africa are still under-resourced and live in impoverished conditions. This is reflected in poor living standards characterized by unemployment, uneasy access to basic amenities, unequal distribution of wealth, poor medical facilities in rural communities, etc. The prevalence of the HIV/AIDS endemic has also worsened the situation. However, the South African government has constantly supported initiatives to enhance better healthcare in rural communities.

This research presents a case study of caregivers working in Du Noon, an informal settlement in Western Cape, South Africa. Du Noon is overpopulated and home to lots of foreigners who have migrated in search of better living standards thus stretching an already over-burdened community. Naturally, this development supports poor health practices which encourage the spread of diseases within the community. Health facilities do not sufficiently cater for the ever-increasing healthcare demands and as such lots of people depend on NGOs such as SALT (Sharing Abundant Life Together) who through the help of caregivers and community workers have been providing for some of the healthcare needs of the Du Noon community since 2000.

Findings reveal that although caregivers in this community have lots of stories to share about their work practices, they do not have a platform to share these stories. This research focuses on identifying processes involved in capturing these stories and moderating them into educative and entertaining visual contents for the purpose of sharing the stories within the community.

Using qualitative research methods, empirical and field study provides the needed data as well as understanding of the multi-dynamism of this community. Data analysis is done through interpretive methods for the purpose of understanding the data collected and analysed during the research process. Finally, as a possible research contribution, the research concludes by examining how other technology can enhance the storytelling experience using interaction design methods that enables caregivers participate in the entire design process. Suggestions are also given as to direction for further research within the subject area

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GLOSSARY

Terms/Acronyms/Abbreviations	Definition/Explanation
ARV	Anti-Retro Viral
Blog	Short for Weblog, this is most often a personal log similar to that entered into a diary which is published entry by entry online.
Caregiver	Semi-trained community health care worker
CCHBHC	Comprehensive Community and Home-Based Health Care
CPF	Community Policing Forum
CPUT	Cape Peninsula University of Technology
DSR	Design Science Research
eHealth	Electronic health
FID	Faculty of Informatics and Design
HBHC	Home-based health care
HIV/Aids	Human immunodeficiency virus/acquired immunodeficiency syndrome
ICCC	Innovative care for chronic conditions
ICT	Information and communications technology
INDEHELA	Informatics Development for Health in Africa
ISD4D	Information Systems Development Approach for Societal Development
IT	Information Technology
IxD	Interaction Design
MDG	Millennium Development Goals
mHealth	eHealth which uses mobile technology
Mobile phone	Also known as “cell phone” in South Africa
NGO	Nongovernment organisation
NMMU	Nelson Mandela Metropolitan University
PDA	Personal Digital Assistant
PHC	Primary Health Care
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
RDP	Reconstruction and Development Programme
SAFIPA	South Africa – Finland Partnership
SALT	Sharing Abundant Life Together
TB	Tuberculosis
UCD	User-centred design
UI	User Interface
UN	United Nations
UNICEF	United Nations Children’s Fund
UNSD	United Nations Statistics Division
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Healthcare delivery practices have shifted considerably towards homecare; this is because of better possibilities for managing chronic care, controlling health delivery costs, increasing quality of life and quality of health services and the distinct possibility of predicting and thus avoiding serious complications (Maglaveras et al., 2002). According to the World Health Organization, (WHO, 2004), Home-Based Health Care (HBHC) is the provision of health services and social assistance to individuals in their homes. It is an essential healthcare service to communities in need. Presently in South Africa, these healthcare services are provided by local non-profit and non-governmental organizations (Van Zyl, 2010). It is mainly targeted to poverty-stricken and under resourced communities (Botha et al., 2008) and is an important aspect of healthcare in South Africa (Gwyther, 2008).

A clearer direction for this research became apparent after the Faculty of Informatics and Design, IT Department (ITD); Cape Peninsula University of Technology (CPUT) hosted the Informatics Development for Health in Africa (INDEHELA) conference in November, 2011. The conference tagged “ISD4D: A Holistic Information Systems Development Approach for Societal Development” aimed at encouraging research into developing a comprehensive approach to socio-technical IS development that contributes to societal development (The ISD4D approach) for technology providers and service (particularly healthcare) providers in Africa. A Field visit to Du Noon, a Western Cape community in need provided a platform for possible collaboration with caregivers and SALT (Sharing Abundant Life Together), an NGO who with community clinics and hospitals have been carrying out community services in Du Noon, Joe Slovo, Atlantis and Table View since 2003. The visit also provided a first-hand reflection of the community with the aim of carrying out research and hopefully implementing practical and feasible technologies that could provide ICT solutions to this community.

The objective of this research is to co-design with caregivers (as the mediators between patients and care), a contextually relevant storytelling platform for the purpose of sharing. Since design is seen as a knowledge generating activity and design activities as part of a research process yields potentially valuable resource for science (Hoffman, Mentis, Peters, Saab, Schweitzer, & Spielvogel, 2006), this research sees designing a storytelling platform for caregivers as a tool for promoting better health practices in the community. The research also aims at exploring how

Interaction design methods using storytelling as digital medium can be leveraged in a home-based healthcare environment as a means for caregivers to share experiences. This research is a qualitative study

1.2 Background to the research problem

With the increasing pressure created by HIV/AIDS, home-based healthcare has become a vital counter-service (Van Zyl, 2010). This includes support groups for HIV/AIDS patients, awareness drives on drug and substance abuse, and home-based healthcare provision for chronically and terminally ill individuals (Aidsbuzz, 2009). The South African government has made efforts in combating these diseases by implementing initiatives such as the HIV counselling and testing campaign (HCT), (SANAC 2010). However, Nankobogo (2007), asserts that the fight against diseases is not for the government alone; civil society has a major role to play since the epidemic could undermine the collective development effort. In staging this effort, the partnership between government, private sector, and labour bodies is critical.

The World Health Organization (WHO) (2004) proposes HBHC as a palliative solution which could provide access to basic healthcare facilities in poor communities. Botha et al., (2008) wrote that in South Africa, HBHC delivers primary healthcare to under resourced communities; greatly relieving the public health system and communities by increasing communities' accessibility to healthcare service at no additional cost to the citizens. Gwyther(2008) notes that as a result of the over-burdened health facilities and the need for wide spread relief for various diseases such as TB and HIV/AIDS in South Africa, primary health care (PHC) is being delivered more frequently by caregivers based in the communities in need. He adds that these caregivers are usually managed by nongovernmental organizations (NGOs) and rely on governmental, international and private funding.

Delen, (2011) identifying the importance of caregivers and HBHC writes that "Home-based health care is an essential strategy for the support of many people suffering from TB, HIV/Aids and other chronic conditions in South Africa." A caregiver's duty is not restricted to basic nursing support like observing the taking of medication, wound care, physiotherapy and post-discharge care, rehabilitation and frail care, but includes provision of emotional support and advice about good health practices with patients and their families (Gwyther, 2008). WHO (2004), proposed a framework that is more inclusive of the patient and family, health care organization and community at policy levels. Byrne & Sahay (2007) suggested a "flexible but comprehensive platform on

which to redesign health systems that can provide support and sensitivity to local resources and demands”

In supporting an effective health education and public health efforts, there is need to inform and educate the public about health issues through persuasive health campaigns. Storytelling has been explored as a helpful tool in medical education contexts owing to its ability to be memorable as well as inspire reflection (Gray, 2009). Furthermore, stories tend to be familiar, centrally important to communication, require contemplation, evaluation and reflection. They are memorable because they are familiar, and resonate with one’s own experience (Gray, 2009). Gray (ibid.) explains that human beings are storytellers and storytelling by patients in clinical encounter by way of communicating health information could help medical practitioners with providing relevant care to the patients. Similarly, storytelling by patients could offer constructive meaning and health details leading to valuable diagnosis. Furthermore, research by the Kujali Living Lab (Delen, 2011) show that caregivers have stories to share about their work experiences and have expressed their willingness to tell stories about their care activities. This research focuses on designing a platform that enables caregivers share their stories which in turn could promote information sharing.

The Kujali Living Lab, (CPUT) was set up in 2009 as a pilot for the “South African – Finland Partnership” (SAFIPA) Socio-technology for Africa project. The term “Kujali” is Swahili word which translates “*to care*”. The primary focus of Kujali Living Lab includes developing Information and Communication Technology (ICT) solutions for poor and under-resourced communities with the aim of promoting better healthcare and well-being. Most Kujali projects respond to contemporary trends where technology such as Personal Digital Assistant (PDA) plays a major role in healthcare. The Kujali Living Lab, comprising of students from the faculty of informatics and design, CPUT focuses on designing and developing technological solutions that can be relevantly deployed in HBHC. Between 2009 and 2010, student interns at Kujali Living Lab embarked on their first major research project. According to Delen (2011), the research team was made up of IT and design students who examined the HBHC from different areas of specialization and various perspectives. This was the first cross-disciplinary study in the Faculty of Informatics and Design, CPUT. Because Kujali focuses on communities in need, the team went to Kayamandi, a community in need located in Stellenbosch. In order to understand the dynamism of this community, it was necessary to collaborate with the Stellenbosch Hospice in Kayamandi who have been actively involved with HBHC in the area.

The Stellenbosch Hospice, through their caregivers, provides care to the Kayamandi community. The Research team conducted interviews with caregivers, patients/clients, nurses, and coordinators and equally accompanied them in their daily '*care journeys*'. Among other things, one of the findings was that caregivers through their interaction with patients over time had a lot of stories to tell about their care practice. Findings also reveal that these stories are not consciously collected for retrieval or sharing. These developments guided the researcher's thinking that stories by caregivers could be collated, moderated and converted to edutain materials which can later be distributed within the HBHC for the purpose of knowledge sharing and learning. Thus, with this background, the researcher started identified a researchable problem.

1.3 Statement of research problem

Citing Peffers et al., (2007), Ellis & Levy, (2010) pointed out that the identification of the problem motivating the study should be the first step in design and development. This is important because in order for design to offer a potentially meaningful contribution, the problem must be one that can be addressed by some form of human creativity or interaction.

HBHC in under-resourced communities is known to be responsible for the delivery of care at the homes of the patients. Semi-trained caregivers are usually assigned by Nurses and in most cases, a hospice to visit patients in their homes. Their duties include monitoring and reporting of patients' condition to the hospice. However, in actual practice, caregivers are usually involved in many other forms of care provision activities which are outside the scope of healthcare activities, e.g. cleaning houses, cooking food, washing and sometimes bathing patients who are too weak to fend for themselves, etc. These care activities sometimes give rise to emotional attachment between caregivers and their patients where the caregiver is prepared to give more of their time in ensuring that the patient is comfortable and well taken care of. Over time, caregivers through interaction with patients gain more experiences and knowledge about their care practice.

However, the sharing of experiences and knowledge by caregivers in the HBHC community is underexploited; there is potential in developing platforms for caregivers to share stories about their knowledge and experiences.

1.4 Research question

Having identified the problem of unavailability of a platform that supports storytelling by caregivers in Kayamandi, it became necessary to consider addressing this problem as the research area changed focus to a new community. The purpose for adopting a new research community by the researcher was because most of the student interns who conducted the initial research at Kayamandi have completed their research activities. Furthermore, the problem of distance was a major concern for the researcher as Kayamandi is farther in distance and this could have a negative effect on the research process. It became necessary to focus on Du Noon, a community closer to the researcher. Although findings from Kayamandi provided a direction for this research, the researcher had to validate happenings in the new community to ascertain similarities and differences. This research will focus on activities by caregivers in Du Noon, another under-resourced community in need and will seek to address problems associated with unavailability of a platform that supports storytelling by caregivers within the context of the new community.

Preliminary inquiry by the researcher in the new community showed that there is no platform that supports storytelling by caregivers. With so many stories to tell about their experiences, the research considers the question of how to design a platform that supports storytelling by caregivers in the HBHC for the purpose of sharing.

Usually, the research question can be followed by several sub-questions in order to narrow the focus of the study while leaving open, a room for more questioning (Fraenkel & Wallen, 2006). These research sub-questions are listed below:

Sub-questions:

Table 1.1: Research Questions, methods and objectives

Research sub-questions	Research method(s)	Objectives
Why is a HBHC service and caregivers important to the community?	Literature analysis	To describe the relevance of HBHC in any community, especially, the poor communities as well as establish theoretical definition of caregivers as well as their roles in the HBHC Community

In what context and platform has storytelling been used for the purpose of sharing and disseminating information?	Literature analysis	Determine the impact of storytelling in some projects worldwide. To understand the relevance of storytelling as well as access its relevance to this specific project and community
What kind of knowledge and experiences are relevant to share among caregivers?	Field studies and interviews with caregivers and NGOs in the chosen research community.	To define what stories caregivers would like to share and how they can be converted to informational materials
How can platforms that enable caregivers share stories about their work practice be co-designed with caregivers?	Interviews with caregivers in the research community. Literature review	To find out which platforms are best for sharing information among caregivers.
How can a digital platform for sharing storytelling be designed for caregivers?"	Research-through-design. Interviews with caregivers in the research community.	To gain insight on the best digital platform to design for sharing among caregivers
How can existing facts, knowledge, experience and values by caregivers in the HBHC be converted into stories?	Interviews with caregivers in the research community.	To identify the process undertaken to gather caregivers' knowledge and experience, and the process of converting them into stories

1.5 Related Work/Current status of the research area

The World Health Organization (WHO) is constantly involved in the process of developing prototypes for community level health care that supports the poor and underdeveloped countries. One of such HBHC model is in South East Asia where the prototype developed is equally relevant for the study of HBHC in the Third World countries. Countries in the South-East Asia Region (SEAR) face major challenges emanating from increasing health care costs. This model known as comprehensive community- and home-based health care (CCHBHC) has been developed to ensure better accessibility to health and quality community health care (WHO, 2004). As a result, inaccessibility to health services by citizens has become an important focus area that the SEAR countries seek to address. In 2004, stakeholders in the medical institutions developed a collaborative initiative with a resolve to shorten hospital stay. Similarly, the increase in cases of non-communicable diseases and an ageing

population require long-term and chronic care; thus, for cost-effective care, a lot of health care interventions can be effectively carried out within the community or at home. For most people, receiving care at home is the setting of choice. Therefore, it has become necessary to extend healthcare services beyond the hospital walls, especially to those in under-resourced and underprivileged communities.

A similar framework has been initiated in South America. In Mexico, a framework for the innovative care of chronic conditions (ICCC) is being formulated. This initiative is aimed at patients who earn low to middle income. These patients who suffer from chronic conditions usually require periodic examination and treatment from a delegated health care provider. This framework comprises of a tripartite partnership between the care giver, the patient and the community (WHO, 2009). By extension, it also involves the various stakeholders at different levels in the health care system such as health care organizations, community, family members, financing as well as policy. There are also notable positive outcomes evidenced in projects such as the Veracruz initiative for diabetes awareness (VIDA) in Mexico where better quality care was achieved through collaborative problem solving by stakeholders and strengthening of best practices (Barceló et al, 2010). All of these are primarily targeted at people living in poor conditions from the grassroots.

The prevalence of mobile phones in rural communities could provide be exploited for the purpose of digital storytelling. A prototype for storytelling, developed in South Africa has already been tested in Kenya (Reitmaier, Bidwell, Marsden, 2010) with the objective of creating a mobile digital storytelling prototype to address the needs of the community. The software was tested at the Adiedo community situated close to Lake Victoria in western Kenya, about 80km south of Kisumu with an adult literacy rate of 58%, compared to 87% in Nairobi, Kenya's capital. This community is predominantly from the Luo tribe, with farming as their main economic activity. The ability to create and share digital stories proved to benefit members of this rural community as they engaged one another in sharing stories about their work activities. More information about this is discussed in Chapter 2 (2.5. Exploring Storytelling to promote learning)

Similarly, the field of Interaction design can provide a grassroots approach for designing platforms that can address various problems including the call for collaborative solutions in the HBHC. Interaction Design (IxD) is design with digital materials, shaping interactive digital systems, services and products with a particular focus on users and use experience; Löwgren, (2007). He also defined it as a field that explores new possibilities for human interaction and communication by means of

digital or digitally enabled artefacts and media. Peters, M., et al (2007) opined that *“Design is a knowledge generating activity and design activities as part of a research process yield a potentially valuable resource for science. This knowledge can take the form of identified design parameters, design criteria and criteria weighting, generation of design alternatives, and rules and guidelines for choosing between alternatives, among others.”* Interactive products are used in all walks of everyday life in today’s society. Consequently the scope of interaction design is very broad, including business software and interactive media as well as games and even interactive art installations. The interaction designer focuses on creating designs that deliver value for the user and a high quality use experience, through user-cantered, sustainable and socially responsible design. The scope of Interaction Design includes the incorporation of various forms of design and technological ideas aimed at achieving usability of an intervention. Storytelling combined with technology, to an interaction designer can function as a tool for interaction.

Sharing through storytelling has been recognized as critical to the ongoing development and growth of an organization. The act of sharing involves the transfer of knowledge from one person to another or among many people, thus adding value to organizational activities; the sharing of knowledge within an organization is a catalyst for growth within that organization. Mitchell, H. J. (2003). Carnerio, A. (2001) suggests that sharing should be encouraged because it is one of the most important tools of creativity and, intellectual assets, unlike physical assets, increase in value with use. Sharing knowledge can occur in various ways and constant effort to share knowledge should be stimulated within organizations because knowledge increases with constant use and sharing knowledge allows both parties not only to retain the resource but to amplify and expand it through the exchange process itself. (Allee, V. 1999)

Furthermore, sharing knowledge through storytelling about work practice within organizations could provide an opportunity to discuss practices that could direct the organization towards future development and growth. Clarke and Rollo (2001) support the notion that sharing provides an opportunity for knowledge generation through which the future success of organizations is determined; the act of sharing knowledge could develop a more dynamic environment that has the ability to create its own momentum that encourage value and positive outcomes for employees and the organization. The importance of knowledge sharing has been expounded by many authors in several analyses such as Davenport and Prusak (1998), Kluge, Stein, Licht (2001), Metcalf and Grant (2002), and Wright and Taylor (2003).

1.6 Research Design

This research is aimed at exploring how Interaction design methods using storytelling as digital medium can be leveraged in a home-based healthcare environment as a means for caregivers to share experiences and knowledge. The study will be qualitative in nature because according to Runeson & Höst (2008), a qualitative study in research is essentially useful in cases where information is work-oriented or place specific. Furthermore, qualitative research is also reliant on human opinion and qualitative feedback and this research is carried out in a specific home-based health care community where primary focus is on moderating caregivers' stories for the purpose of sharing.

This research also uses principles of research-through-design which involves the process of setting up a design project as a vehicle for generating knowledge. The concept of research-through-design is further defined as the process of exploring possible futures, starting from a situation at hand, intending to change the situation for the better by developing and introducing some sort of product or service, i.e., the concrete outcome of the design process. It involves considering practical and technical as well as aesthetic and ethical qualities as well as developing an understanding of the task – the goal of the design work in parallel with the space of possible solutions; Löwgren (2007). Further discussions on research-through-design and its implications on this research are discussed in Chapter 3.6.2. (*Design concepts, Research and Strategies*)

The International Council of Societies of Industrial Design (ICSID, 2002) defined design as a creative activity aimed at establishing multi-faceted qualities of objects, processes, services and their systems in whole life cycles. Design has to do with products, services and systems conceived with tools, organizations and logic introduced by industrialization. Furthermore, design is considered a key component of innovative humanization of technologies and the crucial factor of cultural and economic exchange. Design can also be seen as a knowledge generating activity whose activities as part of a research process yields potential and valuable resource for science.

The research methodology uses ethnography where data is derived from “*direct observation of behaviour in a particular group*”. (Babbie and Mouton, 2001 cited in Van Zyl, 2010). Participants were questioned by means of structured and unstructured interviews and further data was collected using video tapping, digital pictures, audio recordings as well as participant observation from field work.

Participant observation has been acknowledged as a “*defining method of research in cultural anthropology*” (Bernard, 1998 cited in Van Zyl, 2010).

Below is a summary and overview of the chapters in this research.

Chapter 1 will introduce the thesis by stating its objectives and structure. Here the research questions are posed together with the proposed methods for answering them.

Chapter 2 focuses on relevant literature as basis for a background understanding into health challenges in poor various countries. An overview of world policy to resolve these challenges will be discussed with emphasis on a South African perspective. Furthermore, definition of HBHC is provided as well as WHO’s classification of countries by income is examined. Literature is also provided on storytelling as a concept for knowledge sharing and Interaction design.

Chapter 3 will focus on identifying the researcher’s hypothesis, conceptualization, as well as the research design type. Here, the Epistemological and Ontological standpoints are discussed while design concepts and theories are identified.

Chapter 4 provides information on research findings and how qualitative methods were used for capturing data from the research community. Account is provided on research activities such as Interviews, voluntary work, participant and non-participant observation, iterative design and development activities as they occur in their natural contexts. Also in this chapter, information is provided on some social and natural gaps and how these gaps were negotiated.

Chapter 5 will discuss and interpret the research findings mentioned in Chapter 4. Discussion on the adopted frameworks for data analysis will also be explained in details and in context. Similarly, summary of key findings are provided while the objectives and relevance of the E2 Storyworld project, a direct product of this research is further elaborated.

Chapter 6 is the concluding chapter and presents a review of all the chapters. The research questions are revisited while a summary of the research contributions are provided. It also highlights the researcher’s reflection on the research process and how concepts from the field of interaction design (IxD) are used at various stages in the project. Finally, this chapter will include a proposal for further research.

1.7 Delineation of research

According to Hevner et al (2004), it is important for research to focus only on a specific subset of the overall process, problem or solution and Ellis & Levy (2010) believes that delineating a research as well as defining the intentional constrictions of the research is an important part of the research. This research focuses on the

design considerations for a platform that supports storytelling by caregivers in the HBHC but does not exhaustively look at the various care activities by other stakeholders in HBHC like the nurses or doctors; neither will it mention patient's involvement at the care process. The focus will be on the processes involved in capturing stories from caregivers with the purpose of sharing these stories with limited focus on the effectiveness of these stories in creating change in the community.

The research will describe the process of gaining acceptance in a very sensitive community dominated by female caregivers and people living with HIV for collecting stories. It will only identify basic stages in converting these stories into visual content as it is far too ambitious and time-consuming, to attempt to cover all aspects involved in designing and developing a designated or dedicated mobile application or web-based platform for sharing these stories; this research focuses on using existing technology such as mobile phones as a platform for storytelling and limited attention is paid to the user interface and user interactions with the platform.

Brief ethnographic study is used to understand and define some of the issues in the community, in order to help understand the environmental factors, the problem and possible solution. The ethnographic study carried out is not intended to be holistic and comprehensive thus lending itself to further research and query. Data collected in the process is simply meant to help define the factors in the community in order to clarify the complex issues surrounding the problem domain.

1.8 Research contribution

This research was inspired by findings conducted by student interns at Kujali Living Lab, CPUT. The research was conducted between 2009 and 2010 in Kayamandi. The primary aim of this research is understand the process involved in designing platforms that support storytelling by caregivers in the Du Noon community for the purpose of sharing their experiences in the community. This research identifies research processes and methodologies used by the researcher to capture stories from caregivers in Du Noon community. Although this research focused on Du Noon, as a specific community, information from the research methodology could be useful in other communities where similar research is carried out.

Finally, this research provides a body of knowledge into how storytelling can be used for information and knowledge sharing. Citing similar research in the field, this research also provides recommendations for further research with the aim of generating new ideas and possibilities. The arguments and suggestions in this

research is intended to offer new directions to guide for further research and exploration of other possibilities of in designing a platform that supports storytelling as a tool for informal learning and societal development.

1.9 Research Limitations and Ethical Considerations

Livari, (2007) defined ethics in the context of research as “the responsibility of a scientist for the consequences of his research and its results”. Since the research is being conducted in a field of HBHC, there are ethical issues to consider. However, this research has taken into consideration that stories told about caregivers of people suffering from various challenges might “*give-away*” the identity of some; therefore, the researcher has carefully avoided the use of actual names, gender, age and location. Similarly, no personal or private information or details was gathered or looked at during the research, nor is it the intent of the research to reveal any personal or ethically unsound information.

The researcher has ensured that the processes undertaken in designing of platform that supports storytelling do not in any way contain ethically questionable information about the caregiver. There is however, a possible area of the research that might raise the need for ethical considerations. This is because there is a need to define the context (community) of the research which requires an understanding of the problem domain and the variables therein. However, careful steps have been taken to ensure that no names of actual people are mentioned in the stories.

This ethical concern can however, be easily managed as permission has been granted by the target HBHC research participants to do an ethnographic study in order to help contextualise the community. CPUT, the institution where the researcher is studying has also granted permission to undertake the research. The ethnographic study and the document study were deemed sufficient to contextualise the problem and solution domain.

CHAPTER TWO

LITERATURE REVIEW

2. Introduction

In research of a subjective nature, it is essential to place the study within the context of an existing body of knowledge (Levy & Ellis, 2006) in order to establish the presence, relevance and nature of the problem driving the research (Ellis & Levy, 2008). This chapter will focus on identifying relevant literature for the purpose of providing contextual understanding of healthcare services in some developing countries around the world. This project is largely influenced by one of the objectives of the Kujali Living Lab, CPUT which is to conduct research in under-resourced communities with the aim of providing relevant Information and Communication Technology (ICT) solutions deployable in home-based healthcare (HBHC). As a starting point, the dynamics of healthcare globally, in developing countries and specifically in South Africa will be considered while definition, relevance and relationship between HBHC and caregivers will also be addressed. Furthermore, the decision to tilt the research to focus on storytelling by caregivers in promoting information sharing will be identified. Similarly, literature will identify concepts from interaction design where technology functions as a mediator between people with the aim of sharing and dissemination of information

2.1 Healthcare around the world

In this section, literature will identify concepts of developing versus developed countries with reference to the World Bank Organization (WHO) categorisation of high, middle and low income countries. This is necessary to provide background knowledge into the context of this research. A look at the Millennium Development Goals (MDG) will provide a basis for discussing why countries are focussing on providing effective healthcare services.

2.1.1 WHO classification

WHO (2010, 2012) categorizes countries by income into five major types. They are

- Low-income economies (\$1,005 or less)
- Lower-middle-income economies (\$1,006 - \$3,975)
- Upper-middle-income economies (\$3,976 - \$12,275)
- High-income economies (\$12,276 or more)
- High-income OECD members

However, the United Nations Statistics Division (UNSD, 2008) believes that in the United Nations (UN) system, there are no established conventions for the designation of "*developed*" and "*developing*" countries. Notwithstanding, Annan (2000), believes that a developed country is one that allows all its citizens to enjoy a free and healthy life in a safe environment. Furthermore, the identifications of countries as "*developed*" or "*developing*" are intended for statistical convenience and do not necessarily express a judgment about the stage reached by a particular country or area in the development process (UNSD, 2008). This background is provided because the research is conducted in South Africa which is categorized by the WHO as an Upper middle income country with remarkable developmental healthcare process. Before focussing on healthcare in South Africa, an understanding of a global perspective of healthcare will be discussed.

2.1.2 Global Healthcare perspective

One of the developmental processes in countries around the world includes the provision of basic healthcare for citizens. This was reiterated at the International Conference on Primary Health Care (PHC) convened in Alma-Ata, (now Almaty, Kazakhstan) in 1978 where global health policy makers and practitioners adopted the "Health for all" (HFA) agenda as a way of addressing issues pertaining to public health; the conference identified PHC as a strategy in attaining the HFA goals (Cengage, 2002). The strategy outlined a model that would respond more quickly, equitably, appropriately, and effectively to basic health. The objective seeks to address specific political, social and economic causes of poor healthcare, disease prevention and control, easy universal accessibility, health promotion, self-reliance, community participation as well as inter-sectoral collaboration (Magnussen, Ehiri & Jolly. 2004).

Similarly, United Nations (UN, 2010) identified the Millennium Development Goals (MDG) which are eight international development goals that all 193 United Nations member states and at least 23 international organizations agreed to achieve by the year 2015. Adopted at the United Nations Millennium Summit in 2000, the MDG seeks to address greatest challenges facing the world such as critical economic and social development priorities, human needs as well as equal rights. The MDGs are:

1. Eradicating extreme poverty and hunger
2. Achieving universal primary education
3. Promoting gender equality and empowering women
4. Reducing child mortality rates

5. Improving maternal health
6. Combating HIV/AIDS, malaria, and other diseases
7. Ensuring environmental sustainability
8. Developing a global partnership for development

These goals are expected to guide countries around the world address the needs of their citizens. However, since three of the goals (4-6) above are health-related, it becomes important for governments around the world to seriously focus on providing healthcare for citizens. WHO (2012) defines health as a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity. The following section considers how various countries around the world through various initiatives are aligning with the MDGs.

2.1.3 Healthcare policies around the world

This section will look at how some countries around the world have contextually addressed some issues regarding healthcare by adopting and implementing various concepts, frameworks and policies in line with WHO health policies as well as the MDGs.

WHO developed the Innovative Care for Chronic Conditions (ICCC) framework, a model for collaboration with the MacColl Institute for Health Care Innovation (WHO, 2009). This framework identifies that the magnitude of change needed in current healthcare systems to address chronic conditions are overwhelming thus healthcare providers around the world need a strategy to help their systems evolve to meet increasing challenges. The framework however acknowledges that in some countries, factors like timing, knowledge, and resources might need to align in support of a complete overhaul of existing health system so as to effectively address chronic problems while in other countries, a gradual approach to change and small steps in the right direction will be a better tactic (WHO, *ibid*). The ICCC framework which seeks to make healthcare systems capable of improving care for chronic conditions comprises of fundamental components within the patient (micro), organization/community (meso), and policy (macro) levels. These components are described as “*building-blocks*” that can be used to create or re-design healthcare systems that can more effectively manage long-term health problems. Decision-makers can thus use these building-blocks to develop new systems, initiate changes in existing systems, or make strategic plans for future systems (WHO, 2002).

The ICCC framework comprising of healthcare partnership between the patient, healthcare organization and the community has already been deployed in Mexico with the Veracruz Initiative for Diabetic Awareness (VIDA) (Barceló et al, 2010) resulting in achievement of quality healthcare through the improvement of problem solving processes using collaborative methods where best practices are identified and implemented. The world health organisation (WHO, 2009) indicates that the framework is anchored upon this flexible but comprehensive base which aims to build or redesign health systems in accordance with local resources and demands.

Similarly most countries of the South-East Asia Region (SEAR) comprising of Bangladesh, Bhutan, DPR Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste have established several community-based healthcare services, such as community-based rehabilitation, community-based care and support programmes for people living with HIV/AIDS (PLHA), community midwifery, community health nursing, community mental health and other community services for target diseases (WHO, 2004). With few exceptions, many of these services, although integrated into the PHC structure lacked horizontal integration or proper coordination with other related key programmes in the region. This development identified the need to provide comprehensive and well-coordinated health services that supports essential healthcare package at community level. As a result, SEAR undertook the initiative for the development of a generic model for comprehensive community and home-based health care (CCHBHC) which provides direction to Member Countries on how they can further strengthen community health services in response to the changing health needs and services requirements of people in the region (WHO, 2004).

Furthermore, the CCHBHC model also suggested that for cost-effective care, health interventions could be effectively carried out within the community or at home. It has become necessary to extend healthcare services beyond the hospital, especially to those in under-resourced and underprivileged communities because for many, receiving care at home is the setting of choice. Thus, the CCHBHC model has since been developed to ensure better accessibility to health and quality community healthcare (WHO, 2004). Underpinned by the partnership between healthcare workers, clients or patients and members of the local community, CCHBHC can be provided in numerous settings in the community, by various stakeholders including care assistants, health professionals, and non-formal caregivers such as family members and volunteers.

Equally, because population health in Japan is one the best in the world, with the longest life expectancy and lowest infant mortality, the population has aged considerably, with over 21% aged 65 years or older (Tatara & Okamoto, 2009). The continuous emergence of the “*elderly population*” has been characterized by chronic morbid conditions such as stroke or dementia. This increase in elderly population has affected healthcare in the region as evident in the decreasing availability in the number of hospital beds; as a result, greater numbers of frail elderly patients and their families are now opting to spend their last years of life at home (Hashimoto, 2001). HBHC has therefore become an integral component of long-term care for Japanese elderly patients (Hirakawa, Kuzuya, Enoki & Uemura, 2010). Good home care requires appropriate support to the family caregivers of elderly patients with a chronic disease such as dementia, which can be a burden at different levels; however, since elderly patients differ in terms of health conditions and activities of daily living (ADLs), the issues surrounding their care are usually complex (Hirakawa et al, 2010). This makes the process of relaying accurate and tailored information to them extremely crucial.

In India and Ethiopia, the Home Based Life Saving Skills (HBLSS) has been adopted as a family focused program for use in settings where home birth is common (Miller, Buffington, Beck, Graft-Johnson, Daly, Otchere, McNatt, Turan, & Bray 2006). Under this program, caregivers, community and family members as well as expecting mothers are taught basic skills in preventive care for women and new-borns including those living with HIV/AIDS. These include safe and evidence-based emergency first aid home care that is both culturally acceptable and clinically feasible. As part of the teaching method, pictorial cards are used for birth preparedness, problem recognition (like trouble breathing), obstructed and prolonged labour. In India, these skills have already been tested between 2000-2003 in communities like Maitha Block, Uttar Pradesh, and Kanpur Dehat. Similarly, these skills were tested in Ethiopia, between 2000-2004 in Liben Woreda, Oromiya Region, and Borana Zone. Monitoring and evaluation focused on four indicators; coverage, performance, case management and community support. The main results include reduced medical expenses; avoidance of transport constraints, and breastfeeding within one hour of birth ((Miller et al 2006)

Furthermore, as part of an on-going commitment to the promotion of better health policies anchored on equitable access to healthcare, various African governments have also initiated or supported solutions aimed at achieving the MDG. For instance in Ghana, the Ministry of Health has implemented revised sections of the Standard Treatment Guidelines (STGs), Essential Medicines List (EML), National Health

Insurance Drug List (NHIDL), and other guidelines for health workers in a bid to provide effective Anti-malaria drug policy for Ghana (MOH, 2009). The revision included development of the Behavioural Change Communication to ensure that messages are communicated to healthcare workers and members of the public using appropriate communication tools and media. Similarly, the African Medical and Research Foundation (AMREF) working in Kibwezi, Kenya have addressed several development challenges, particularly those related to poverty and ill health (Kibua, Muia, & Keraka 2009). As a result, the Kibwezi Health Centre was set up to attend to community needs. Similarly, various community-based rehabilitation of the disabled were carried out, campaigns promoting water sanitation and hygiene were initiated, food aid and disaster management were provided as well as communication skills for caregivers were encouraged (Kibua et al, 2009).

The preceding literatures are relevant as background to establish the direction of this research which will be carried out within the South African HBHC context. Identifying the dynamics of healthcare in other countries (specifically, the HBHC) is necessary in this research for the purpose of reference, comparison and understanding of how the HBHC in South African (like other countries) is applying aspects of the MDG in the South African context.

2.2 The South African healthcare Context

South Africa, unlike some other African countries like Ghana, Tanzania, Cote d'Ivoire, Madagascar, Guinea, and Kenya has a relatively well-developed private health sector with the public systems traditionally subsidized by the government from general revenues (Castro-Leal, Dayton, Demery & Mehra, 2000). As a result, South Africa is constantly making notable progress towards improving access to affordable palliative care (Wairagala, 2010). However, Palmer, Mills, Wadee, Gilson, & Schneider, (2002) observed that a new model of private primary healthcare provision is emerging in South Africa where private companies provide standardized primary care services at a relatively low cost. And although public sector primary care is free in South Africa, around 30% of people in the urban areas prefer to pay to attend facilities in the private sector partly due to inaccessibility of public services, perceptions of greater privacy, speed of service, quality of diagnosis, prescribing and counselling. Palmer et al. (ibid) added that the implication of this model could be viewed as both negative and positive for the patients. Positive, in terms of patients' satisfaction with the care received in the private clinics but negative because they are paying for care that is already available at no charge in the public sector. Similarly, for the public sector, in its current mode of operation, this new model of private healthcare provision presents

threats and opportunities. One direct threat is competition for the services of nurses, who traditionally employed by the public sector, are now in short supply as they are leaving the increasingly over-burdened public sector for better pay and more conducive working conditions in private sectors (ibid).

Furthermore, although the South African Constitution has outlawed any form of discrimination and guarantees the principles of socioeconomic rights including the right to health; a complete opposite prior to the 1994 when South Africa had a fragmented health system designed along racial lines (Odhiambo, 2011); most public healthcare facilities in South Africa are still underfunded (Van Zyl, 2010) with many communities stretched and under-resourced (MCSA, 2012) resulting in a loss of adequate health services. The newly democratically elected African National Government, (ANC) in 1994 introduced a number of social policy reforms aimed at positively impacting on healthcare work (Harrison, 2009); these included the free PHC program which focused specifically on women and young children, access to legal abortion, affordable generic drugs and, more recently, rapid implementation of antiretroviral therapy (ART) for HIV/AIDS patients. Healthcare in South Africa is predominantly affected by the HIV/AIDS epidemic with South Africa having the highest number of people with HIV/AIDS in the world (Akintola, 2010). According to Statistics South Africa (2012), the estimated overall HIV prevalence rate is approximately 10.6%. The total number of people living with HIV is estimated at approximately 5.38 million in 2011. An estimated 16,6% of the adult population aged 15–49 years is HIV positive. It is believed that HIV/AIDS is one of the leading causes of death of women of reproductive age globally with more than 7,400 new infections every day (UNAIDS 2010).

As a counter-action, The Global Aids Response Progress Report, (GARPR, 2012) indicated that South Africa has just completed the development of a new National Strategic Plan (NSP) for Sexually Transmitted Infection (STI), HIV, and TB for 2012-2016. The NSP's goals and strategic objectives which aims at tackling the epidemic are guided by evidence from various reports, and other epidemiological studies. Furthermore, the Department of Health has adopted this new PHC model as a way of promoting better healthcare delivery and prevention of diseases by placing greater emphasis on both the individual and the family. It emphasizes inter-sectoral collaboration as well as strong community participation. The three pillars of the new PHC model are deployment of PHC outreach teams comprising of professional nurses, enrolled nurses and community health workers (GARPR, 2012).

2.3 The HBHC and Caregivers

This section looks at the WHO definition of HBHC; it gives a brief background to how HBHC started in South Africa as well as discuss its relevance to the provision of accessible healthcare to communities. It also defines the relevance of the caregiver within the HBHC context.

2.3.1. The HBHC

World Health Organization (2004) defined HBHC as

“...the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.”

With the help of the Christian Reformed World Relief Committee (CRWRC), the first HBHC project began in Dingaanstat, located in the KwaZulu-Natal province of South Africa in 2001 (Haveman, 2005). Together with a Canadian short-term volunteer working under the CRWRC representatives, a strategy and prototype for a HBHC identified the need of providing volunteers to visit sick people in their homes. This was in response to the overcrowded hospitals which could not accommodate every patient. The local department of health selected and trained twenty-one volunteers who began visiting homebound clients in this first attempt of the program. The program was entitled *“A Home Based Health Care Program for the Chronically Ill.”* With a conscious effort to avoid the use of HIV/AIDS in the program title due to the stigma associated with the disease at the time (ibid).

HBHC is usually a community-oriented service targeted at individuals with physical and mental nursing needs; it may also extend to emotional, social, and even financial assistance for those who cannot afford or access proper healthcare facilities (WHO, 2004). According to Van Zyl & De la Harpe (2012), for many community residents, hampered by ill health and immobility, access to consistent home-based care is an only hope. As a result, government is supporting HBHC as a way of reducing the pressure on public health facilities and as a result, long patient’s stay in hospitals is being reduced by providing care for these patients in their homes by caregivers. Akintola, (2010) noted that the public health sector is constantly under severe strain as a result of the high proportion of people seeking health care.

2.3.2. The Caregiver

A variety of terms like Community Caregiver (CCG), Community-Based Health Worker, Home-Based Carer, Ancillary Health Care Worker, DOTS Supporter and *Onompilo* have been used to describe a caregiver (Cameron, Coetzee, & Ngidi, 2009). These terms are usually used to identify those who work in the community, carry out functions related to healthcare (Cameron, et al. 2009) playing a key role in empowering people with healthcare knowledge and facilitating access to PHC services. According to (Cameron, et al. *ibid*) it has taken over twenty years for caregivers to gain some form of recognition by the formal health care sector and for standardized training, career pathways and formal support to be considered. The impact of HIV/AIDS endemic has ensured that an increase in the number of people requiring care and support. The escalating costs of care and hospitals' inability to cope with the demand for beds has led to a decentralize form of care at the community level, placing the responsibility, the costs and the burden on Non-Government Organizations (NGOs), Community Based Organizations (CBOs) and family carers (*ibid*). Many patients discharged from hospital do not have family members to turn to for care within a home setting; and some family members are unwilling to care for fear of becoming infected themselves.

Due to the growing need for assistance with care in South Africa as more households are becoming affected with HIV/AIDS and other chronic disease (Homan, et al. 2005), the role of the caregivers has become essential in HBHC (Akintola, 2010). Caregivers are the delivery points through which patients experience the needed care and service network at their own homes thus reducing the need to travel to access care (Van Zyl, 2010). This development facilitates an interpersonal engagement between the caregiver and the patient as care is now made available in the comforts of their homes. Similarly, through the assistance of caregivers, poor and chronic patients are gradually beginning to access health service within reach of even the most peripheral communities and homesteads (*ibid*).

A caregiver's activity includes (but not limited to) the following:

- Providing physical care such as bed bathing, mouth care, wound care, cleaning those with frequent bouts of diarrhea, etc.
- Training family members how to care for PLWHA
- Securing relevant grants to assist patient's care
- Referrals to clinics, hospitals and hospice programs when conditions are critical
- Providing emotional support

2.4. Healthcare advancement using Technology

This section will identify some advancement achieved through technology with specific focus on how ICT can and has been used in healthcare. It will also discuss the use of mobile technology in healthcare.

Healthcare remains one of the most important sectors where governments of developing countries strive to enhance the situation by employing affordable ICT solutions (Wouters, Barjis, Maponya, Maritz, & Mashiri, 2009). Similarly, Tap (2010) noted that technology is expected to play a key role in providing quality healthcare at a lower cost as studies suggest that IT in healthcare can improve the quality of care and also reduce costs. Furthermore, ICT is believed to facilitate new means and open up new horizons which in turn, and in the context of adopted technology, expectations, requirements and demands of the society can further lend to better information and development (Hameed, 2003). However, although ICT could provide better information and decision support to improve healthcare, Van Belle (2006), argues that this objective will only be realized if medical practitioners decide to adopt new technologies. He identified concerns by Anderson (1997) which stated that in the 1990s, administrative healthcare systems reached a measure of maturity but the shift to systems capable of supporting clinical work by healthcare professionals has been slow. However, Van Belle (ibid), believes that this shift is necessary in order to provide better support structures for public healthcare which will in turn enable doctors to facilitate the provision of high quality, better informed and cost-effective public healthcare to all the citizens of South Africa. Therefore, as the fundamental building blocks of information systems are constantly being updated and new possibilities identified, Hameed (2003) opines that technology integration has become relevant in several aspects of social, economic and political systems in order to establish an information core that satisfies the modern needs in the PHC. The next section addresses one of these technology integration possibilities which are the shift to mobility

2.4.1. Mobile Technology in Healthcare

ICT developments have resulted in an additional fundamental component known as mobility where mobility, in this context, refers to the application of mobile computing and technology that supports mobile working practices thus enabling a style of work and information access that one would commonly refer to as a situated (Hameed, 2003). Mobile computing has been defined as computing technology that comprise of software, hardware and communications that are specifically associated with mobility (Zaslavsky & Tari, 1988). Similarly, Ghosh, (2005) defines mobile computing as

mobility originating from the desire to move either toward resources or away from scarcity. Hameed (ibid) also refers to it as a form of technology that is not fixed and is capable of being portable.

There has been a rapid increase in the use of mobile technologies by health and social care providers; these include use of smart phones, Ultra Mobile PCs (UMPC), computer tablets, and other portable Personal Digital Assistant (PDA) that provide easy access to information (Dearnley, Haigh, & Fairhall, 2008). Similarly, Dearnley et al (2008) noted that there is reported application of mobile technologies among paramedics (Norman, 2005), doctors (Fischer et al., 2003; Scheck McAlearney et al., 2004) and nurses for care purposes as tracking medication, supporting preference – based care planning and research (Miller et al., 2005). The research also opined that PDAs are beginning to play major roles in enhancing care practice by reducing medical errors as well as providing easy access to healthcare information.

An example of this is the Mobile Alliance for Maternal Action (MAMA) which delivers vital healthcare information to new and expectant mothers via mobile phones. Launched in 2011, the project seeks to enhance global capability of new and existing mobile health information programs for expectant mothers in under-resourced communities. MAMA is presently providing mobile health information services in countries with elevated maternal and infant mortality and morbidity and high use of mobile phones such as Bangladesh, India and South Africa. This program partners with local governments, mobile operators as well as NGOs in these countries to ensure that its efforts can be expanded or replicated with the aim of reaching most mothers. Under this project, mothers can ask specific questions relating to their health or their baby's health and receive relevant information via their mobile phones.

Statistics provided by BlueMagnet (2011) show that there are 5 Billion handsets in the world; 34 million adults in South Africans of which 26 million are mobile phone users. This is a remarkable increase from the UN Foundation's 2008 observation that over 3.5 billion mobile phones are in use around the world. As a result, organizations are harnessing technology to help overcome humanitarian challenges through modern telecommunications and creative use (UN Foundation, 2008). This development is seen as having the power to change lives and help the UN solve some of the world's biggest challenges such as re-connecting families separated by disaster, help emergency relief workers respond more quickly, empower health workers with data to help combat disease and epidemics, track the impacts of climate change, and even help in the resolution of civil conflicts. The innovative use of

mobile communication proves that wireless technology can be a vehicle to propel social change by enabling the NGO community to bridge the digital divide and deliver services more effectively, particularly in areas where IT infrastructure is limited.

The preceding literature is to provide background knowledge that over the years, ICT has been effectively deployed for solutions in various sectors including healthcare. Given this background, the following literature will look at the concept of informal learning with focus on how informal learning can be deployed in healthcare through storytelling. It will consider the concept of technology by way of digital storytelling is explored in the HBHC context.

2.5. Exploring Storytelling to promote learning

Harrison (2006) defined informal learning as all the learning that takes place away from the world of organized formal training. He added informal learning is deep and pervasive (representing over 80% of learning that occurs in organizations), uncontrolled (occurs through colleagues and self-discovery), and powerful. Informal learning is also been defined as learning emanating from daily life activities related to work, family, or leisure (Colardyn, & Bjornavold, 2004). Informal learning may be intentional or non-intentional. It is also referred to as experiential or accidental learning and does not usually lead to certification (ibid). Knowledge Advisors Research (2009) categorizes informal learning into four major types. They are Communities of Practice (CoPs), Mentoring and Coaching (M&C), Virtual Knowledge Sharing (VKS), Electronic Performance Support Systems (EPSS). This research will lean towards CoPs which is defined as groups of people in organizations that form to share what they know, to learn from each other regarding some aspects of their work and to provide a social context for that work. Work in this context refers to the HBHC where caregivers function (ibid) where knowledge sharing is by use of storytelling.

Storytelling can be defined as the oral presentation of a story from memory by an individual to a person or group (Gallets, 2005). Garzotto & Forfori (2006) believes that storytelling is crucial in promoting informal learning. Storytelling has been the focus of much attention in various applications such as interactive tourism guides, education, and entertainment (Brooks, 1996; Kretschmer et al., 2001; Mateas and Stern, 2003) and has been seen as a way to communicate information, learn about life, transmit culture, make sense of experience, and express one's emotions since primitive forms of language emerged ages ago (Gray, 2009). However, for storytelling to be meaningful, it needs to have relevance to the context of use (Giles, 2010) because it is important to recognize the appropriate approaches as well as be sensitive to the

specific cultural framework, available resources and existing local programmes (Delen, 2011).

Furthermore, Mitchell, (2003) opines that storytelling is now being recognized as having a place of value within the knowledge sharing environment such as education, business or health organizations. Knowledge sharing has been seen as critical to the ongoing development and growth of organizations. The act of sharing involves the transfer of knowledge from one person to another or among many people, thus adding value to organizational activities; the sharing of knowledge within an organization is a catalyst for growth within that organization. Carnerio, (2001) suggests that knowledge sharing should be encouraged because it is one of the most important tools of creativity and, intellectual assets, unlike physical assets, increase in value with use. Sharing knowledge can occur in various ways and constant effort to share knowledge should be stimulated within organizations because knowledge increases with constant use and sharing knowledge allows both parties not only to retain the resource but to amplify and expand it through the exchange process itself (Allee, 1999).

Sharing knowledge about work practice through storytelling within organizations could provide an opportunity to discuss practices that could direct organizations towards future development and growth (Clarke & Rollo, 2001); according to this research, sharing provides an opportunity for knowledge generation through which the future success of organizations is determined; the act of sharing knowledge could develop a more dynamic environment that has the ability to create its own momentum that encourage value and positive outcomes for employees and the organization. The importance of knowledge sharing has been expounded by many authors in several literatures such as Davenport and Prusak (1998), Kluge, Stein, Licht (2001), Metcalf and Grant (2002), and Wright and Taylor (2003). However, before now, the process of sharing has been hampered because it is not easy to encourage voluntary sharing of knowledge by employees due to competition between organizations (Marshall et al, 1996). There is also a prevalent notion upheld by Marshall (2007) that “knowledge is power, so hoard it”. In collaborating Marshall’s view, Allee (1997) added that the previous impediment to sharing which is “Knowledge is power, so hoard it” is fast becoming extinct with today’s extensive use of technology and the impact it has had on organizations. The old knowledge equation is rapidly being put to rest and replaced with a new one that supports sharing. Now, the universal knowledge equation is “Knowledge is power, so share it”

The shift of storytelling into digital media coupled with the increase in prevalence of mobile phones in rural communities can provide communities with the platform to create digital stories on their handsets (Reitmaier et al., 2010). According to this research, a prototype that supports storytelling has already been tested in Kenya. Informed by ethnography, the researchers designed a mobile digital storytelling prototype tailored to the needs of the rural community. This prototype was originally designed with a rural community in South Africa's Eastern Cape and further field testing with a prototype took place in Adiedo, Kenya. The researchers wanted to learn more about the users, their stories as well as their context in relation to the prototype with the aim of seeing how this information could be leveraged to shape the design of future mobile digital storytelling systems. They spent a total of seven days in-situ, recruited a young man as research assistant and translator. He was fluent in English and Dholuo, a local dialect. This relationship with the research assistant was important to the field testing process as he became essential to introducing the prototype to the community. Once familiarized with the prototype, he was able to ask villagers to create digital stories, with his assistance. This allowed for the uncovering of usability problems by observing the prototype being used in different scenarios and contexts.

Garzotto & Forfori (2006) through the "FaTe2" project notes that storytelling, edutainment, and collaborative interaction are all powerful paradigms to promote learning. The project explored combinations of these paradigms by providing multi-user, web-based two and three dimensional virtual space for children between age seven and eleven. With this platform, children were able to perform collaborative storytelling activities. The "Fate2" project described storytelling as the capacity to listen, tell and reflect on stories which promotes child's development, cognitive functions and skills, communication, recognition, recall, analysis and interpretation. The project not only provided a 2D interaction space where children watched, read, or listened to multimedia fairy tale, it also gave them the ability to manipulate the multimedia characters and objects in each scene, thus promoting learning through interaction.

The concept of storytelling has also been explored in several schools. Most notably is the Columbia University of Medicine where caregivers-in-training receive training on close reading and examining stories by patients during their clinical interactions. This process requires caregivers to write down their own stories about their patients with the aim of promoting better understanding of their patient's experiences (Gray, 2009). Similarly, in another medical setting, Clinicians and educators noticed positive

improvements by integrating storytelling into communicating with breast cancer patients (McQueen & Kreuter, 2010). It was also discovered that women identified more with the breast cancer survivors in the storytelling video as valuable, trusted and credible messengers of health information and indicated that storytelling made interaction between medical staff and patients easier to understand, more engaging, and had a greater emotional impact (ibid).

The next section will look at storytelling within the field of interaction design. The definition of Interaction design will be provided for.

2.6. Solutions through Interaction Design

Messeter, (2009) defined Interaction design as design with digital materials, shaping interactive digital systems, services and products with a particular focus on users and use experience. Interaction design has also been defined by Hallnäs, & Redström, (2006) as a shift of focus from what a thing does as we use it to what we do in the acts that define use. Interaction design seeks to provide interactive products to support people in their everyday lives by particularly creating user experiences that enhance and extend the way people work, communicate and interact (Preece, Rogers & Sharp, 2002). Thus, the focus of interaction designers over the past decades have shifted to the context of use as a matter of concern (Hallnäs, & Redström, 2006) and this had led to placing emphasis on the concept of designing interactive digital systems and services that are place-specific and contextually relevant (Messeter, ibid).

Discussions in the field of interaction design has constantly emphasised the need for contextualizing solutions to the satisfaction of the end-user. For instance, the concept of *“place-specific computing”* has been suggested as a genre of interaction design dealing with the shaping of interactions among people, place-specific resources and global socio-technical networks, mediated by digital technology, and influenced by the structuring conditions of place (Messeter, 2009). Löwgren & Stolterman (2004) argues that interaction design must reflect processes that are arranged within existing resource constraints to create, shape, and decide all use-oriented qualities (structural, functional, ethical, and aesthetic) of a digital artefact. Thackara (2001) believes that interaction design should focus on processes and services that conform to an individual's needs and preferences.

Interaction design has also been deployed in providing solutions in healthcare. Harrison, Koppel & Bar-Lev, (2007) noted that Healthcare Information Technologies (HIT), such as electronic medical records (EMR), computerized physician order entry

(CPOE), and decision support systems (DSS), has the potential to enhance safety, quality, and patient-centeredness of care, while helping to contain costs and increase efficiency. However, designers of product (or service) should ensure new technologies are easy to learn, effective to use, and provide an enjoyable user experience (ibid). Therefore, designing usable interactive products entails considering who is going to be using them and where they are going to be used; it also includes understanding the kind of activities people do when interacting with the products, the appropriateness of different kinds of interfaces and arrangements of input and output devices (Harrison, et al. 2007).

Similarly, Interactive Technological innovations in the 21st century have reshaped the field of medicine and the delivery of health care services (Ogembo-Kachienga & Ogara 2004). Recent technological advancements in medicine have provided a remarkable range of diagnostic, therapeutic, and rehabilitative tools and instruments which has contributed to a more effective cure of specific disease and illness as well as improved quality of healthcare provided by various health facilities (ibid).

Furthermore, since Human-computer interaction (HCI), a branch of interaction design is the study of the interaction between people and computers (Huang, 2009) one of the major concerns of practitioners in the field of HCI is to design interactive computing systems for human use by making computers more usable and more receptive to the user's needs. As discussed (in section 2.4.1) above, mobility is seen as an improvement in terms of usage and accessibility. This is because among the many ICT options available to government to improve the efficiency and effectiveness of its delivery process of PHC, mobile & wireless technologies offer some exciting opportunities for a low cost, high reach service (Murthy,2008). According WHO (2009), Mobile Health (mHealth) is an area of electronic health (eHealth) concerned with the provision of health services and information via mobile technologies such as mobile phones and Personal Digital Assistants (PDAs).

Finally, given the background that interaction designers could play a role in designing ICT solutions (such as mobile solutions) deployable in healthcare, this research will focus on designing a digital storytelling platform for caregivers in the HBHC within the Du Noon community, Cape Town. As discussed above, understanding the dynamics and context of the research community as well as interaction with the caregivers would provide information for designing a contextually relevant solution. This is necessary because considering the end users and their goals should be the driving force behind developing a product (Sharp, Rogers & Preece, 2007). Sanders &

Stappers (2008) suggests that the need to co-design with the end users of the anticipated platform is very important as co-designing integrates the creativity of designers and people not trained in design, working together in the design development process.

The next chapter which is on Research Design and Methodology will identify the researcher's hypothesis, conceptualization, as well as the research design type. It will also look at the Epistemological and Ontological standpoints.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3. Introduction

The chapter will identify the researcher's hypothesis, conceptualization, as well as the research design type. The Epistemological and Ontological standpoints will be discussed while key design concepts and theories surrounding the research will also be identified. Reasons for adopting a qualitative research method for this project will also be discussed. Data collection and analysis methods will also be explained.

3.1. Research Hypothesis

The researcher hypothesizes that given the outcome of a recent research by the Kujali Living Lab in Kayamandi (Delen, 2011) which reveal that caregivers in the HBHC have a lot of stories to tell and do not presently have platforms to share these stories, there is potential in designing and developing platforms which support storytelling by caregivers for the purpose of disseminating the stories in the community. Through qualitative research methods in Du Noon, the researcher seeks to show that the process of designing platforms that support storytelling is possible and can be an effective way for knowledge sharing.

3.2. Research Design

Research design can be defined as a "*blue-print*" from which a proper study can be carried out while exercising control over other aspects that have influence on the results of the study (Burns & Groove, 2001). Naturally, this involves the process of planning and implementing the study in a way that would improve the quality of findings while acting as a foundation for the activities taking. In order to gain more knowledge of the research community, the epistemological and ontological standpoints will be discussed.

3.2.1. Epistemological and Ontological standpoints

Derived from the Greek word '*episteme*', meaning '*knowledge*', epistemology is a branch of philosophy concerned with the possibility and extent of human knowledge; Epistemology can be defined as the study of knowing which deals with the theories and nature of knowledge (Slick, 2011). It seeks to find the truth by identifying how we know things, what we know, why we know, is what we know true? And what are the limits of knowledge. In order for a claim to be considered as truth, the claim must have a foundation. However, establishing a foundation for a claim could be difficult thus through scientific process and discipline, epistemology aims to provide a foundation for what we consider to be true knowledge. Basically, epistemology is the

study of human knowledge which aims not only to understand phenomena, but rather to provide valid and reliable understandings of reality (Mouton & Marais, 1990).

Epistemology defines two ways by which knowledge can be acquired. These are rationalism and empiricism. Rationalism is a branch of philosophy where truth is determined by reason. Here, reason is considered as the only source of knowledge through which all experience is interpreted, and that such knowledge can be obtained through reason alone. Empiricism is the philosophy that focuses on how we know things. Empiricism states that the only thing knowable is that which is discernible through human senses such as smelling, seeing, hearing, touching, etc. Therefore, all of our understanding, all of our concepts, reflects what our senses have told us about the external world.

Ontology refers to the study of being or reality with primary focus on aspect or aspects of social reality (Mouton & Marais, 1990). It is the study of the nature of being which seeks to understand reality, its essence, its relation to existence (Slick, 2011). It is the study of the most basic essence of what something is beyond which it cannot be known.

According to the definition provided by CreationWiki (2012), there are three main components of epistemology. These are;

1. Knowledge
2. Beliefs
3. Truth

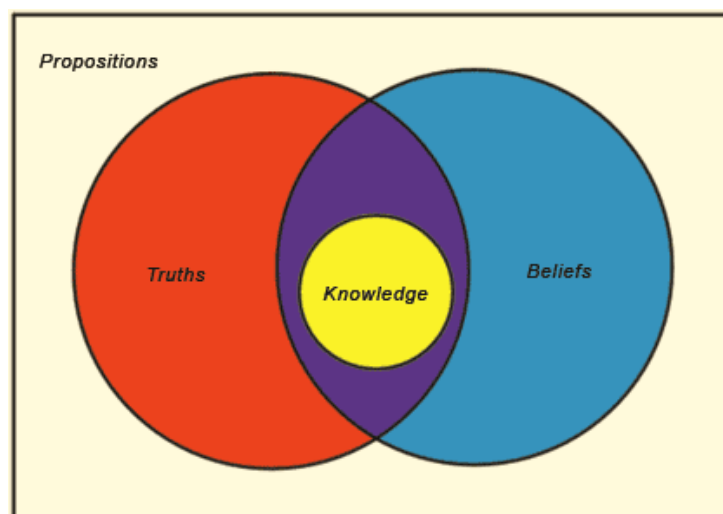


Fig.3.1: A simplification of Plato's definition of knowledge (CreationWiki, 2012)

Knowledge can be divided into three main types;

- Knowledge by acquaintance (you know a person).
- Know-how (know how to do something)
- Knowledge by description which is propositional content. There can be a great deal of propositional knowledge about a person without ever meeting the person, or acquiring acquaintance knowledge. Knowledge is dependent upon beliefs and perceptions of what and how a truth corresponds to reality. Not all knowledge is made up of true propositional content and therefore not all epistemology is warranted. Finally, within epistemology, there are three ways to determine the truth of a proposition. They are the correspondence, pragmatic and coherence theories of truth.

Using these philosophies as background knowledge, the research will seek to acquire 'the truth' from the research community by getting knowledge through empirical means. Observing the social reality (ontology) from the research area will provide an opportunity to gain knowledge (epistemology).

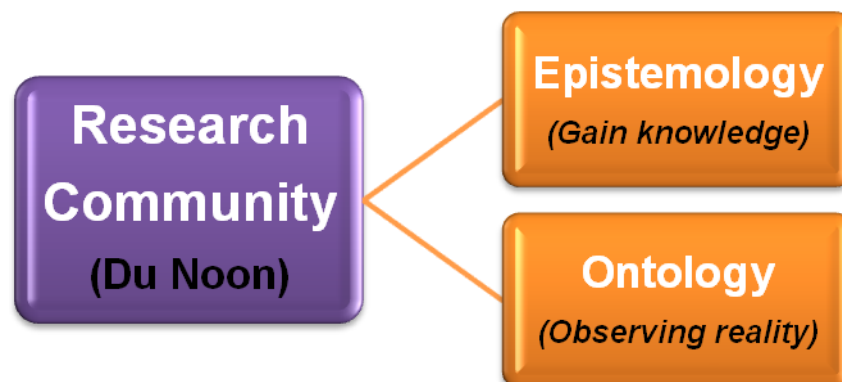


Fig.3.2: Gaining knowledge by observing reality

Finally, driving this research will be the interpretivist standpoint which seeks to understand and explain findings accumulated in the research by interpreting the data. The aim is to find methods beneficial to the research in terms of validity of data. Another reason is to identify processes which can be employed in similar research in order to assist in identification of the problems, interpreting collected data and identifying probable solutions. The methods adopted in this research as well as the conceptualization process are discussed.

3.3. Research Paradigm

In order to conduct this research logically as reflected in the diagram above, certain philosophical traditions were adopted and basis for adoption are explained. Commenting on opinions expressed by Merriam (1998), Adendorff, (2004) argues added that linking educational research with philosophical traditions helps to illustrate various research orientations. He went ahead to mention the stand by Carr & Kemmis (1986) where three basic forms of educational research were presented. These are positivist, interpretive and critical research.

The table below identifies some of the characteristics of these forms of research.

	Research approach	Characteristics
1.	Positivist Research	Knowledge gained is objective and quantifiable
2.	Interpretive	Knowledge is gained as researcher is a participant observer
3.	Critical	Knowledge gained is an ideological critique of power, privilege and oppression

Table 3.1: Research approaches (source Adendorff, 2004)

This research uses the interpretive research approach where the researcher is an active participant observer during the data collection process. Adendorff, (2004) added that in the interpretive research, the researcher does not stand above or outside, but is a participant observer seeking to identify meanings of various actions expressed within specific social context. Furthermore, interpretive research does not focus on providing causal explanations of human life, but is concerned with deepening and extending knowledge of why social life is perceived and experienced the way it is.

Interpretive research assumes that our knowledge of reality is gained only through social constructions such as language, consciousness, shared meanings, documents and other artefacts (Berntsen, Sampson & Østerlie, 2000). Interpretive research aims at producing an understanding of the context and the process whereby the information system influences and is influenced by its context (Walsham, 1993). According to Klein & Myers (1999), a key component in interpretive research is seeking meaning in context; that is, the subject matter must be set in its social and historical context so the reader can see how the current situation emerged.

Context plays a major role in this research because data were collected from the research community from which interpretation was made. Delen, (2011) upholds the submission by Levin-Rozalis (2004), that because Interpretivism acknowledges that human behaviour is subjective and depends on contextual and personal perceptions, the researcher must discover and describe the world of study from the perspective of the people who live therein, and must not impose an outside view. This perception is adopted in this research where the researcher through co-designing and interaction with the caregivers seeks to design platforms that are contextually relevant to the research community as opposed to imposing a preconceived intervention which might be contextually irrelevant. The choice of influence of interpretive research on this project is further amplified in the table below.

Influence of Interpretivism on research		
Feature		Description
1.	Purpose of research	To understand the process or processes involved in designing and developing a platform that supports storytelling by caregivers about their work practices in a particular community (Du Noon). The purpose also includes how these stories told by caregivers can be moderated into visual content for the purpose of sharing within the community.
2.	Nature of reality (Ontology)	<ul style="list-style-type: none"> • There are multiple constructs of realities • Reality is relative and can be explored • Reality is constructed through human interactions • Discover how people make sense of their worlds in the natural setting by means of routines, conversation and interaction. • Many social realities exist due to varying human experience, knowledge, views and interpretations
3.	Nature of knowledge; relationship between inquirer and inquired-into (epistemology)	<ul style="list-style-type: none"> • Events are understood through the mental process of interpretation influenced by and interact with social context. • Inquirer (researcher) and the inquired-into (participants/community) are engaged in interactive processes of talking and listening, co-designing, etc
4.	Methodology	Processes of data collected by interviews, observation, participation in activity (Volunteering to work with caregivers and NGO)

Table 3.2: Influence of Interpretivism on research (Influenced by Adendorff, 2004)

Interpretive research often involves using qualitative methods to source, understand and analyse data collected during the research process. The methods adopted in this research follow a set of principles proposed by Klein and Myers (1999) for conducting and evaluating interpretive research. These include ethnography, field and case studies. Furthermore, this research is driven by the definition of naive inductivism by Mouton & Marais, (1990) as the belief that objective research obtains when a

researcher approaches the research domain in an open-minded and receptive manner, thereby eliminating bias. This became necessary because upholding a bias stand in the research community could negatively affect the validity of data collection and analysis. Upholding this argument, Mouton & Marais, (1990) added that research process must originate from the identification of either an empirical or conceptual problem because the transition from identifying a problem to collecting data to solve the problem is usually preceded by conceptualization.



Figure 3.3: Development of research problem
(Adapted from Mouton & Marais, 1990)

3.4. Conceptualization

Mouton & Marais further argues that the best way to explain conceptualization is to consider closely, the notion of a concept. Thus, they defined concept as the most basic constructions through which people order and categorize reality; they are the primary instruments employed in order to comprehend experiences. Thus, a concept could mean an abstract or general idea inferred or derived from specific instances. Grounded with these definitions of a concept, conceptualization can be defined as a process which is aimed at acquiring internal theoretical or connotative validity (Mouton & Marais, 1990).

Conceptualization can also be defined as the learner's initial contact with other peoples' concepts about the research area; at this stage there is a negotiation between the learner's existing pre-conceived assumptions of the subject area with the new additional piece of information (Click4it, 2012). This definition describes this research because direction for further research emanated from a prior research conducted by student interns at the Kujali Living Lab between 2009 and 2010. The research was conducted at Kayamandi, an under-resourced community in Stellenbosch, Cape Town. Although primary focus on the initial research was not centered on storytelling, one of the issues raised in the discussions was that

caregivers in this community had a lot of stories to tell and had no available platform for expression and sharing their stories. Thus, this research, conducted in Du Noon was conceived from identified problems in the research at Kayamandi. However, in order to conduct a meaningful and credible research, new facts (or data) need to be learnt from the new research community. A new *learning-terrain* needs to be taken in the new community so as to decipher the peculiarity of the community. This will lead to learning new facts which will enhance the validity of data collected. Furthermore, conceptualization theory is based on constructivism where emphasis is laid on learning through performance of task. These tasks are aimed at providing an opportunity for learning or generating information (Click4it, 2012).

Thus the following assumptions are made about learning:

1. Learning is a by-product of understanding which the learner builds while performing a specific task.
2. It is helpful to visualize a model that sees learning as a progression through stages.
3. Understanding is enhanced by frequent feedback from peers and teachers as well as participants in the research process.
4. Learning is situated within a defined social and organizational context.

These assumptions about leaning have been mentioned in this research because they correspond with the steps taken in the research process and have influenced the way the research was conducted. The table below gives more clarity on this.

Assumptions about Learning		
Nos.	Assumptions	Influence on research
1.	Learning is a by-product of understanding which the learner builds while performing a specific task.	The research is primarily concerned about identifying processes involved in collecting and collating stories by caregivers from a specific community. This task encourages learning which in turn produces understanding.
2.	It is helpful to visualize learning as a progression through stages.	There are various stages involved between initial contact and the actual research activity. These include the period of gaining trust and acceptance within the research community. Each stage provides an opportunity for learning to occur.
3.	Understanding is enhanced by frequent feedback from peers and teachers as	This is in line with collaboration, co-designing and participatory design where everyone is seen as a

	well as participants in the research process.	stakeholder in the entire process.
4.	Learning is situated within a defined social and organizational context.	As opposed to a generalized assumption, it is important to contextualize the learning process.

Table 3.3: Assumptions about learning

Furthermore, Concept mapping has been defined as a general method that can enable any individual or groups describe their ideas about some topic in a detailed pictorial form. There are different types of methods adopted with varied names such as "concept mapping", "mental mapping" or "concept webbing." All of them are similar because they result in a pictorial representation of ideas (Click4it, 2012). A concept mapping process involves six steps that can take weeks or months depending on the peculiarity and context of the situation.

1. **Preparation Step:** There are three things done at this stage. They include
 - a. Researcher works with the initiator(s) (i.e., whoever requests the process initially) to identify who the participants will be.
 - b. Identify the stakeholders to develop the focus for the project.
 - c. Decide appropriate schedule for the mapping.
2. **Generation Step:** Here the stakeholders develop a large set of statements that address the focus area of the research. E.g. determine specific research activities, generate statements describing specific outcomes, methods to be adopted, etc.
3. **Structuring Step:** Merging similar statements, objectives into a whole. It also involves rating the objectives and placing them in order of preference.
4. **Representation Step:** This is the stage where the analysis is done and "representing" it in map form.
5. **Interpretation Step:** At this stage, the researcher works with the stakeholder group to help them develop their own labels and interpretations for the various maps.
6. **Utilization Step:** This final stage involves using the maps generated to address the original focus. The maps can be used as a visual framework for operationalizing the program and can also be used as the basis for developing measures and displaying results.

Essentially, concept mapping is a structured process, focused on a topic or construct of interest, involving input from one or more participants, that produces an interpretable pictorial view (*concept map*) of their ideas and concepts and how these

are interrelated. Concept mapping helps to think more effectively without losing their focus. It also helps to manage the complexity of ideas without trivializing them or losing detail. For this research, the idea for concept mapping is adopted in this because it helps to visually represent the terrain through which the research will follow. Below is a pictorial representation of the project plan from conception to completion.

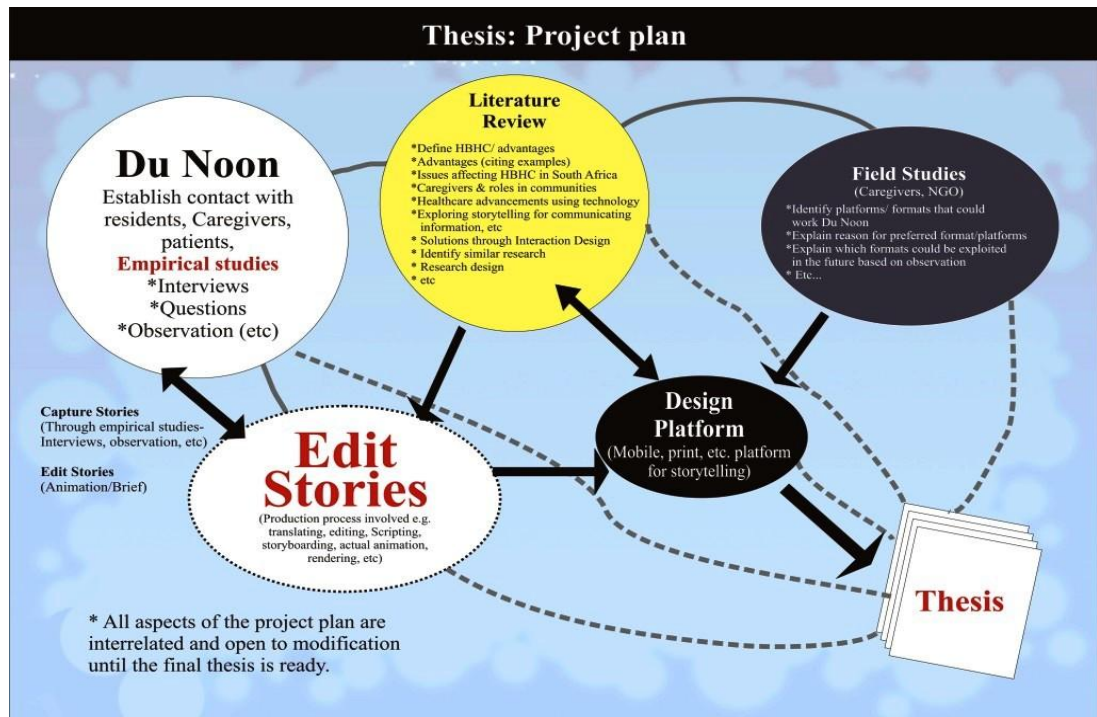


Figure 3.4: Project plan (*Concept mapping*)

3.5. Research design type

As mentioned in the introduction, this research will use qualitative methods for information inquiry and data collection in Du Noon. Qualitative research is defined as a form of systematic empirical inquiry into meaning (Shank, 2002). It is a type of inquiry that is grounded in the world of experience. Similarly, Denzin & Lincoln (2000) believes that qualitative research involves an interpretive and naturalistic approach, studying things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.

Holliday, (2002) identifies some unique characteristics of qualitative research as

1. Describing actions or activities within a specific setting
2. Invites rather than tries to control the possibility of a rich array of variables
3. Approaches research in terms of human relationships
4. Invokes the need to discover as much about how research subjects (or participants) feel about the information they provide

Furthermore, “qualitative research does not pretend to solve the problems...but does not see them as constraints. Rather than find ways to reduce the effect of uncontrollable social variables, it investigates them directly” (Holliday, 2002).

The table below identifies how this research is influenced by the characteristics highlighted by Holliday, (2002) above.

	Holliday’s description	Influence on research
1.	Describing actions or activities within a specific setting	Activities described are from caregivers at Du Noon
2.	Invites rather than tries to control the possibility of a rich array of variables	Objectivity in collecting data as opposed to imposing concepts
3.	Approaches research in terms of human relationships	Relationship and interaction with research participants provides data
4.	Invokes the need to discover as much about how research subjects (or participants) feel about the information they provide	Empirical approach where data is derived from experiment and observation rather than theory

Table 3.4: Influence of qualitative research on project

Data collected for this research are exclusively originated from Du Noon which is the research community. The decision to adopt this method of inquiry in Du Noon is grounded on the importance highlighted by Ospina, (2004) where, discussing on importance of qualitative research, he expounded on researches conducted by Conger, (1998); Bryman et al, (1988) and Alvesson, (1996). These importance include

- a. flexibility to follow unexpected ideas during research and explore processes effectively
- b. sensitivity to contextual factors;
- c. ability to study symbolic dimensions and social meaning;
- d. increased opportunities
 - I. to develop empirically supported new ideas and theories;
 - II. for in-depth and longitudinal explorations of leadership phenomena
 - III. For more relevance and interest for practitioners.

Although quantitative and qualitative methods represent two logical ways for inquiry, each method approaches empirical research differently. Ospina, (2004) gave clarification about assumptions that ground each method as distinguished by Everet & Louis (1981). These are “*inquiry from the outside*”, often implemented via quantitative studies and “*inquiry from the inside*” via qualitative studies.

Quantitative Research	Qualitative Research
<i>"inquiry from the outside"</i>	<i>"inquiry from the inside"</i>

Table 3.5: Assumptions about research methods

These approaches differ in the degree of the researcher's immersion in terms of experiential engagement, direct contact with the subjects, and physical involvement in the setting. In the "inside" or qualitative approach, the researcher aims for a holistic picture from historically unique situations, where idiosyncrasies are important for meaning. The researcher uses an inductive mode, letting the data speak. In contrast, traditional "outside" or quantitative researchers aim to isolate the phenomenon, to reduce the level of complexity in the analysis and to test hypotheses derived previously.

An analogy that inspires the choice of qualitative method for this research is given by Shank, (2002). Shank uses two metaphors to distinguish ways of '*seeing*' in research. These are:

1. **The Window:** This helps the researcher to look through so as to get a precise view of a subject. Just like the microscopes, windows help to do inquiry from the outside. The researcher then tries to correct for smudges (to avoid bias) or to clarify in what ways the window is flawed (to identify error).
2. **The Lantern:** This metaphor helps to shed more light in dark corners. This metaphor characterizes qualitative researchers as discoverers and reconcilers of meaning where no meaning has been clearly understood before.

Explaining this further, Shank added that the approaches to inquiry described with The Window or *inquiry from the outside*, (quantitative research), are best known as logical positivism and post-positivism while The Lantern or *inquiry from the inside* (qualitative research) represent an approach known as Interpretivism. This research adopts "The Lantern" approach with the aim of gaining first-hand and in-depth knowledge in the research community *from the inside*.

The qualitative method used in this research applies a multiple critical case study approach (*case study here refers to stories told by caregivers*). Participant observation, telephoning, electronic mail correspondence, structured and unstructured responsive interviews were conducted and an interpretive analysis was used to analyse the data. This method was adopted because one of the main strength of qualitative research is its ability to study phenomena which are simply unavailable elsewhere apart from the research context (Silverman, 2006). Since this research is specifically examining the process of designing a platform that supports storytelling by caregivers from a specific HBHC context, qualitative research method

was chosen by the researcher as suitable because apart from providing information about the human side of an issue, strength of qualitative research is its ability in providing complex textual descriptions of people's experience in a given research issue (Boyce & Neale, 2006). Thus, qualitative methods enlighten one on issue relating to often contradictory behaviours, beliefs, opinions, emotions, and relationships of individuals. They are also effective in identifying intangible factors, such as social norms, socioeconomic status, gender roles, ethnicity, and religion, whose role in the research. Figure 3.4 below is a pictorial description showing the qualitative tools used in the research process.



Figure 3.5: Qualitative tools in research

3.6. Purpose of research

The purpose of this research is both exploratory and descriptive. It seeks to explore the process and possibility of capturing and using storytelling by caregivers for the purpose of sharing. Data collected in this exploratory process will give a description of the findings for the purpose of knowledge generation and further research.

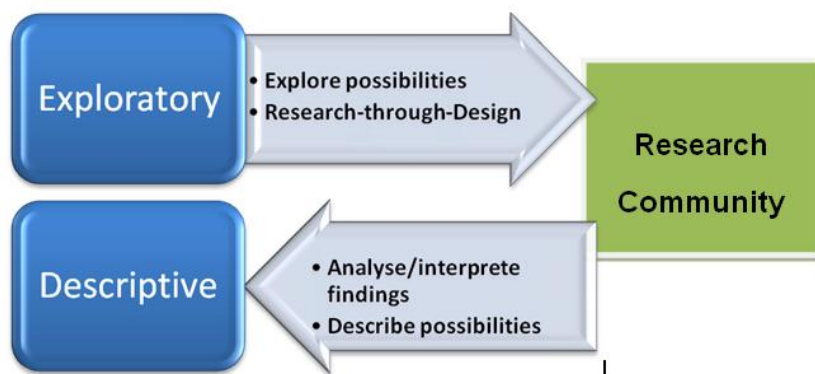


Figure 3.6: Purpose for adopting exploratory and descriptive research.

3.6.1. Epistemological and Ontological standpoints

Citing literatures by Merriam (1998), Shaw (1978) and Creswell (1998), Adendorff (2004) argues that the end product of a study should be a thick description of the phenomena being studied which must include many variables and portray interaction over a period of time. Exploratory research as a useful preliminary step assists the researcher who has limited amount of experience with or knowledge about the research issue thus ensuring that a more rigorous, conclusive future study will not begin with an inadequate understanding of the nature of the problem. This implies that with exploratory research, the researcher seeks to answer the questions “*What is it?*” And “*Why is it?*” Answers for these questions provide the findings which are discussed in Chapter 4. Furthermore, as data were collected and new knowledge emerged, the researcher lent to becoming descriptive. Descriptive research is conducted to describe phenomena in the context in which they exist (*Anon*). It is used to identify and obtain information on the characteristics of a particular problem or issue. Descriptive research goes further in examining a problem than exploratory research

3.6.2. Research Paradigm

One of the research strategies that have continued to receive increased scholarly attention recently is Design Science Research (DSR); although this research strategy is not new, (*as it originates from engineering and architecture*) it become popular in information systems (IS) research only recently. Hence, there is a need for IS scholars to embark on further research to enhance understanding and generate knowledge on how it can yield new findings in the study of IS processes (Wayne, 2010). Citing discussions by Walls et al. (1992), Wayne, (2010) explains that DSR process involves the search for a relevant problem, the design and construction of an IT artefact, as well as its’ ex ante and ex post evaluation; thus, the fundamental research attention in DSR is given to the ‘*design*’ of artificial artefacts and the process of creating something new that does not yet exist. Hence, in this context, design is a process (*or set of activities*) of ‘creating something new’ and a product (i.e., the artefact that results out of this process).

Furthermore, one important goal in DSR is to search and solve practically relevant real-world problems (*or classes of problems*). DSR is a general research approach with a set of defining characteristics and can be used in combination with different research methods. One of the major requirements for DSR artefacts as opined by Hevner et al., (2004) is that artefacts must be proven to address an identified problem in order to be regarded as a credible research data. Artefacts are expected to contain

assumptions, design decisions and logic; thus, if the artefact successfully addresses an identified problem, then the underlying knowledge can be assumed to be credible. The evaluation helps to show the utility of the artefact and aid in explaining how the artefact addresses the identified problem as well as identifying the underlying knowledge contribution. Given these definitions of DSR, this research seeks to address a real-life problem identified among caregivers within the HBHC community in Du Noon.

As discussed above, DRS can be used in combination with several research methods. One of the methods which was mentioned in the research sub-questions (*Chapter 1, Table 1.1: Research Questions, methods and objectives*) was research-through-design, a method which is becoming prominent in the field of interaction design. Before discussing further, for clarity purposes, consideration needs to be given to Simonsen et al, (2010) who identifies three different design-research relations and argue that much can be learned from exploring and combining these perspectives.

These are

1. Research *for* design (Research-based design)
2. Research *into* design (research analysing how design works)
3. Research *through* design (design-based research) which also include design through research

Describing the various methods, Simonsen et al, (2010) explains that research for design is believed to have had the longest tradition and has been used in various fields such as engineering, product or industrial design, computer science and informatics. In this method, investigation of materials, mechanics and function has always informed design. In the second method, research into design, (also labelled as 'science of design'), studies are made into how design processes work. This development has shifted and expanded considerably to include new theoretical resources such as phenomenology and actor-network-theory (ANT). In these two methods, there is a distinction between design and research, designers and researchers although design studies may inform research for design.

The third method is research through design. In this method, design and research cannot be isolated because research works through design and design works through research. Here, there is a synchronization of both research and design working together in a continuous loop until a final solution is derived. Simonsen et al, (2010)

argues that this method has become central to contemporary design challenges and opportunities. This method is adopted in this research because it defines the process where initial contact with the research community presented a design which led to inquiry and further design. It is “...*about the complex multi-directional integrations of research and design, where design becomes as much a medium as research...*” (Simonsen et al, 2010).



Figure 3:7: Continuous loops in research-through-design

Zimmerman, Forlizzi, & Evenson, (2007) opines that in the field of Interaction Design, research through design is an approach where designers produce novel integrations of HCI research with the aim to create the right thing. This could be in the form of a product, service or system that could transform the world from its current state to a preferred state. This process enables interaction designers make meaningful research contributions founded on their strength in addressing prevalent problems. This design concept is adopted in this research because the desired design is intended to solve a real-life issue in the research community.

3.7. Methodology

Research methods can be defined as all the methods or techniques that are used for the conduction of research while Research methodology refers to ways to systematically solve the research problem (Anon). Since qualitative approach to research is mainly concerned with subjective assessment of attitudes, opinions and behaviour, the researcher depended heavily on subjects who are actively involved in HBHC services in the research community.

3.7.1. Research subjects

The research subjects were two caregivers and workers at SALT, an NGO at Du Noon for information and data collection. (*Workers were not interviewed but*

observed). Since the research focused on the process of getting stories from caregivers (and not patients), no patient was interviewed; this was also because caregivers and the NGO stated from the beginning of the research that due to the sensitivity of most of their patient's health issues, I would not be allowed to speak with anyone but can observe them if necessary.

One of the caregivers Mrs. Elizabeth Kula was chosen as a subject in the research because she has been working in Du Noon for more than fifteen years and has a broad and rooted understanding of the dynamics in the area. The second caregiver, Mrs. Patricia Fekema has over ten years working experience in the community as a care provider. She also manages her own NGO known as *Zusakhe* (which means "to-build"). Finally, the NGO SALT was chosen as a subject because apart from providing care to women in Du Noon, they have facilities that provide healthcare, educational and legal services to the community.



Figure 3.8: Research Subjects

3.8. Source of data

Primary sources of data for this research were qualitative methods such as interviews (structured and unstructured), with the sample group, participant-observation, observation notes, photographs, video and audio recordings, literature and case studies. The table below defines how the characteristics of qualitative methods adopted for this research affected the process of data collection in the research community. The process which is derived from Holliday, (2002) is divided into activities, beliefs and steps.

	Characteristics of Qualitative Research	Practical application in research community
Activities		
1.	Looks deep into the quality of social life	In order to understand the unique dynamics of Du Noon, it was necessary to consider aspects of the social life, perceptions, lifestyles, etc
2.	Locates the study within particular settings	The research was located within the HBHC setting (specifically, caregivers) and did not focus on generalized healthcare issues in Du Noon which are well beyond the scope of this research
3.	Initial foray into the social setting leads to further, more informed exploration as themes and focuses emerge	Expectedly, as the research process progressed, new information emerged through interaction with the research participants
Beliefs		
4.	Conviction that what is important to look for will emerge	Research always start with a fuzzy-front-end, but important focus areas emerged with more interaction in the research community
5.	Confidence in an ability to device research procedures to fit the situation and the nature of the people in it, as they are revealed	Research procedures kept changing due to the uniqueness of the context. For instance, the researcher had to volunteer to serve food in order to be accepted in the community. This was not previously envisaged.
6.	Realities contains mysteries to which the researcher must submit, and can do no more than interpret	One of the realities during this process was that most of the stories were from HIV/AIDS patients who were predominantly ladies and the researcher could not be allowed to speak directly with them. The caregivers functioned as the mediator to capture stories.
Steps		
7.	Decide the subject is interesting (e.g. in its own right, or because it represents an area of interest)	The concept of storytelling by caregivers was seen as interesting and an area of interest by the researcher.
8.	Explore the subject and let focus and themes emerge	As the subject was explored in Du Noon, pre-conceived focus on HIV/AIDS shifted to a more important need to be accepted to conduct the research in the first place due to the sensitivity of the topic
9.	Devise research instruments during process	Basic research instruments used in the research were observation of caregivers in their work practice, interviews, case studies, photographs, videos,
10.	Principled development of research strategy to suit the scenario being studied as it is revealed	As mentioned earlier, the strategy adopted was to serve as a volunteer. This allowed for building rapport, friendship and trust which eventually opened more doors for discussion and acceptance.

Table 3.6: Contextualizing characteristics of qualitative method

3.9. Data analysis

This section looks at the need to validate data collected and the implication on the research. It also discusses how these data are converted into visual content as well as the methods used in the process.

3.9.1. Validation of Data

According to Holliday, (2002), there is need, in research to justify how the research strategy best suits the research setting not only in terms of feasibility but also in

researcher-participant relationships. This is necessary because to meet the exigencies of the social situation being undertaken, freedom is needed to search creatively, the best way to approach the scenario. Given this background, this research adopts notions upheld by Holliday. These are itemized in Table 4.6 below. Their implications on the research are also identified.

SOURCES OF VALIDITY		
	Suggestions by Holliday, (2002)	Implications on this research
1.	Choice of social setting <ul style="list-style-type: none"> How it represents the research topic... How feasible (e.g. access) How substantial (e.g. Duration) 	The research is situated in Du Noon, a specific social setting from which interaction with caregivers provides an opportunity to address research topic. Access to participants was feasible and unhindered thus providing relevant data. Duration of data collection for this research was 7months (November, 2011 – May, 2012), while preparation (deciding on research community, literature reviews, writing proposals,) began in June 2011.
2.	Choice of research activities <ul style="list-style-type: none"> How they suit the social setting How appropriate to researcher-participant relationships 	Research activities were to focus on an under-resourced community in Western Cape and Du Noon fits perfectly with the desired social setting. The setting was also conducive for the researcher and the participants.
3.	Choice of themes and focuses <ul style="list-style-type: none"> How they emerged Why they are significant How far they are representative of the social setting 	Themes (and focuses) started emerging through analysis of data collected through interaction (interviews, observation) with the participants (and the community/social setting); these were significant because they provided contextual direction for the research as opposed to a pre-conceived idea of the researcher.

Table 3.7: Contextualizing validity of data source

This research is also guided by ethnography which is the branch of anthropology that provides scientific description of individual human societies (anon). Blomberg, Burrell & Guest (2003) defined it as accounts which always provide a descriptive understanding of people's everyday activities. Accordingly, ethnographers are basically concerned with understanding events and activities as they occur and not with evaluating the efficacy of people's everyday practices. For purposes of clarity, this research adopted this method because it does not seek to evaluate caregiving

practices in Du Noon but to describe processes used in collecting and collating stories by caregivers in this community for the propose of visually communicating them to the community.

According to Blomberg et al (2003), this is not to imply that ethnographic accounts cannot or should not be used to suggest how things could be different or to highlight inequities in current ways of doing things. However, they argued that to suggest changes or to evaluate a situation, the researcher first needs to understand it as it is. In their argument, they mentioned the slogan developed by the technology group at Xerox Palo Alto Research Centre which says *“that innovation requires an understanding of the present”*. To understand the *“present”*, data collected for this research were through qualitative methods such as interviews, observation, telephoning, emails, text messages, video tapping and audio recording of the participants, pictures. The image below shows various instances where these were used to collect and validate data

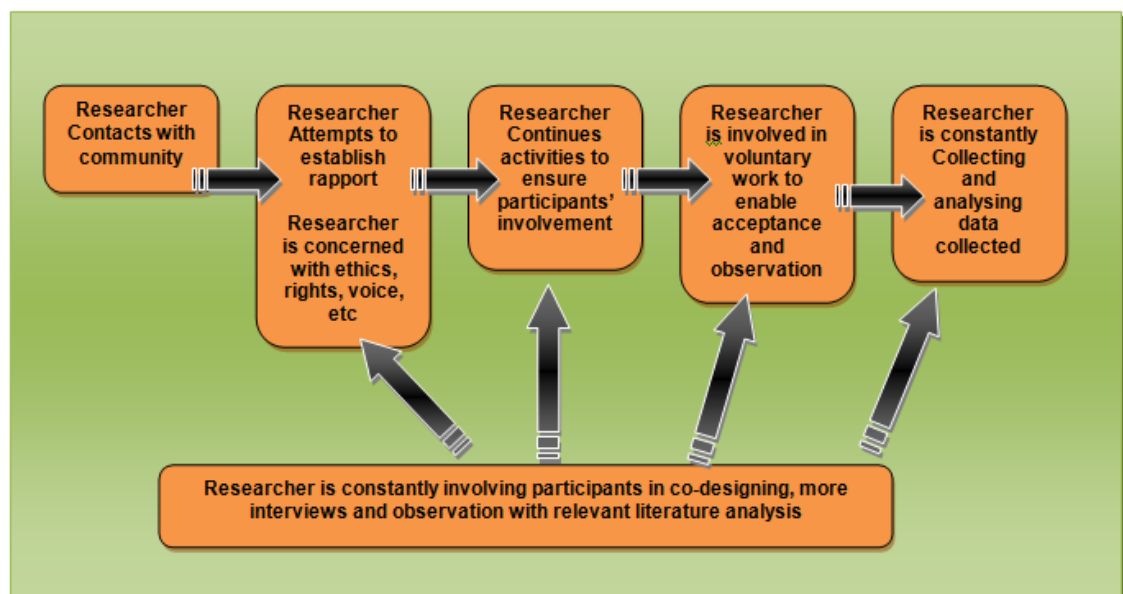


Figure 3:9: Steps to source data (Inspired by Holliday, 2002)

Another important aspect of the research which will be discussed is the process of converting these stories into visual content. It is important to state here that the researcher is a formally trained multimedia, design and visual arts personnel and can easily use various design and animation software. Thus, the entire process cannot be described here because of the complexity of explaining the functions of each menu in the software and the fact that one's ability to use the software is dependent on some

form of formal (or informal) training. However, attempt has been made to describe the steps taken in creating a visual platform for the stories.

3.9.2. Data analysis and coding

Data collected throughout this research was analysed using the framework developed by Srivastava & Hopwood, (2009) which supports iteration in data analysis. They argued that the role of iteration in qualitative data analysis should not be seen as a mere repetitive and mechanical task but as a reflexive process capable of sparking insight and developing meaning. Reflexive iteration involves visiting and revisiting the data and connecting them with emerging insights, progressively leading to refined focus and new knowledge. Citing the literature by Strauss & Corbin, (1998), Srivastava & Hopwood, (2009) believes that qualitative analysis is led by an inductive approach where the patterns, themes, and categories of analysis come from the data and “they emerge out of the data rather than being imposed on them prior to data collection and analysis” (Patton, 1980, cited by Srivastava & Hopwood, 2009). They added that Patterns, themes, and categories do not emerge on their own but are driven by what the researcher wants to know and how the researcher interprets what the data are communicating according to subscribed theoretical frameworks, subjective perspectives, ontological and epistemological positions, and intuitive field understandings.

In this framework, qualitative data analysis comprises of three iterative questions aimed at engaging the researcher in processes of continuous meaning-making activities

Nos.	Questions	Function
Q1:	What are the data telling me?	Explicitly engaging with theoretical, subjective, ontological, epistemological, and field understandings
Q2:	What is it I want to know?	According to research objectives, questions, and theoretical points of interest
Q3:	What is the dialectical relationship between what the data are telling me and what I want to know?	Refining the focus and linking back to research questions

Table 3.8: Iterative questions for data analysis (Srivastava & Hopwood, 2009)

Furthermore, an additional framework adopted in this research for the analysis of data was the thematic networks. Stirling (2001) proposes this framework for data analysis as a simple way of organizing a thematic analysis of qualitative data. Thematic analyses seek to uncover the themes that are prominent in a text at different levels, and thematic networks aim to facilitate the structuring and depiction of

these themes. Thematic analysis is not in any way a new method, but one that shares the key features of any hermeneutic analysis (Stirling, *ibid*).

A thematic network offers a web-like network as an organizing principle and a representational means. It makes explicit the procedures that may be employed in going from text to interpretation. Thematic networks systematize the extraction of:

1. **Basic Themes:** (Lowest-order premises evident in the text)
2. **Organizing Themes:** (Categories of basic themes grouped together to summarize more abstract principles)
3. **Global Themes:** (Super-ordinate themes enclosing the most relevant metaphors in the whole text). These are later represented as web-like maps illustrating the prominent themes at each of the three levels, as well as the connection between them.

Basic Themes are simple premises characteristic of the data, and say little about the text or group of texts as a whole. For a Basic Theme to be meaningful beyond its immediate meaning, it needs to be read within the context of other Basic Themes. Together, they represent an Organizing Theme.

Organizing Theme coordinates Basic Themes into clusters of similar issues of meaning that summarize the principal assumptions of a group of Basic Themes. They are more abstract and more revealing of what the texts entail; they help to enhance the meaning and significance of a broader theme that unites several Organizing Themes. Organizing Themes simultaneously group the main ideas proposed by several Basic Themes, and dissect the main assumptions underlying a broader theme ensuring therefore that a group of Organizing Themes constitute a Global Theme.

Global Themes are super-ordinate themes that cover principal metaphors in the data as a whole. A Global Theme can also be seen as '*a claim*' in that it is a concluding or final tenet. As such, Global Themes group sets of Organizing Themes that together present an argument, a position or an assertion on a given issue or reality. Thus Global Themes explains to us what the texts as a whole imply within the context of a given analysis. They are both a summary of the main themes and a revealing interpretation of the texts. Importantly, a set of texts may well yield more than one Global Theme, depending on the complexity of the data and the analytic aims; however, these will be much fewer in number than the Organizing and Basic Themes.

A Global Theme is the essence of a thematic network; therefore, an analysis may result in more than one thematic network

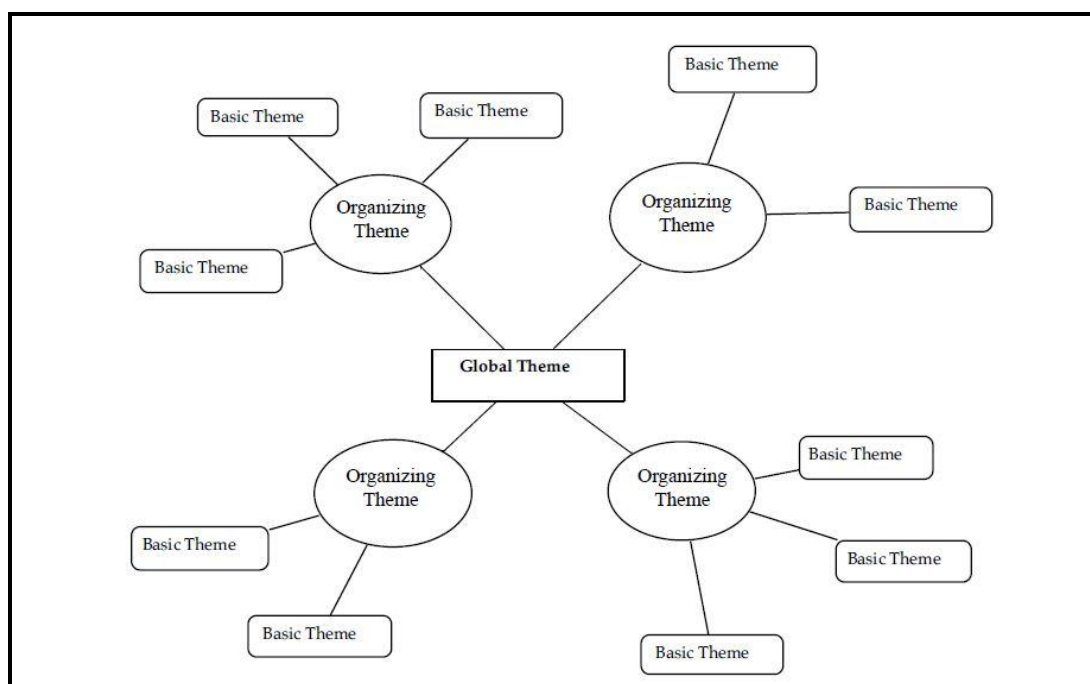


Fig.3.10: Structure of thematic networks (Stirling, 2001)

A thematic network usually evolves starting from the Basic Themes, working inwards toward a Global Theme. As series of Basic Themes are derived, they are sorted according to the underlying story they are telling and these become the Organizing Themes. Organizing Themes are then reinterpreted in light of their Basic Themes, combined together to illustrate a single conclusion or super-ordinate theme that becomes the Global Theme. Thematic networks are presented graphically as web-like nets to avoid notions of hierarchy, giving fluidity to the themes and emphasizing the interconnectivity across the network. Importantly, however, the networks are only a tool in analysis, not the analysis itself. As a thematic network is constructed, it then serves as an organizing principle and an illustrative tool in the data interpretation.

This framework was adopted in this research because of its feasibility and relevance to the research. As data were collected from the research community, basic themes emerged and for better understanding of the data beyond the peripheral, similar themes were merged to form organizing themes where the importance of the data transcended the obvious meanings. At each stage, interpretation of the data provided insight and learning for the researcher. As understanding of collected data are gained, the organizing themes were combined to form a more cohesive appreciation of the emerging reality. Below is a set of steps informing the analysis of data in this research using the thematic networks.

ANALYSIS STAGE A: REDUCTION OR BREAKDOWN OF TEXT

Step 1. Code Material

- (a) Devise a coding framework
- (b) Dissect text into text segments using the coding framework

Step 2. Identify Themes

- (a) Abstract themes from coded text segments
- (b) Refine themes

Step 3. Construct Thematic Networks

- (a) Arrange themes
- (b) Select Basic Themes
- (c) Rearrange into Organizing Themes
- (d) Deduce Global Theme(s)
- (e) Illustrate as thematic network(s)
- (f) Verify and refine the network(s)

ANALYSIS STAGE B: EXPLORATION OF TEXT

Step 4. Describe and Explore Thematic Networks

- (a) Describe the network
- (b) Explore the network

Step 5. Summarize Thematic Networks

ANALYSIS STAGE C: INTEGRATION OF EXPLORATION

Step 6. Interpret Patterns

Fig.3.11: Steps in data analyses using thematic networks (Stirling, 2001).

CHAPTER FOUR

RESEARCH FINDINGS

4. Introduction

In this chapter, detailed information will be provided describing how data was collected from the research community. Using qualitative methods for capturing, a step by step account will be provided about research activities in their natural contexts. Interviews, voluntary work, participant (*and non-participant*) observation and detailed iterative design and development activities provides the research with valuable data for analysis and interpretation. Through regular interaction with the research participants in their community, an enabling environment for dialogue, co-design and feedback is established. The primary respondents in this study were two caregivers and an NGO in Du Noon, Western Cape.

4. 1. Background to the research

This research at Du Noon builds on a previous research project conducted by student interns at Kujali Living Lab in 2010. It was initiated by the Department of Information Technology, CPUT) as a pilot for the “South Africa – Finland Partnership” (SAFIPA): Socio-technology for Africa project (Delen, 2011). The project was developed in response to an emerging trend where Personal Digital Assistant (PDA) technology began to play a major role in care practice and delivery. As a result, it became apparent that distinct technological solutions within the Home Based Health Care (HBHC) environment were potentially relevant in addressing issues affecting communities in need. The research team comprised of both IT and design students who investigated HBHC from different specialization perspectives thus making it the first cross-disciplinary study in the Faculty of Informatics and Design, CPUT (Delen, 2011)

Furthermore, the research by the Kujali Living Lab was conducted in close collaboration with The Stellenbosch Hospice in Kayamandi, Cape Town, South Africa. The above mentioned institution was selected for the research because of their active involvement with HBHC across impoverished areas and because they welcomed research endeavours that would explore some of the key issues in caregiving such as information and data management (Van Zyl, 2010). As a result, the research team conducted (in-depth) interviews with caregivers, patients/clients, nurses, and coordinators and were also allowed to accompany and assist caregivers in their daily ‘care journeys’. One of the outcomes of the research was the revelation that caregivers had a lot of stories to share about their care practice and the fact that they

eventually become emotionally attached to patients, patients' families and those they cared for as a result of the relationship they have developed over time (Delen, 2011).

4. 2. The ISD4D initiative

The IT department of CPUT, Cape Town campus between 17th and 19th November, 2011 played host to delegates, students and scholars from various institutions and countries around the world in a networking workshop tagged “ISD4D: A Holistic Information Systems Development Approach for Societal Development”. The aim of this event was to encourage meaningful discussions among participants at various levels as well as to initiate directions for new research into developing a comprehensive approach to socio-technical IS development capable of contributing to societal development (ISD4D approach) for technology and healthcare service in Africa.



Pic.1 & 2: A cross section of delegates at the ISD4D workshop (November 2011)

The conference was attended by delegates drawn from various African and International countries such as Finland, Nigeria, Mozambique, Cameroun, Swaziland, Angola, South Africa, etc. They embarked on a field trip to Du Noon, one of the under-resourced communities in Cape Town on Friday, 18th November, 2011. Delegates at this visit were from the University of Eastern Finland, Finland, Obafemi Awolowo University (OAU), Nigeria, Universidade Eduardo Mondlane, Mozambique; Cape Peninsula University of Technology, Cape Town and Nelson Mandela Metropolitan University (NMMU), Port Elizabeth, South Africa.

Du Noon was selected for this visit because it was closer to the CPUT, Cape Town campus where the conference was held in terms of distance. Du Noon is just a 20km drive from the Cape Town City Centre. Distance was a major consideration because effective research activities in the community could be largely affected by it. Since,

compared to other communities in need, Du Noon was relatively closer to Cape Town, CBD; it became practically feasible to consider visiting Du Noon. It also had some major health and socio-economic concerns such as the large influx of immigrants which strains the already insufficient health facilities. These factors, among other things inspired the team to consider undertaking research in Du Noon. It is important to state here that one of the delegates from Cape Town had been working with an organization in Du Noon for a while in the capacity of a birth attendant; thus, her “*insider*” view was also a contributing factor to the decision to visit Du Noon.

Another purpose of the visit was to offer a “*first handshake*” to the community through representatives (*from the community*) such as NGO workers and caregivers. It was also a formal introduction for the team into a complex and dynamic community that could benefit from practical ICT ‘solutions’. The team was hosted by Sharing Abundant Life Together (SALT), an organization that works closely with the communities of Du Noon and Joe Slovo. The meeting was held at the View Church, located in Table View. SALT’s primary mission is to “*Rescue the poor, Fight for Justice and Restore Dignity*”. It was established as a non-profit organization in 2003 to help alleviate some of the foremost challenges experienced in the vicinity of Table View. The organization supplies food parcels to people living with HIV/AIDS to assist them with their nutrition needs when taking their ARV medication. They also engage in caring for patients weekly counseling and legal advice. The team was given a basic overview of SALT’s activities by their director, Mrs. Paulene Klerk.



Pic.3- 4: Paulene Klerk of SALT addressing delegates.



Pic.5 Prof. Korpela asking a question

Pic.6 Cross section of delegates

After the meeting, the team was taken into the community to see things for themselves. The first stop was Zusakhe, a community organisation headed by Patricia Fekema who showed the team around the premises, elaborating on some of the services Zusakhe provides within the community. The team also embarked on a short tour of the community to see taken through the township, take pictures and visually assimilate the dynamics of the community. Lucy, a member of SALT and Elizabeth Kula, a caregiver in the community led the group, informing and answering questions from the group.



Pic.7: Lucy (SALT) and Elizabeth Kula led the delegates around Du Noon



Pic.8: Patricia Fekema taking questions



Pic.9: Delegates taking notes



Pic.10-11 A typical dwelling in Du Noon is made from wood and zinc



Pic.12 Du Noon Clinic

4. 3. Further research in Du Noon

Given the findings resulting from the visit by the team to Du Noon, fresh concepts and new ideas began to emerge for the purpose of further research. It became necessary to guide the research to focus on a specific area of the original idea (which was to explore storytelling by caregivers in the HBHC community for the purpose of sharing). Like the previous research carried out by the Kujali team in Kayamandi, the visit to Du Noon by the team led the researcher to discover that those who offer care in this community also had stories about their work practice. Until now, these stories have not been captured or stored in any retrieval platform. They only existed in the minds of the caregivers. This development was identified as a gap and a researchable problem because these stories by caregivers, if well captured, moderated and distributed could promote better health practices within the community. It could also be used for knowledge generation about HBHC in Du Noon.

The choice of exploring a platform that supports storytelling stems out of the researchers' background in animation, multimedia, arts and film production. Naturally, the researcher decided to lean towards a "safer terrain" where possibility of generating knowledge through the research is more feasible. As a result, it became necessary for the researcher to explore the relationship established by the visit in order to aid the research into process of capturing stories from caregivers, moderating, interpreting and distributing. However, another concern was discovered from the visit. Caregivers also had stories about their problems and limitations in their daily activities and are willing to share these stories. It becomes necessary for the researcher to delineate the research because attempting to capture numerous stories and problems faced by caregivers in Du Noon is obviously beyond the scope of this research and is definitely a direction for further research. The researcher found out that focus at this time should be on stories that describe caregivers' daily interactions and emotive engagement in the care space.

Another major finding from the Du Noon visit was the difference in the culture of the researcher and what obtains in the research community. Identifying this difference proved to be a major advantage of this research because instead of focussing on just capturing stories from caregivers in the community, there was also an urgent need to identify the cultural gaps, build a bridge for a meeting point that enables interaction, collaboration, co-designing an uninhibited research.

4. 4. Identifying social and cultural gaps

Dressler (2002) defines culture as a shared body of custom which is reproduced through time which makes societies distinctive. Belshek, (n.d.), also believes that although culture has various definitions, it affects the way people conduct themselves in their society because of their ideas, values, attitudes, and normative or expected patterns of behaviour. Citing definitions by Hall, (1974) and Hofstede (2008), Belshek opines that culture is not genetically inherited, and cannot exist in isolation, but is usually shared by members of a society. He added that culture is the collective programming of the mind which distinguishes members of one group from another and is usually passed from generation to generation, continually modified as each generation adds something of its own before passing it on.

Similarly, the American Psychological Association (APA, 2012) defined culture as

“the quality in a person or society that arises from a concern for what is regarded as excellent in arts, letters, manners, scholarly pursuits...a particular form or stage of civilization, as that of a certain nation or period, development or improvement of the mind by education or training, behaviours and beliefs characteristic of a particular social, ethnic, or age group...”

As a non-South African, the researcher was mindful of these cultural gaps that might become limitations in the research process.

The researcher as part of The Kujali Living Lab which comprise of individuals from different countries and cultures in Africa understood that there was a critical need “to develop a new repertoire of skills and abilities to manage and/or work with people whose cultures and value systems can be significantly different from those at home” (Tung, 1995, cited in Zhang & Lowry 2008). Furthermore, understanding the role of culture is crucial to the study of information technologies because culture at various levels, including national, organizational, and group, can determine the successful implementation as well as use of information technology (Leidner & Kayworth, 2006). Leidner and Kayworth (*ibid*) also noted that due to its’ multiple divergent definitions and measures, culture is a challenging variable to research. Some of the initial gaps (limitations) identified by the researcher from the onset were

1. Language barrier: The researcher only spoke English language which might be a major concern and limitation to effective communication.

2. Education: A lot of the prospective participants in the community whose stories will be used are illiterate and might not understand the relevance of the research.
3. Bias from the community: The researcher is from a nation that has a suspicious reputation within the community as a result of past and recent happenings. These concerns were made clear by one of the caregivers from the onset.
4. Sensitivity of the research area: Although the research was not particularly focusing on HIV/AIDS, most of the prospective participants whose stories are told are either positive or associated with someone who is.
5. Stigmatization: There has been a lot of stigma associated with people living with HIV/AIDS. A lot of people in the community who are infected are still stigmatized.
6. Gender considerations: The researcher was delving into a HBHC community which till now is an area heavily dominated by women.
7. Failure of previous expectations: One of the caregivers expressed reservations about the possibility of any meaningful result from a new research based on her experience with previous failed projects.

After identifying these problems, it became necessary for the researcher to devise a process of negotiation that would ensure easy access to information and unrestrained research.

4. 5. Negotiating with respondents

In spite of these limitations, it is possible to negotiate between culture over time through intense interaction and collaboration (Walsham, 2002 cited in Katharina, Roman, & Wayne, 2010). Discussing cultural gaps, Usunier (1996) argued that the more articulated a gap is between negotiating parties, the greater the potential for misinterpretation and the more time they will spend dialoguing. He identifies four ways by which culture can negatively affect negotiation.

- By conditioning one's perception of reality.
- By blocking out information inconsistent or unfamiliar with culturally grounded assumptions;
- By projecting meaning onto the other party's words and actions;
- By possibly impelling the ethnocentric observer to an incorrect attribution of motive.

The ability to negotiate successfully is critical in many social interactions thus negotiation is a tool by which humans can resolve differences in various settings including diplomacy and personal relationships (Haim, Gal, Kraus & Blumberg, n.d.). Negotiation is also a tool for solving conflict situations, some of which requires more intensive preparation, planning, and negotiating than others (Belshek, n.d.). In order to gain acceptance in this new community, it became necessary for the researcher to depend on individuals from within the community who have been doing community work for long time. These individuals are to function in the capacity of gatekeepers.

According to Shenton & Hayter (2004), a fundamental tasks in embarking on a fieldwork for qualitative research lies in “gaining access”. This involves both securing entry into a particular organisation (or community) and ensuring that individuals involved in the research will provide meaningful data for the research process. This notion is upheld by Wanat (2008) who believes that negotiating access is largely based on building rapport and good relationships with gatekeepers. Through the ISD4D visit to Du Noon, the researcher was able to meet individuals who would help the research process. These people have rooted knowledge in the dynamics of the community.

In order to make a good first impression during the visit, the researcher prepared a short animation for Doreen Mugendi, a nurse and researcher who as part of the ISD4D team, was researching on Prevention of Mother to Child Transmission (PMTCT), through breast feeding. The animation was a 2D animation and about a minute long. The animation incorporated aspects of motion graphics, music and audio narration. The video was saved on mobile phones and made available to some members of the delegates. During the visit, the researcher made the video available to the staff at SALT as well as the caregivers who were excited about the concept. They picked interest in the platform which for this research was a good start.

It became necessary to follow up on the outcome of this meeting so the researcher got the information and contact details of the people who would form the core participants (gatekeepers) in the research. These were, Pauline Klerk, Elizabeth Kula and Patricia Fekema. These people were chosen because of their roles in the community. Pauline Klerk is the director at SALT. She coordinates everything from implementing the vision of the organization to making major decisions and directions for the organization. She also has a lot of staff working with her. Patricia Fekema is a caregiver and the Manager of Zusakhe, an NGO situated in Du Noon. Elizabeth Kula is a caregiver who has been working closely with the community for over twenty

years. Frequent calls were made to establish this relationship and nurture it to a position of trust where the participant is comfortable for a face to face meeting.

4. 6. Exploring an acceptance strategy

As familiarity began to grow between the researcher and the gatekeepers, the researcher also noticed some level of withdrawal and discomfort from the caregivers who work in the community. Worried by this development, the researcher queried this and was informed by the caregivers that the ladies cannot speak directly to me for many reasons. These include:

1. That the ladies feel uncomfortable seeing a male in their midst
2. There is still a subdued form of stigmatization in the community concerning people living with HIV/Aids and TB.
3. A lot of the ladies in Du Noon are Xhosa speaking. Language is major problem because majority of the ladies cannot communicate meaningfully in English and the researcher at this time cannot speak Xhosa language.
4. Ethics demand that the researcher respect the privacy of the ladies.

These limitations (or concerns) were made known earlier in the research by the caregivers. This development also corresponds with the original objective which is to explore developing a platform for caregivers (not patients) to tell their stories. It therefore follows that the stories for this research will depend largely on the caregivers and NGO who work directly with the ladies. This also implied that there was a need to strengthen the relationship with the caregivers in order to have credible and relevant information. As a step forward, the researcher decided that aside making periodic calls, interviews and visits, another way to gain acceptance into the community was to become a volunteer in SALT, one of the organizations that attend to community needs. A full description of the voluntary work, transcript of interviews with the caregivers and staff at SALT are available as appendix in this thesis.

Volunteering to serve at SALT became an important discovery in this research. This is because aside gaining trust with the research participants at the NGO; they were willing to share more information (stories) with the researcher because of trust gained over time. This also translated into acceptance by the ladies who eventually became more relaxed and comfortable as they started seeing the researcher as a “friend” serving and attending to their needs. It is important to note that before being allowed to serve the ladies, the researcher was asked if it conflicted with his own culture to serve ladies. This was a cultural concern expressed by one of the staff at SALT. She

said that in some African cultures, it was not proper for men to serve food and drinks to ladies. The researcher informed her that there was no problem serving the ladies. Having overcome the first hurdle of trust and cultural differences, it was time to get more data for the research with the next step been understanding Du Noon as a community from an insider with experience.

4. 7. Findings from Du Noon

The next section looks at some of the findings from the research community.

4.7.1. Socio-economic context

One of the earliest gatekeepers contacted was Mrs. Elizabeth Kula, a caregiver who has been working in Du Noon for more than fifteen years. This information from an *“insider”* gave the researcher access to useful data which describes the community. It is important to state that the information provided is a personal expression of the research participant and not necessarily a general view by everyone in the community.

Du Noon was originally used for farming by white farmers but at the demise of apartheid, the farmers sold their lands to the newly elected democratic government. Du Noon as a community was set up by the government in 1996. In order to address the problem of housing, the government developed and implemented the Reconstruction and Development Programme (RDP) framework to address the immense socioeconomic problems which was a result of the struggle against its predecessors under the Apartheid regime. Du Noon can be classified as "informal settlement", a "previously disadvantaged area" or a "township". It is located to the east of Table View, and north of Killarney Gardens. Many people living in Du Noon are very poor and many of them still live in what is known as “shacks” or "Wendy houses".



Pic.13 Du Noon

According to Mrs. Kula, in order to address the problem of accommodation, houses were built by the government and allocated at a highly subsidized price to indigenes through a specific allocation process. The RDP houses as they are known are about 40 square meters in size. They usually accommodate a family of between 6 – 14 people. The population of Du Noon used to be about 40, 000 people but population has tripled over the years to about 120 – 160, 000 people clamouring for the same amenities. Most people who benefited from the house allocation have pulled down the original structures and erected new and bigger ones. The aim is to rent some rooms out to foreigners in order to get money to support themselves.



Pic.14 – 15 (A typical Du Noon accommodation)

The area is over-populated. The unemployment level is so high with the level of education very low. Many of those who have jobs work as domestic workers in nearby affluent areas like Table View, Bay Side, Park Lands, etc. There are also some small business entrepreneurs (*Pic.16*) who support themselves and their families through petty businesses. There is a mixed population in the area as most of them are locals from eastern and northern cape. There are many migrants in search of better life who flood the community in search of a fresh start, thus clamour for existence is rife. Du Noon is type of African microcosm. Foreigners from Somalia, Nigeria, Angola, Mozambique, and many other African countries reside in the area. This escalating population has constantly contributed to violence, theft, rape, drug abuse, etc. Teenage pregnancy is a huge problem with many teenage girls dropping out of school and infected with HIV. It is estimated that 50% of the population of Du Noon is infected with the virus; however, various NGOs and church organizations continue to educate the community about safe sex, use of ARV's and healthy nutrition.



Pic.16: A visit to a small business entrepreneur in Du Noon

Expectedly, sanitation in Do Noon is very poor. Most families and residents have to share toilets and other amenities. About 4 to 5 families share a toilet and a family usually consists of between 6 and more people. Although the community has provision for running tap water, they still need to with a tap with 20 -30. Due to poor health sanitation practices, the drainage is sometimes blocked with wastes and this eventually causes the drainage to burst open, spilling water on the road. The smell is always terrible and affects the air.



Pic.17 -18: (A set of toilets in Du Noon)

There are NGOs and churches working in the community to alleviate the burdens of residents through many projects. These include SALT, MOSAIC clinic, St. Laurens Anglican Church and the like. However, many people still do not have jobs and go into neighbouring communities and industries looking for employment. Most of the middle-aged (40-55years) cannot find jobs and depend on charity from neighbouring

communities where they beg for food and money to support themselves. There are many elderly and bed-ridden people in the area.

There is always a rise in crime (especially theft and burglary) during festive periods. Criminals, made up of unemployed youths, break into homes forcing residents to part with their valuables. This development has been a major source of concern for residents for many years. The community decided to tackle crime in their own way by setting up a Community Policing Forum (CPF) aimed at reducing crime. Most of the streets are filled are tarred and have speed-breakers to avoid accidents by speeding drivers. In spite of all these findings, it is important to note that residents always look for a good opportunity to relax and have a great time. For instance, the “KWA-GEORGE” is a popular relaxation spot in Du Noon where people come to have “*Chisanyame*” (a Xhosa word referring to barbecue).

Another gate keeper who played a major role in providing data in this research was Mrs. Patricia Fekema. She also shed some light about The Swap Shop, another unique project in Du Noon.

4.7.2. The Swap shop

This is a concept that started in August 2011 to promote a clean environment. As previously mentioned, the community is over populated and this has had a negative effect on sanitation. Most of the streets are usually littered with plastic bags and empty bottles. This development inspired Mrs Patricia Fekema to come up with a concept which seeks to address the problem of sanitation. Explaining this, she said that residents are encouraged to collect plastic bags and bottles that litter the streets and bring them to her office where they swap them for “points”. According to Mrs. Fekema,

“...depending on the number of points you earn, you can trade them for gifts such as clothes, shoes and food stuff”

The swapping takes place on Tuesday mornings. This initiative has been widely and readily accepted by the community thus resulting in a cleaner environment. Residents no longer dispose of their plastic bags and bottles in the bin but diligently preserve them for the swap shop. Most of them actually walk around the streets searching for plastic bags and bottles. On Tuesdays, recycled refuse is collected and stored in a big Banana boxes and later taken to nearby companies for recycling.

Due to the community response to this initiative, Wednesdays were added to collect plastics from men and children while Tuesdays are reserved exclusively for women. The men who were initially shy to participate in this initiative now show interest because they could get foodstuff and clothes in return. The outcome of this is that most families are now able to cater for themselves and the men are particularly happy that they have to work and not beg for financial assistance. According to Mrs Fekema

“They see it as a more dignified way of making ends meet as opposed to relying solely on government grants”.

As the news of this initiative spread to neighbouring communities, residents of Joe Slovo and Atlantis have indicated their interest to replicate it in their area.



Pic.19: (Banana bags used in the Swap Shop)

4. 8. Identifying relevant caregivers' stories

Having gathered basic information about the life and activities at Du Noon, it was time to narrow the search to relevant data that answer the research questions. The first of these was to inquire about the situation of HBHC in the community. The finding provided by one of the caregivers (and supported by all research respondents) was that like many South African townships, Du Noon was suffering from lack of basic infrastructure in their clinics. The validity of this information was further justified when in January 2012, residents embarked on a demonstration to draw the attention of the government to their plight. The incident was captured online (WCN, 2012) in an article titled "Du Noon clinic closed by health committee dissatisfied with city's upgrading efforts". According to this report, residents were dissatisfied with the condition of health in their community.

“The Du Noon clinic was the centre of protests earlier this year, when residents complained about its sub-standard infrastructure which impacted on levels of care. After initially being forcefully shut down by Du Noon residents for four days in January, City officials undertook the revamp of buildings and in the meantime maintained a skeleton crew at the clinic for chronically ill patients and the dispensation of ARV and TB medication”.

The caregivers reiterated that they need to work overtime under very demanding conditions that are not always conducive in order to cater for patients who rely on them for emotional support and care. Two of the research respondents (Mrs. Fekema and Paulene of SALT) have physical structures where they attend to patients weekly. This is important because since some of their patients are still stigmatized in the community, it is important to have a place where patients can be attended to without prying eyes. Constant visits by caregivers to patients in their homes usually arouse suspicion from the community and in order to protect the patients, it became necessary to have a place away from the patients' home where care can be given.

Asked about the kind of stories they would love to share, they informed that although their community is still under the pressure of coping with HIV/AIDS, they would love to address other issues also. The focus at the beginning of this research was on HIV/AIDS and TB but after interacting with the community through the caregivers other themes started emerging.



Fig 4.1: Researcher's preconception of focus

Caregivers mentioned that although they would love to share stories about patients who have risen above the limitations of the disease, other salient issues that need to

be addressed aside TB, HIV/AIDS and maternal health included parental role in child upbringing, sex education, alcohol abuse and maternal health.



Fig 4.2: Researcher's new findings

4. 9. Identifying relevant story platforms

The researcher also discovered that presuming that a mobile platform was the needed solution for sharing stories in the community was misleading. Literature presented in chapter 2 show that the use of mobile phones has become popular around the world. Similarly, recent statistics (BlueMagnet, 2012) show that there are 34 million adult in South Africans and 26 Million are mobile phone users. However, findings during this research show that many people in Du Noon do not have mobile phones that support any form of video format. This discovery led the researcher to consider other platforms that will enable sharing of caregivers stories within the community.

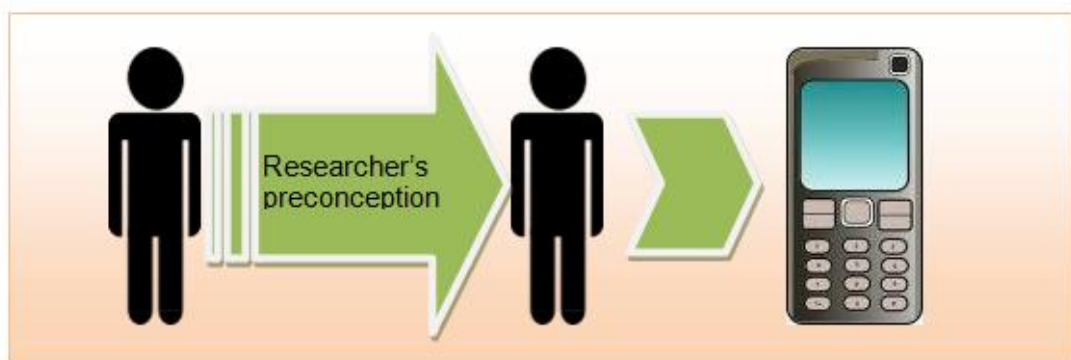


Fig 4.3: Researcher's preconceived platform

With more interaction with the respondents, the researcher was advised to explore adding print to the preconceived platform in order to effectively reach more people in the community. And because most of the indigenes in Du Noon are Xhosa speaking, the caregivers also suggested that the stories be translated into Xhosa language.



Fig 4.4: Researcher's & suggested platform

4. 10. Considering relevant language

There was a need to explore translating the animations and cartoon strips into Xhosa language because many of the ladies could not read or understand the stories which were originally done in English. This was valuable feedback from the caregivers after they showed the video clips and cartoon strips to patients in the community. Since the researcher could not speak the language, Siphokazi Tswane, a Masters student from CPUT and Xhosa speaking person was asked to translate the stories into Xhosa. Audio translations were used for the videos. This enhanced the relevance of the stories in the community as more people were able to understand the stories and the message they present. Copies of the actual cartoons strips and links to the some online videos are provided as appendix in this thesis.

4. 11. Beyond the research findings

Having determined the above information from the research action, the researcher also discovered that many stakeholders from other sectors like agriculture, education, IT, and engineering in CPUT became interested in exploring storytelling as a way of disseminating information. They found the concept relevant to their fields and as a result various pilot projects were done along the line of storytelling; links to online videos and cartoon strips are available as appendix.

It is also important to note that the researcher is the project leader of E2 Storyworld, a project in the Kujali Living Lab of Cape Peninsula University, Cape Town campus which explores storytelling for the purpose of informal learning and sharing information. The relevance of this research, analysis of data from the research community, interpretation of findings, and further discussion will be the focus of Chapter 5.

CHAPTER FIVE

DISCUSSION AND INTERPRETATION OF FINDINGS

5. Introduction

In this chapter, the research findings mentioned in Chapter 4 will be discussed while analysis and interpretation to data from Du Noon, the research community will be provided for clarification. Discussion on the framework(s) adopted for data analysis will also be explained in detail and in context. Furthermore, insight will also be provided into the objectives and relevance of the E2 Storyworld project which is a direct product of this research.

5.1. The use of tools in research phases

According to Bazeley (2009), although identifying themes has its place in qualitative research, they are a starting point in a report of findings from a study. Therefore, effective reporting requires the use of data and the ideas generated from the data to build an argument that establishes the point or points one wishes to make. As explained in Chapter 4 (*Session 4.8. Data Analysis and coding*), research data was analyzed using the framework developed by Srivastava & Hopwood (2009). This framework supports reflexive iteration in data analysis which involves continuous visiting and revisiting of the data while connecting them with emerging insights, progressively leading to elaborated focus and novel cognition. In other to provide a continuous generation of meaning this framework adopts three iterative questions.

Q1: What are the data telling me?

Q2: What is it I want to know?

Q3: What is the dialectical relationship between what the data are telling me and what I want to know?

Contrary to itemizing individual tools and the point of usage, this research in adopting this framework will discuss summaries of findings and how these tools were used (contextually) to analyse the data. This is reflected in the table below.

Nos.	Questions	Contextualizing emerging themes	Tools used
Q1:	<p>What are the data telling me?</p> <p>Function <i>Explicitly engaging with theoretical, subjective, ontological, epistemological, and field understandings</i></p>	<ul style="list-style-type: none"> Healthcare in Du Noon is a major concern for caregivers due to unequipped clinic facilities. Caregivers are open to solutions aimed at addressing healthcare issues in the community. Caregivers unanimously agreed that storytelling in the healthcare sector has been underexploited in the community. More platforms like print (and web) need to be explored as opposed to just mobile. Translation to indigenous language is important for meaningful communication. 	<ul style="list-style-type: none"> Structured and Unstructured interviews. Observation
Q2:	<p>What is it I want to know?</p> <p>Function <i>According to research objectives, questions, and theoretical points of interest.</i></p>	<ul style="list-style-type: none"> What kinds of knowledge/experiences are relevant to share among caregivers? How can platforms that enable caregivers share stories about their work practice be designed? How can existing facts, knowledge, experience and values by caregivers in the HBHC be converted into stories? 	<ul style="list-style-type: none"> Structured and Unstructured interviews. Observation Research-through-design Co-designing
Q3:	<p>What is the dialectical relationship between what the data are telling me and what I want to know?</p> <p>Function <i>Refining the focus and linking back to research questions</i></p>	<ul style="list-style-type: none"> Caregivers are encouraged to share more stories with the researcher knowing that their stories can provide information for people in the community. Caregivers are willing to suggest platforms suitable for their context as opposed to imposition by the researcher. One good way to be accepted in a “culture” for the purpose of research is to volunteer to serve the custodians of that “culture”. (Note that culture is ambiguous and here refers to the belief, way of life, perceptions of the Du Noon community) There is need for further research in Du Noon community extending the focus beyond sharing to evaluating impact of stories on the community. 	<ul style="list-style-type: none"> Structured and Unstructured interviews. Observation Research-through-design Co-designing Literature reviews

Table 5.1: Contextualizing reflexive iteration framework and research tools

5.2. Summary of Key Research Findings

Having analysed the data using Reflexive Iteration and Thematic Networks framework, below is a summary of key findings from the research community based on analysis and interpretation of data collected.

5.2.1. Summary of main findings

- HIV/AIDS is a major problem in Du Noon community as presumed by the researcher before the commencement of the research but findings show that the problems associated with HIV/AIDS include stigmatization and inability of infected individuals to get jobs easily due to their status.
- However, findings show that caregivers in this community have identified other pressing need such as maternal health, drug and alcohol abuse, need for parental guidance, teenage pregnancies resulting in early school drop-outs, crime, etc.
- Findings reveal that performing a research in a “*sensitive*” community is possible. (*Sensitive in terms of a community with health concerns like HIV/AIDS and largely dominated by ladies*) by ensuring that the respondents are comfortable with your research. In this particular case, the researcher was not judgmental and bias towards the health status of some of the ladies whose stories were told.
- The researcher needed to work at being accepted in this community for the purpose of unhindered access to data because of previous bias stands upheld by members of the community towards the origin of the researcher. When the respondents became comfortable with the researcher, they provided more information.
- Findings show that contextualizing solution for this community is necessary for relevance because designing a solution without grounding the logic and design in Du Noon context could have led to a misleading, unrealistic and irrelevant solution. Thus, the preconceived notion that mobile solution is best for this community was probed further.

5.2.2. Summary of community findings

- Findings reveal that caregivers were working in an environment that affects their efficiency level in terms of meeting with all the care needs of patients living with HIV/AIDS.
- Findings from this community show that a large population of people living with HIV were ladies and are usually single mothers saddled with the responsibility of fending for their families.
- Findings in Du Noon show that since the researcher was a male researching within ladies, acceptance in this community could be difficult if adequate steps to explore use of gatekeepers are not followed. The researcher depended heavily on gatekeepers from the NGO, SALT and with two other ladies working as caregivers in the community.

5.2.3. Summary of caregivers view on storytelling

- Findings show that caregivers are dissatisfied with infrastructures in the HBHC in their community as this limits their performance ability; hence they quickly accepted the possibility to explore storytelling.
- Findings also reveal that they are receptive to any design (or platform) that can be used to address problems in their community as this will extend their scope of influence.
- Caregivers who were part of this project were all willing to tell stories about their work practices. They derived pleasure in telling their stories and in the researcher listening to them. They told stories ranging from maternal health to drug and alcohol abuse. They saw themselves as custodians of detailed health information of most patients in the community.
- Findings show that caregivers were concerned about the relevance and success of the concept and provided an enabling environment for the research by willingly providing detailed accounts of each story so that the researcher would not miss out on vital messages. To this end, the researcher always cross-checked edited stories and facts with the caregivers to ensure that no information is lost in the process of converting and editing stories.
- Caregivers in this community noticed that most of the stories were in English language and this will hinder the anticipated impact in the community as most residents are Xhosa speaking. Thus, they advice on translating these stories into indigenous languages to enhance acceptance and effective communication in the community.

5.2.4. Summary of stories acceptance in the community

- Findings show that caregivers' stories were relevantly meaningful within the Du Noon community as they could relate to the stories
- Findings also show that many community members in Du Noon who are the end-users of the content were not very happy with the initial video platforms as most of them at the point of this research did not posses mobile phones capable of displaying video contents.
- Community members felt alienated from the project and expressed same to their caregivers who informed the researcher of the need to consider another platform, hence the design of a print version.
- The print version was readily accepted in the community as an efficient way of disseminating stories by caregivers.
- Findings reveal that the initial prints had minimal impact in the community because they were all written in English language which made it difficult to

understand. Thus, the end-users expressed the need to translate the stories into Xhosa language.

- Findings show that community members were happy that their stories were carefully converted into edutain materials without divulging their identities.
- They believed that although the cartoon characters were funny-looking, they conveyed useful and serious information that could change lives within the community.
- Findings show that community members expressed fulfilment that their stories could have positive influence on the lives of people passing through the same problems within the community.
- Findings show that the community members are willing to share more stories which will be converted into edutain materials with their caregivers.

5.2.5. Summary of data findings

- HBHC is beneficial to communities in need but more effort need to be done to encourage caregivers perform better.
- Acceptance for the purpose of research is possible through negotiating cultures. Since most of the people in Du Noon are predominantly Xhosa speaking people, it was necessary to ensure that most of these stories are translated into Xhosa language. The researcher had to engage the skills of indigenous Xhosa speaking lady to translate the stories.
- Findings show that storytelling by caregivers (*and health practitioners*) in Du Noon community has been underexploited. No caregiver who took part in this research could specifically say if storytelling has ever been used as a tool for information sharing in this community before now.
- Findings show that there is potential in exploring storytelling by caregivers for the purpose of sharing in Du Noon community as caregivers have more stories beyond the scope of this research to share.

5.2.6. Summary of activity phases

- Findings show an environment under-resourced, frustrated and in need of motivations. Each phase revealed that caregivers want to do more to help attend patients' needs but are handicapped by poor infrastructures.
- Activity in this community reveal a need for further research into improving current social circumstances, education, Information systems and technology.
- Healthcare strategies as well as the working conditions of caregivers need improvement. Many caregivers still do not have access to periodic skills

update and trainings. Similarly, many of them lack good mobile phones to share stories with their patients.

5.2.7. Summary of production phases

- A basic grounding in the use of drawing, script writing and design software is necessary to translate textual into visual.
- However, since the field of Interaction Design encourages multidisciplinary coexistence, relying on people with design qualities could also be adopted should the researcher lack design; scripting and animation knowledge. In this case, the researcher has to be firm on directions he wants the research to take.
- Findings show that dividing the production process into 3 importance phases (namely Pre-production, Production and Post-production) helps for logical arrangement and direction. (Refer to Fig. 5.1)
- Findings show that producing a visual content that is relevant and meaningful to the community is largely dependent on contextualizing the content. This is possible through co-designing with stakeholders from the research community because deciding on what is best for a community could be misleading without involving the actual users in all design stages. In this case, the researcher being the designer of the experience co-designed with the caregivers who are the owners of the experience. Although the caregivers were not skilled in drawings and illustrations, they provided clues as to best diagrams that would be acceptable and relatable to actual stories.

5.2.8. Summary of respondents' findings

- Since caregivers are an integral part of this research process, the researcher was in constant interaction with them to validate content and ensure that interpretation did not detract from the original message.
- Findings show that respondents were happy that the researcher always consulted with them to ensure that the interpretation of their stories were true. This led to confidence that storytelling could be explored further in Du Noon.
- Respondents were the first to point out the need to explore print version of their stories for distribution in their community. They immediately informed the researcher of the need.
- Respondents were however of the opinion that producing only visual content could have a restricted reach because many people in the community who would use this stories do not have mobile phones that support video.

5.2.9. Design findings

- As described above, findings also show that adopting an appropriate design for the research process is essential but must be contextually relevant because one of the earliest surprising discoveries was that the '*brilliant*' video animation could not be distributed everywhere in Du Noon since not everyone has the facility on their mobile phones..
- Findings show that each community (and culture) is unique and will need a corresponding unique design. Du Noon is under-resourced and most residents are poor, not able to purchase expensive mobile phones; thus, it was necessary to design a print version of caregivers' stories for distribution in Du Noon.

5.2.9.1. Findings on stigma (and other vices)

- There are still suppressed cases of stigma in the community which need to be addressed. Most women are unable to get good paying jobs once their HIV status is known to be positive.
- Findings reveal that due to the case of stigma in Du Noon, most of the caregivers are beginning to devise a means of meeting their patients in neutral locations (e.g. SALT invites ladies to their premises every Thursday) because most community members generally believe that once they see a caregiver visiting someone in their homes, the person must be HIV positive.
- Findings from Du Noon show that there is a prevalence of crime, drug abuse and theft in the community but the community police are doing a lot to combat crime and maintain security.
- Findings from Du Noon also show that xenophobia cases that have characterized the community in recent times have drastically been tackled and foreigners are becoming comfortable living in Du Noon.

5.3. Interpretation of main findings

These findings point toward a diverse community of different nationals that could benefit from various ICT solutions especially in the healthcare where available resources are not sufficient for the population. However, the provision of relevant solution to the Du Noon community is only possible by an inclusive and participatory process whereby stakeholders are active participants (*or co-designers*) of their solutions.

Furthermore, looking at the methods adopted in extracting these findings, it shows that ethnographic methods played a prominent role and enabled the capture of valid

research data. This was however preceded by adopting an Interactive Design (IxD) research method known as research-through-design as an initial contact to arouse curiosity and interest from the research community. This invariably led to a series of interaction, co-designing and iteration between the researcher and the stakeholders. Similarly, adopting participatory design methods empowered the caregivers to become active contributors in the process as opposed to imposing preconceived ideas upon them. It also allowed for valuable contribution and willingness on the part of the caregivers to provide valuable data for the research. This is important as data in this research needed to be carefully handled without identifying identities of individuals whose stories have been used.

Thus, patience, caution and understanding are required in collecting data from a sensitive community laden with HIV/AIDS and other health issues. This brings to fore the need for ethical considerations and knowledge on how to capture, manage, analyse and interpret data without infringing on the rights of others. During the earliest stages of this research, the researcher was patient with eventual respondents who pointed out their unwillingness to be a part of the research. One of them later revealed that her unwillingness stemmed from previous researchers who promised so much and delivered so little to alleviate their sufferings. Thus, the researcher pointed out that the research was purely for knowledge generation purposes with a possible ability to effect positive change. This was necessary so as not to raise unnecessary expectations that might not be met by the research.

Furthermore, ethically speaking, one of the caregivers made it clear from the onset that the researcher would not be allowed to interrogate any of the ladies living with HIV or be allowed to sit in any of their sessions. The researcher willingly and readily agreed to these rules of engagement in order to gain acceptance as refusal could have jeopardized the entire process. This was also necessary so as not to scare the ladies away from their sessions thus, truncating their healing process. However, as familiarity and rapport grew, the researcher was allowed to sit in sessions but not interview the ladies.

5.4. Exploring more design proposals

The need to explore more design solutions is a major finding in this research. The importance of identifying relevant solutions that are contextually relevant is essential for future research. This is particularly necessary because the dynamics of Du Noon as an impoverished community might be absolutely different from a place like Table View although both communities are not too far apart in terms of distance. Thus, one

of the proposals of this project is to argue that through research, ICT solutions and designs need to be “place-specific” and contextually beneficial to the end-user. According to Messeter (2009), over the last two decades, context of use has become a prominent matter of concern for interaction designers.

There is therefore, need in further research to identify through participatory designs and co-designing with the end user, to design (and develop) solutions that would be relevant in the community thus furthering the understanding of the problem context and how technology can adequately play an assistive role in community development.

5.5. Answering the research questions

Below is a table reiterating the research questions, methods and objectives of the research mentioned in Chapter 1; this is followed by discussions on how each of the questions was answered and how the objectives were achieved using the methods outlined.

Research sub-questions	Research method(s)	Objectives
Why is a HBHC service and caregivers important to the community?	Literature analysis	To describe the relevance of HBHC in any community, especially, the poor communities as well as establish theoretical definition of caregivers as well as their roles in the HBHC Community
In what context and platform has storytelling been used for the purpose of sharing and disseminating information?	Literature analysis	Determine the impact of storytelling in some projects worldwide. To understand the relevance of storytelling as well as access its relevance to this specific project and community
What kind of knowledge and experiences are relevant to share among caregivers?	Field studies and interviews with caregivers and NGOs in the chosen research community.	To define what stories caregivers would like to share and how they can be converted to informational materials

How can platforms that enable caregivers share stories about their work practice be co-designed with caregivers?	Interviews with caregivers in the research community. Literature review	To find out which platforms are best for sharing information among caregivers.
How can a digital platform for sharing storytelling be designed for caregivers?"	Research-through-design. Interviews with caregivers in the research community.	To gain insight on the best digital platform to design for sharing among caregivers
How can existing facts, knowledge, experience and values by caregivers in the HBHC be converted into stories?	Interviews with caregivers in the research community.	To identify the process undertaken to gather caregivers' knowledge and experience, and the process of converting them into stories

5.5.1. Why is a HBHC service and caregivers important to the community?

Chapter 2 presents literature review on the Millennium Development Goals (MDG) of which healthcare is paramount. It identifies the need for government around the world to provide healthcare to citizens especially those living in poor and impoverished communities. Using literature analysis, this research stated the importance of providing care for patients and the need to shorten patients' hospital stay without diminishing in the provision of quality care has necessitated the adoption of HBHC by various governments around the world. Extending care beyond the walls of the hospital depend largely on caregivers who are usually semi-trained personnel from within the community. This was further discussed within the South African context where most communities are still under-resourced and impoverished (van Zyl, 2010) and HBHC are seen as a way of extending care to these communities.

The role of the caregiver in the community and within the HBHC context was also highlighted using literature review in Chapter 2. It noted that because the public health sector is constantly under severe strain, a high proportion of people in the community are constantly seeking health care (Akintola, 2010). It identified deaths associated with HIV/AIDS as well as increasing emigration of health personnel to developed countries as some strains on the public sector. This has resulted in government is supporting HBHC as a way of reducing the pressure on public health facilities. Thus, prolong patient's stay in hospitals is being reduced by providing care

for patients in their homes through caregivers. Finally, HBHC as a community-oriented service is seen as providing the needed care to individuals with physical and mental nursing needs as well as emotional, social, and even financial assistance for those who cannot afford or access proper healthcare facilities

5.5.2. In what context and platform has storytelling been used for the purpose of sharing and disseminating information?

Literature review of research works by Gray (2009), Mateas and Stern (2003), Kretschmer et al., (2001) and Brooks (1996) reveal that Storytelling has been a proven way to communicate information, learn about life, transmit culture, make sense of experience, as well as express one's emotions and that storytelling has been the focus of much attention in various applications such as interactive tourism guides, education, and entertainment. Similarly, Jones, Harwood, Bainbridge, Buchanan, Frohlich, Rachovides, Frank, and Lalmas (2008) notes that millions of people now routinely create and share videos on web sites such as YouTube pointing out that the success of these user-generated video content portals builds upon much rapid technological advances where many homes now have high-speed internet access and computers with sophisticated video editing and display capabilities. These possibilities have influenced the sharing of personally customized videos online.

Furthermore, literature review show that the shift of storytelling into digital media and the increase in usage of mobile phones in rural communities provide communities with the platform to create digital stories on their handsets (Reitmaier et al, 2010). It discussed the research in Kenya where mobile digital storytelling is tailored to the needs of the rural community. Aside exploring mobile platforms for digital storytelling, the research allowed for the uncovering of usability problems by observing the use of the platform in different contexts.

Similarly, literature on the "Fate2" by Garzotto & Forfori (2006) revealed that storytelling, edutainment, and collaborative interaction are all powerful tools for promoting learning. The project described storytelling in the context of having the capacity to listen, tell and reflect on stories. The research showed that these activities promotes the child's development, cognitive functions and skills, communication, recognition, recall, analysis and interpretation. Literature review also identified the use of storytelling within the health community in the Columbia University of Medicine where caregivers-in-training received training on close reading and examining stories by patients during their clinical interactions. This process which required caregivers to

write down their own stories about their patients proved to promote better understanding of their patients (Gray, 2009).

5.5.3. What kind of knowledge and experiences are relevant to share among caregivers?

Ethnography was primarily used to gain insight into the kind of knowledge and experiences caregiver in the Du Noon community would love to share. The use of structured and unstructured interviews, field studies, observation and voluntary work with caregivers and NGO in the chosen research community provided clear understanding as to the relevant stories to be shared. Details of the researcher's experience in gaining acceptance in the community, negotiating between cultures and the voluntary work are provided in Chapter 4, (sections 4.5 - 4.7).

5.5.4. How can platforms that enable caregivers share stories about their work practice be co-designed with caregivers?

Literature review in Chapter 2 provided a basis for further storytelling exploration as some projects such as Mitchell (2003), Carnerio (2001) and Allee (1999) show that storytelling has already been exploited with positive outcomes in various settings.

However, in answering the research question within the context, the researcher conducted interviews with caregivers in the research community. The initial attempt to provide a pre-conceived mobile solution proved to be problematic and futuristic. Thus, the concept of co-designing with the caregivers became valuable as interaction with them revealed that a lot of people in the community still do not have mobile phones that support video formats. Through co-designing, caregivers offered valuable insight and suggestions into designing a print version of their stories. The researcher had to convert the videos into cartoon strips and produced a print version. This exercise proved to be contextually relevant and aided the distribution of stories in the community because those members of the community who could not play video files on their phones now had an alternative print version with the complete information available to them.

It is important to restate here for the purpose of clarity that the decision to design a print version of caregivers' stories was solely influenced by the observation and input of the caregivers after they found out that they could not distribute videos via mobile phones in the community.

5.5.5. How can a digital platform for sharing storytelling be designed for caregivers?”

In order to answer this question effectively, the researcher adopted a research concept in Interaction Design field known as Research-through-design (discussed in Chapter 4.4). This concept allows the researcher to first design an intervention (or concept) as a way of generating more knowledge and discovering new directions for more research. This was done when the researcher in his earlier interaction with the caregivers showed them an animation which supports storytelling as a way of creating interest and opening a window for further research in the community.

As rapport was built between the researcher and the caregivers, interviews were conducted with caregivers in the research community as a way of involving them in the design process. Although mobile platforms were used to distribute and disseminate some stories by caregivers to members of the Du Noon community whose mobile phones supports video, the most success recorded was through printed cartoon strips and this information was provided by the caregivers. With the print version, the caregivers were able to reach more community members. The print version was translated into Xhosa language for easy understanding in the community. Thus with this development, a lot of people who could not watch the video versions were not deprived of the opportunity to access the same valuable information embedded in the caregivers stories.

5.5.6. How can existing facts, knowledge, experience and values by caregivers in the HBHC be converted into stories?

As a key question in this research, the researcher resorted to interviews with caregivers in Du Noon, observation and field study to collect data. The idea is to identify the process undertaken to gather caregivers’ knowledge and experience, and the process of converting them into stories. However, in order to convert the data into stories, the researcher relied heavily on his experience and formal trainings in the field of design, script writing, film making and animation.

Although an actual description of detailed scripting, storyboarding, animation, and video editing steps are beyond the scope of this project, the diagram below (Figure 5.1) provides a visual representation of most of the steps and stages. These include

- Pre-production: Gathering raw stories from caregivers by way of interview for the purpose of editing the stories and sifting relevant points.

- Production: Converting edited story into scripts and storyboards to make for easy interpretation and animation. The next step is to animate the characters using animation software like Maya for 3D, or Adobe Flash for 2D.
- Post-production: Rendering of completed work from animation software and post production/visual and after effects is done using Adobe After Effect. The completed work is rendered out as a .3gp format which is a format compatible with playing videos on mobile phones. Furthermore, the print version of each story is done using CorelDRAW X4 for page layout and design.

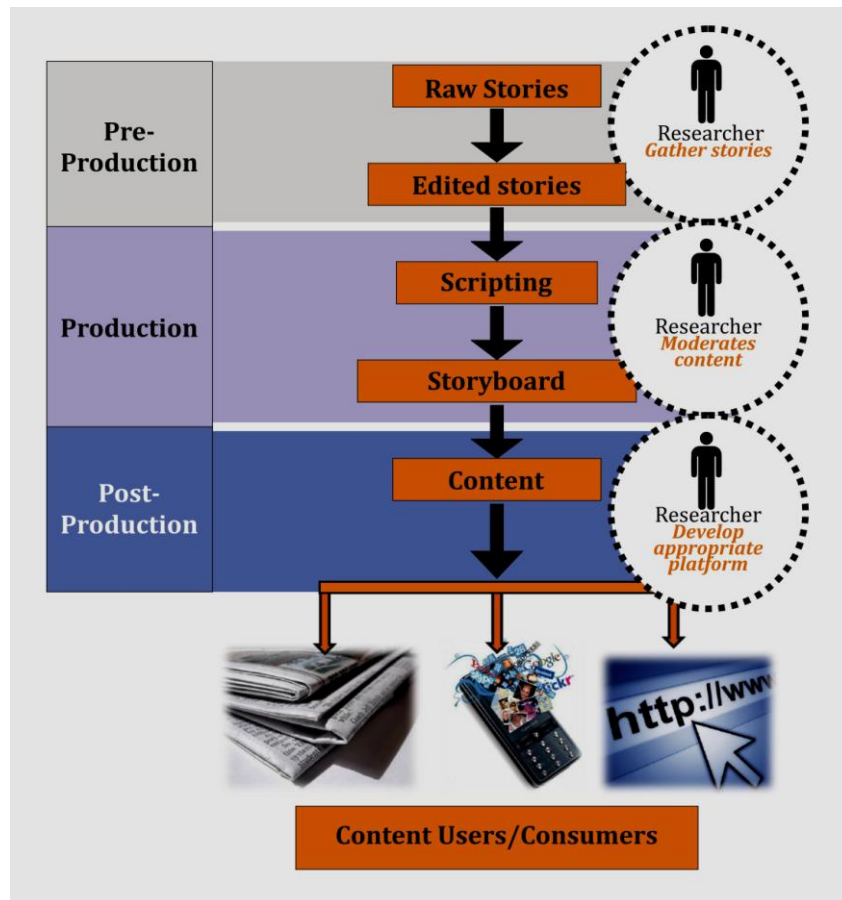


Figure 5:1: Visual representation of production process

5.6. The E2 Project

5.6.1 Introduction

E2 is an acronym for Education and Entertainment. The concept that education and learning can be a ludic, entertaining, playful and pleasurable experience is not new (Veltman, 2004). The term E2 is one of the projects at the Kujali Living Lab at CPUT, Cape Town campus. It began as a project when in April, 2011, the researcher was employed by the Lab. The primary objective was to capture stories from HBHC

communities and moderate them to informative, educative and entertaining materials such as animation, cartoon strips, stories, etc.

The project also began as a “*continuation*” of a research (Delen, 2011) at Kayamandi, a small suburb in Stellenbosch which led to the discovery that caregivers would love to share their stories. Although the project started by focusing exclusively on HBHC, more directions for exploration have since been open up. The platform/technology which will explore storytelling as the tool for sharing is envisaged to be educative and entertaining, hence the term “E2”.

5.6.2. Aims and Objectives of the E2 Storyworld project

Main Objective

- To provide a platform for Caregivers in the HBHC to share about their care giving practices.
- To explore storytelling as a means to promote sharing

Sub-objectives

- To identify what type of stories caregivers in communities would love to share.
- To identify best way/technology/platform to share stories (Mobile, Internet, Print, etc)
- To design (through co-design with caregivers) a platform/technology for sharing stories
- To have a repository of stories that could be useful for health policy makers to better understand HBHC from the caregivers’ point of view
- To contribute to body of knowledge
- To provide a subject for further research and questioning

5.6.3. Content distribution

Distribution of content is through sharing on the internet such as YouTube, Facebook, Tweeter, etc, or on mobile platforms by use of Bluetooth, or by print in the form of magazines, bulletins, etc. Distribution is dependent on the appropriate and feasible platforms that work best in specific communities. A dedicated website is presently been developed for accessing content while a mobile application capable of accessing content from the website from any location is also been developed.

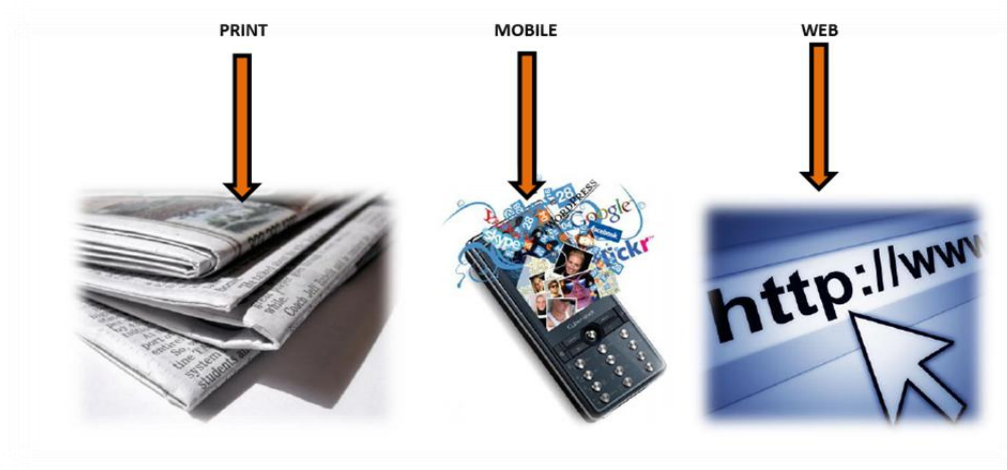


Fig.5.2: Distribution channels for E2 Storyworld



Fig.5.3: E2 Storyworld website

CHAPTER SIX

CONCLUSION

6. Introduction

This final chapter presents an overview of each chapter in the research. The research questions are revisited while a summary of the research contributions is provided. Finally, the researcher's reflections are expressed while recommendations for further research are suggested.

6.1. Chapters review

Chapter 1 starts by introducing the thesis, stating the research questions, sub-questions, objectives and research methods with which to answer them. It also looks at current status or research areas as well as the research design.

Chapter 2 provides literature reviews as a background understanding into healthcare around the world with focus on its challenges as well as an overview of policies (like the MDG) to resolve these challenges. Literature also provides a South African perspective on healthcare and the relevance of HBHC and caregivers to the promotion of continuous care to patients beyond the hospital. The roles of technology and interaction design in addressing some of these challenges are also discussed. Furthermore, literature on exploring storytelling for information sharing provides a referential grounding for the research.

Chapter 3 discusses the research design and methods employed for this research. Here the epistemology and ontological standpoints are stated and discussed, topics of qualitative and interpretive research are also discussed.

Chapter 4 provides information on research findings and how qualitative methods were used for capturing data within the research community. Detailed account is provided on research activities as they occur in their natural contexts. Furthermore, information is provided on some social and natural challenges and how these were addressed.

Chapter 5 discusses and interprets the research findings mentioned using frameworks like the reflexive iteration and thematic networks with the aim of seeking to establish relationships, similarities, differences and meanings in the data collected and to ultimately provide answers for the research questions. There is also a

summary of key findings from the research community while the objectives and relevance of the E2 Storyworld project is further elaborated.

Chapter 6 concludes the research with an overview of all the chapters, a revisiting of the research questions and a summary of the research contributions. Furthermore, there is a personal reflection by the researcher. Lastly this chapter includes a proposal for further research.

6.2. Research question revisited

6.2.1 Statement of the research problem

The sharing of experiences and knowledge by caregivers in the HBHC community is underexploited; there is potential in developing platforms for caregivers to share stories about their knowledge and experiences.

6.2.2 Research question, sub-questions and objectives

Research Question:

Preliminary inquiry by the researcher in Du Noon community showed that there is no platform that supports storytelling by caregivers. With so many stories to tell about their experiences, the research considers the question of how to design a platform that supports storytelling by caregivers in the HBHC for the purpose of sharing.

Research Sub-questions:

Why is a HBHC service and caregivers important to the community?

Caregivers function within the HBHC and provide basic care to the patients in the comfort of their homes whereby reducing long hospital stay. They also provide other forms of care like attending to physical and emotional needs of their patients.

In what context and platform has storytelling been used for the purpose of sharing and disseminating information?

Storytelling has been used as a visual platform within the healthcare context to promote better interaction between medical practitioners and patients. Similarly, information sharing has been enhanced through storytelling.

What kind of knowledge and experiences are relevant to share among caregivers?

Caregivers are willing to share knowledge and experience about their daily interaction with patients within their community.

How can platforms that enable caregivers share stories about their work practice be co-designed with caregivers?

Designing a contextually relevant platform (or platforms) that enable caregivers share their stories is possible through co-designing with caregivers from the very beginning of the design. They must also be carried along and be a part of all the design processes.

How can a digital platform for sharing storytelling be designed for caregivers?

Designing a digital platform is possible through participatory design with the caregivers, but it must be contextually relevant as various poor communities like Du noon still have community members without mobile phones that support video files thus, other platforms must be investigated.

How can existing facts, knowledge, experience and values by caregivers in the HBHC be converted into stories?

Converting caregivers' experiences into stories is possible through visual communication channels such as 2d and 3d animation, cartoon strips, short videos and motion graphics. However, a good skill of scripting, storyboarding and design software is an added advantage.

6.3 Summary of research contributions

- Reiterating the relevance of HBHC and the role of caregivers within the system.
- A new look at HBHC from the position of caregivers who aside providing medical, physical and emotional care to patients in the comfort of their homes are now custodians of stories about their work practice.
- A novel call to urgently collate, process and convert stories by caregivers within the community into edutain materials for the purpose of sharing knowledge and disseminating useful health information.
- A realisation that Storytizing information could help in easy understanding of the information by the intended end-user.
- A new context for using concepts from IxD to re-design solutions which are contextually relevant in the healthcare sector. This goes to reiterate that Interaction Design is not just about the design of technology but also the design of experience as discussed below.

6.4 Reflection

This section will focus on the researcher's reflection on the research process and how concepts from the field of interaction design (IxD) were employed to play vital roles at different stages in the project. Areas of interest will include IxD concepts used in the initial contact with the research community, designing of interaction with respondents at various stages in the research process.

6.4.1. Designing an experience

Anand (2012) opines that Interaction design is not so much about the design of technology, as it is about the design of human experiences made possible through it. Furthermore, he added that while information and interface design are termed '*visible*' for evaluation purposes, the quality of interaction design stays hidden and transcends the tangible (technology) canvas, and takes as its design materials the highly abstract human interactions. Based on this premise, the researcher sees IxD as a discipline that seeks to improve the everyday human experiences. In this research, the main focus of interaction design, in this sense, is not the design of technology per se, but the design of human experiences made possible through technology. This notion necessitated the researcher to design a "*visual experience*" by way of a short animated video during the first meeting with respondents at the research community.

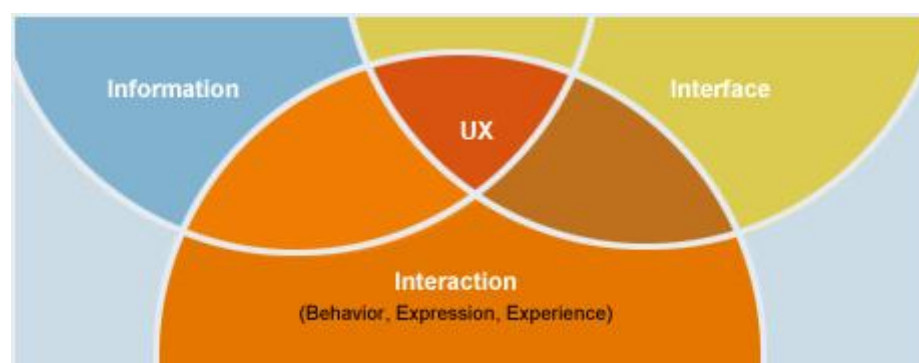


Figure 6.1: Design of Human Experience (Anand, 2012)

This experience appealed to the respondents at Du Noon and opened a door to further interaction and research. This corresponds with one of the concepts in IxD known as Research-through-design defined by Zimmerman, Forlizzi, & Evenson, (2007) as an approach where designers produce novel integrations of Human-Computer Interaction (HCI) research with the aim to create the *right thing* in the form of a product, experience, service or system that could transform a current state to a preferred state. This process enables designers make purposeful research contributions founded on addressing prevalent problems. Research through design is

adopted in this research because apart from attempting to solve a real-life issue in the research community, it was a way to get the respondents on board and to let them understand the possible outcome of the research.

Other areas in which concepts from Interaction design was employed included the researchers' ability to accept the caregivers as a "*mediator*" of some sort in reaching the ladies whose stories are told in this research. The ladies were more comfortable to share their experiences or stories with their caregivers than with the researcher who had been informed from the onset that he would not be allowed for ethical reasons to interact with the ladies one on one. Therefore, the caregivers were incorporated as co-designers of the experience.

Furthermore, this research shows that concepts from IxD if well coordinated can provide useful solutions in different fields such as healthcare. The design of experience in this case provided a platform to address real-life situations in Du Noon which are contextually relevant to the people in this community. The uniqueness of IxD is that it provides an opportunity for people in various disciplines such as media, software development, Engineering, Medicine and many more to collectively address and provide solutions to a particular need in the community.

6.5 Further Research

Further research is required to inculcate aspects of IxD into various South African HBHC landscape. It is necessary for more interaction designers in South Africa to investigate newer frontiers whereby contextually relevant design solutions can be implemented for communities in need. Designing and prototyping of objects, solutions or services that invite and respond to the needs of the end-user is only the beginning of the solution, interaction designer must constantly see themselves as designers of experience that evoke positive emotional reactions.

Interaction design as a course of study is constantly proving to be fundamental to various disciplines, fields, and approaches that are concerned with researching and designing computer-based systems for various people. Since the mid '90s, many private and public companies have come to realize that it is essential to broaden their existing multidisciplinary design teams to include professionals versatile in media and design, including architectural and graphical design, industrial and surface design, interface designs, film, animation and narrative and IxD provides a platform for bridging this gap.

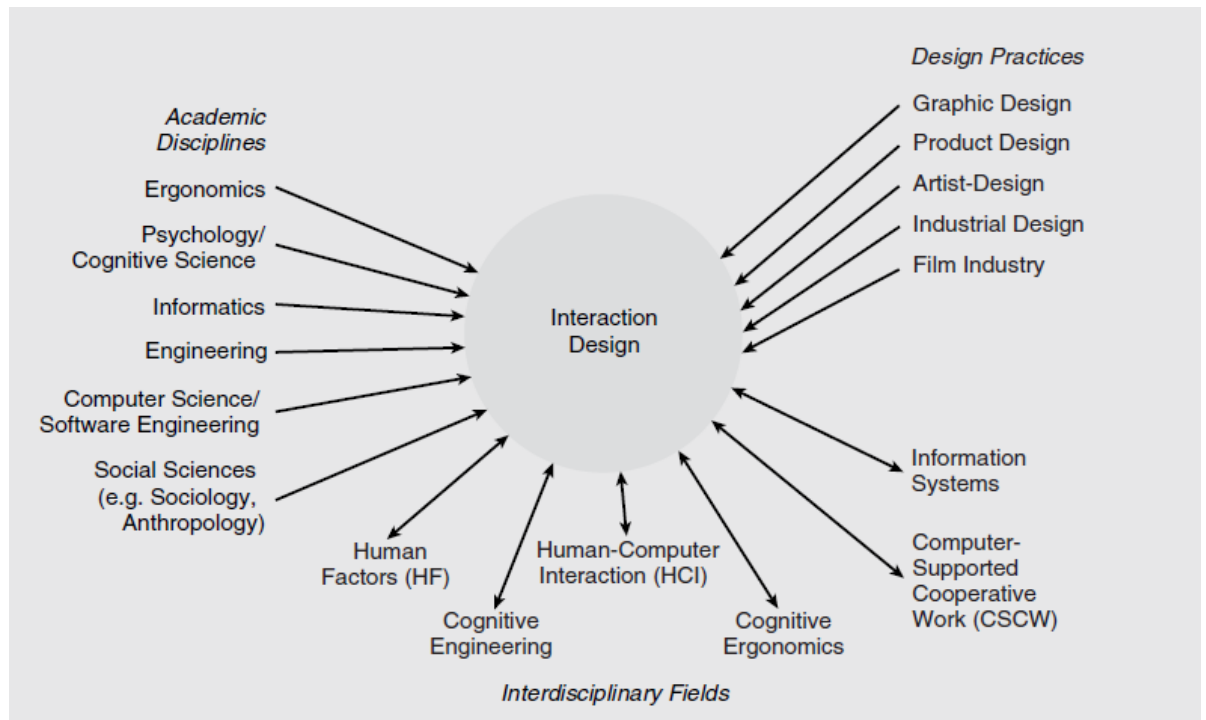


Figure 6.2: Interdisciplinary nature of IxD (Anon)

Finally, as further researches are conducted by interaction designers into different issues, the following recommendations must be considered as necessary and basic:

1. To identify real-life needs in communities
2. Establish requirements to address these needs
3. Develop optional or alternative designs that meet those requirements (This also includes prototyping)
4. Building interactive versions of the designs so that they can be easily communicated and assessed by users thereby generating new knowledge.
5. Evaluate steps and what is being built throughout the process to discover trends and new knowledge.
6. Users should be actively involved throughout the research and development of the project.
7. Specific usability and user experience goals needs to be identified and clearly documented for revisiting, fine tuning and modification.
8. Iteration through all activities is essential and inevitable.

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APPENDICES

APPENDIX A: Audio Transcription

Interview with Mrs. Elizabeth Kula
Transcribed audio recording
@ Du Noon, Cape Town. South Africa
Monday 9 January, 2012 at Du Noon
(11:00am – 1:45pm)

Interviewer:
Michael Chidubem

1. Can you please introduce yourself?

My name is Elizabeth Kula. I am a caregiver here in Du Noon and I have been a caregiver here for more than 15 years taking care of people who need care.

2. What do you mean by people who need care?

What I mean is that a lot of people in Du Noon are poor and the situation with some of them is that they are sick. Most of them have been diagnosed with having HIV. So as a caregiver working with the local clinic here in Du Noon, I go and visit them at home.

3. So what do you do when you visit them at home?

I just ensure that they are taking their drugs and eating well. Apart from that, some of them are so sick and weak that they cannot do much for themselves. So I try to clean the house, sometimes I help to cook and ensure they take their medicines as prescribed by the doctor. Most of them are single mothers and don't have jobs.

4. You said most of the people are poor and don't have jobs...What is life like in Du Noon generally?

Life is tough for a lot of people. But the government is trying to help but the needs of the people are too many. Like the N2 Gateway project is government's attempt to give people a decent life in terms of accommodation. It stretches from Gwalanga through Atlantis. It is also aimed at building houses closer to where people are working. It is also to help the poor people get accommodations. Residents are to pay R500 Monthly for a period of three years. After 3 years, the house belongs to the resident. As a result, shack will not be allowed there. It is a big place and is envisaged to take a period of 7 years to complete. The complex will include facilities like crèches, sports complexes, shops and malls, old age homes, shelters for abused women, etc. The government is trying to accommodate everyone in the community including business owners but to be considered for a house, you must provide Bank statements for support, certified copies of IDs, etc.

5. What would you consider the pressing issues in Du noon?

In Du Noon, drugs abuse is a major issue among the young children. Sadly, most of these drugs are manufactured and sold to our teenagers by foreigners. They introduce them to free drugs and get them hooked up on it. These youths eventually become addicted and are forced to do anything (such as stealing) to get money to sustain the habit. I think the youths are not comfortable with this habit because most times they cover their faces in guilt when taking these drugs, but they are already hooked up on it and find it hard to stop.

6. But is drugs the main issue here in Du noon?

Not at all. Getting addicted to drugs is just the beginning for most of them...

7. How do you mean?

Let me explain. You see, as they start taking drugs, they diversify into stealing. For instance, to sustain the habit, they steal by breaking into house when people are away or even when people are at home. Now, when they come like that, they can gang rape girls, and even women old enough to be their parents. Now, they pass on diseases like HIV in the process. For some, they impregnate innocent girls and this could mark the end of the girls' education.

Furthermore, some ladies are hooked onto drugs and start having unprotected sex with their boyfriends. They become pregnant in the process and some become infected with the HIV virus. So it is from one step to the other... they are inter-related somehow.

8. How do you try to address this problem as a caregiver?

There is little that we can do in situations like this. The major problems in Du Noon can be divided into 50% of drugs abuse and HIV. In spite of the numerous campaigns and technological advancements, our youths are still ignorant meanwhile they presume that they are smart. The problem with our youths is that they want a quick fix. Most of them after taking drugs get into drinking and become drunk which translates into various abuses and when they are "high", they want to have unprotected sex and in the process expose themselves to the possibility of being affected with HIV. It is sad that our youths have this mindset that sex with condoms is not enjoyable. They don't want to use condoms! When we as caregivers try to caution them that this lifestyle is dangerous, most of them usually respond with a question "If we can't enjoy ourselves, who

will? We need to enjoy ourselves while we can". Ultimately, most of our young daughters who ignore these precautions become pregnant, forcing us mothers to become grannies too quickly.

So what we do is just to try and educate them in our little way, we can't really force them to take the advice. We also try to encourage parents to train their children because they are the first role models the children are exposed to.

9. So for now it is more of a word of mouth campaign to address these issues?

Yes! We always tell parents (especially mothers) that they have a major role to play in the lives of their children. Most mothers are domestic workers and leave their young daughters alone at home when they go to work. This practice opens a probable scenario where these girls, alone at home, will fall victim to young boys who approach and ask them for sex. Also, at schools, some children are exposed to pornographic materials by their peers and when alone at home, they want to practice it with their partners who are usually older men. Parents are supposed to monitor closely, the activities of their children. Even if they are not always there, they should make their parental leadership count when they return from their offices or place of work.

10. Having seen a sample of the animation, what do you think...?

Honestly, I am so happy with the concept. Most of our children spend so much time on the internet, on their phones or watching TV. So if you can develop a way whereby they are educated and entertained in the process, it will really help. I have seen a sample of what you intend to do and I am so happy and excited about it. I believe it will go a long way in educating our children on various issues.

11. So would you be willing to provide stories?

Of course! I have so many stories that I can share with you about people in the community. I am willing and ready any time to tell you stories. An animation or cartoon addressing issues in the community is good because I can take it around and distribute to people. I believe that with that, I can even reach more people that word of mouth. But as we have agreed, I will not like you to mention any names because some of them are living with HIV and it will not be nice to mention their names.

12. Thank you so much for your time?

It's my pleasure. If there is anything you need from me to make the project successful, please let me know.

APPENDIX B: True life story from Du Noon

My pain, my gain

Inspired by a true-life story

Written by Michael Chidubem

December, 2011

Narration

It was the dawn of a new South Africa. Everyone had high hopes and expectations as the dividing wall between cultures and races was finally being abolished and destroyed. Indeed, we had just entered the era when everyone can live in a nation where they will not be judged by the colour of their skin, but by the content of their character.

As I prepared to embrace this long anticipated new life, I was surprised to find out that for me, the battle was far from over. I have won a war against just one enemy, but there were yet other enemies. My little daughter has just been diagnosed with having the dreaded HIV disease. This was another enemy I was not prepared to fight, I was caught unawares...unprepared.

This fight was far beyond me. I was not equipped with the necessary information and exposure to fight this battle. It was a war on so many fronts. Firstly, I could not believe that my teenage daughter could have a boyfriend, talk less of falling pregnant. I could not believe that I have just been awakened to the reality that my daughter could die anytime. I did not have the confidence to publicly look for medical assistance. I could not face the outside world with the stigma associated with the disease... worst case; I could not face my family with the guilt that I have failed as a mother to instil Godly values into my daughter.

Each passing day brought a degree of fear and pain. People started suspecting and it was only a matter of time before it became public knowledge. I was heavily stigmatized and ridiculed in my community. My daughter was ostracized and her condition was the object of "community discussion".

Eventually, my daughter started receiving medical attention from our local clinic. With time, her condition began to improve but the stigma didn't subside. My greatest regret as a mother was that I allowed the stigma from the public to prevent me from showing love to my daughter. I felt betrayed. I felt that I didn't belong. I felt pain. The only way I could release this pain was to consciously withdraw my love from my child. I made her feel terrible for being HIV positive.

I wanted a quick solution that could bring things back to normal so I was advised by my friends to stop the medication and I resorted to the alternative of "muti*", prepared by "Sangomas*". For me, this will quickly bring the needed solution but I was so wrong! My daughter's condition deteriorated from bad to worse. When I realized my mistakes, I resumed the medications but it was too late. The virus has spread so much. My daughter developed a kidney failure and after a short battle, she died.

Today, I have learnt a great lesson.

I know better now. I should have been there for my daughter. All she needed was my support, my care and my love. We would have won this battle together. I was so engulfed in trying to solve the problem in my own way that I ignored the solution that has been provided. I allowed pressure from the community to prevent me from being there for my daughter. I failed!

Saying sorry is not enough. I have decided that people in my community must not make the same mistakes that I made. I have decided to educate parents and children on the need to stick to their medications as prescribed by their doctors. I have decided to show love to people living with HIV/AIDs and all other forms of diseases.

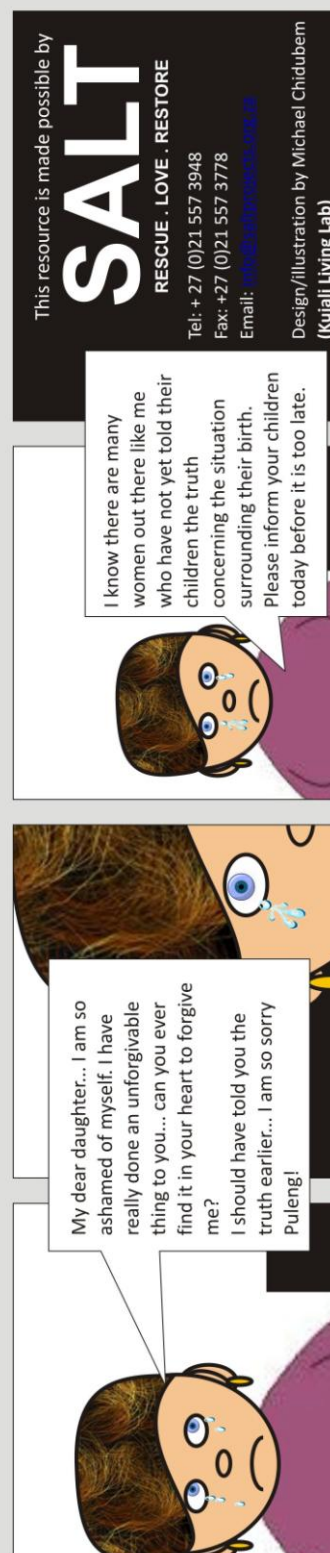
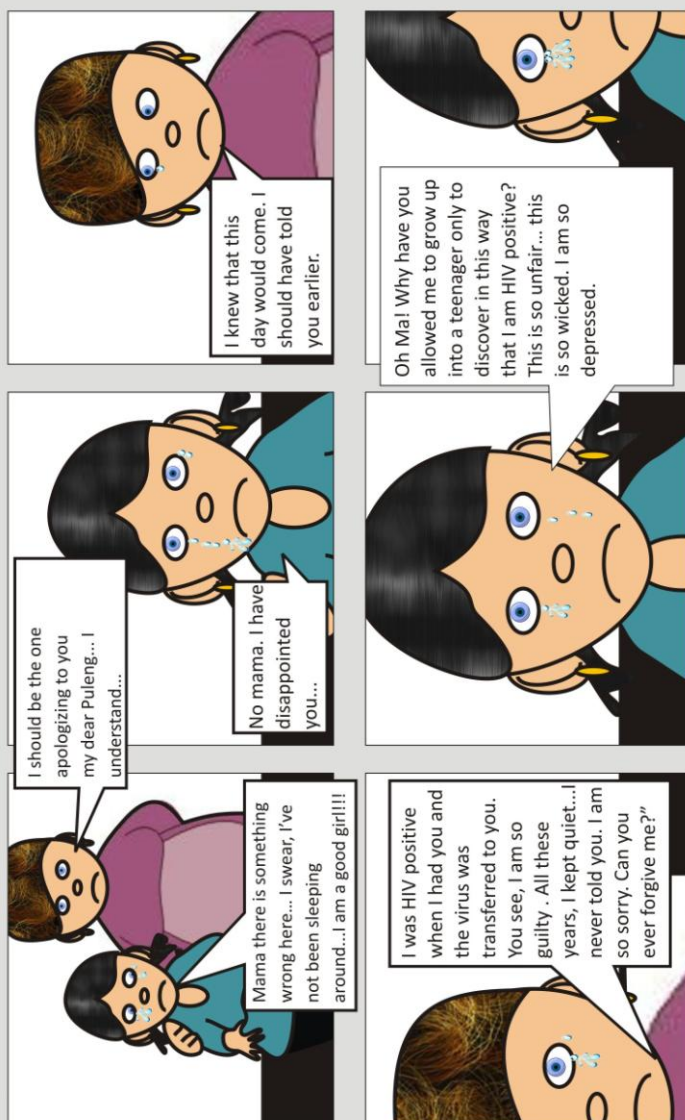
Although I lived for many years with the guilt of being partially responsible for my daughter's death, I have since forgiven myself. For if I had not lost a child the time I did, maybe I would not have had the courage and the opportunity to be a caregiver to thousands of people today. My pain has become my gain. My loss has become my strength. Together we can win this war, just the way we have always won.

APPENDIX C: CARTOON STIP-1

“I kept quiet” ... influenced by actual events...

Why have I done this shameful thing to my dear daughter? I have done everything within my power to make Puleng so happy and live a good life. I was so sure that this lifestyle will yield a better future and that is why I always encourage her to be the best in everything she does. Honestly, she has never given me a reason for sorrow... everything seemed perfect at home until recently.

As the **“Know your status”** campaign for people in our community to get tested for HIV/AIDS gained momentum, Puleng confidently went in to get tested. She had informed me of some of her friends who were so scared because they have been seeing different guys. She was not scared because she is still a virgin. Armed with this, she confidently waited for the result from the doctor. The doctor gave her the most shocking news of her life. **She is HIV positive!!!** She passed out! When she came by, I was kneeling by her bed weeping. I felt for her because she must be so depressed, disappointed and angry. I was also crying.



This resource is made possible by

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(Kujall Living Lab)

APPENDIX D: CARTOON STIP-2

Nomsa has a baby

		
Nomsa just had a baby boy. But she is not happy	Few years ago she was diagnosed with the HIV virus	She is afraid she might affect her baby through breast-feeding
		
She has been taking her medication as prescribed by the doctor	So she doesn't need to worry	Breast-feeding is still the best way to feed your baby
		
Breast milk has natural nutrients that can fight certain diseases in newborn babies	Breast-fed children are usually healthier than formula-fed children	If you take your drugs and live healthy you can breast-feed your baby
	<p>“...Breast feeding remains the most energy efficient way to provide for the dietary needs of the young...”</p> <p>This cartoon strip is based on a comprehensive research by Mrs. Doreen Mugendi. Cartoons and illustrations were by Michael Chidubem. Powered by SALT and Kujali Living Lab</p> <p>Your comments and feedback are welcome: mikeberechi@yahoo.co.uk</p>	
Now Nomsa is happy and can breast-feed her baby as she always wanted to do		

APPENDIX E: Links to online animation

Cut the rope

Cut the rope is a story of a lady who about to commit suicide but through the encouragement and assistance of caregivers and an NGO working in Du Noon, she was able to face the challenges of life and is living very comfortably today.



Available at <http://www.youtube.com/watch?v=hHJZsd5TYkQ>

How to hand rub

Hands rub video. This is a product of the E2 Project by Kujali Living Lab. It was used by a team from Kujali Hub during their visit to Mozambique (2012). This is an example of using video content for the purpose of edutainment. (Edited by Michael Chidubem)



Available at <http://www.youtube.com/watch?v=DiqPhKvxbdU&feature=youtu.be>

Nomsa has a baby

"...Breast feeding remains the most energy efficient way to provide for the dietary needs of the young..." This story is based on a research by Mrs. Doreen Mugendi who is involved in SALT's work in Du Noon. This animation and cartoons were distributed in Du Noon as part of a research work by Michael Chidubem. Cartoons and illustrations were by Michael Chidubem. Powered by the E2 Storyworld Team of Kujali Living Lab



Available at <http://www.youtube.com/watch?v=kgEdD80XPvU&feature=youtu.be>